

Stress, Coping, and Psychological Wellbeing among Parents of Children with Autism Spectrum Disorder

A Dissertation Submitted

To

Sikkim University



In Partial Fulfilment of the Requirement for the Degree of Master of Philosophy

by

Ms Sonu Darnal

**Department of Psychology, School of Human Sciences
February 2018**

इल, सामदुर, तादोंग -737102
क, सिक्किम, भारत
03592-251212, 251415, 251656
फैक्स -251067
ईट - www.cus.ac.in



सिक्किम विश्वविद्यालय SIKKIM UNIVERSITY

6th Mile, Samdur, Tadong -737102
Gangtok, Sikkim, India
Ph. 03592-251212, 251415, 251656
Telefax: 251067
Website: www.cus.ac.in

(भारत के संसद के अधिनियम द्वारा वर्ष 2007 में स्थापित और नैक (एनएएसी) द्वारा वर्ष 2015 में प्रत्यायित केंद्रीय विश्वविद्यालय)
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A handwritten signature in black ink, appearing to read 'Namrata'.

(Namrata)

PhD

Assistant Professor

Department of Psychology

Place: Gangtok

Date: 07-02-18

इल, सामदुर, तादोंग -737102
क, सिक्किम, भारत
03592-251212, 251415, 251656
क्स -251067
इट - www.cus.ac.in



सिक्किम विश्वविद्यालय
SIKKIM UNIVERSITY

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February 07, 2018

DECLARATION BY THE SCHOLAR

The work embodied in the dissertation entitled 'Stress, Coping, and Psychological Wellbeing among Parents of Children with Autism Spectrum Disorder' was conducted at the Department of Psychology under School of Human Sciences, Sikkim University, in partial fulfilment of the required for the award of M.Phil. degree of Sikkim University. The work has not been submitted in part or full to this or any other university or institution, for any degree or diploma.

A handwritten signature in blue ink, appearing to read 'Sonu Darnal'.

Sonu Darnal

Roll No. 16MPPS05

Reg No. 16SU19542

We recommend this dissertation to be placed before the examiners for evaluation.

A handwritten signature in blue ink, appearing to read 'Dr. Satyananda Panda'.

A handwritten signature in blue ink, appearing to read 'Namrata'.

Namrata (PhD)
Supervisor
Assistant Professor
Department of Psychology

Dr Satyananda Panda
Head of the Department
Associate Professor
Department of Psychology

5 माइल, साम्दुर, तावोंग -737102
गंगटोक, सिक्किम, भारत
फोन-03592-251212, 251415, 251656
टेलीफैक्स -251067
वेबसाइट - www.cus.ac.in



सिक्किम विश्वविद्यालय
SIKKIM UNIVERSITY

6th Mile, Samdur, Tadong -737102
Gangtok, Sikkim, India
Ph. 03592-251212, 251415, 251656
Telefax: 251067
Website: www.cus.ac.in

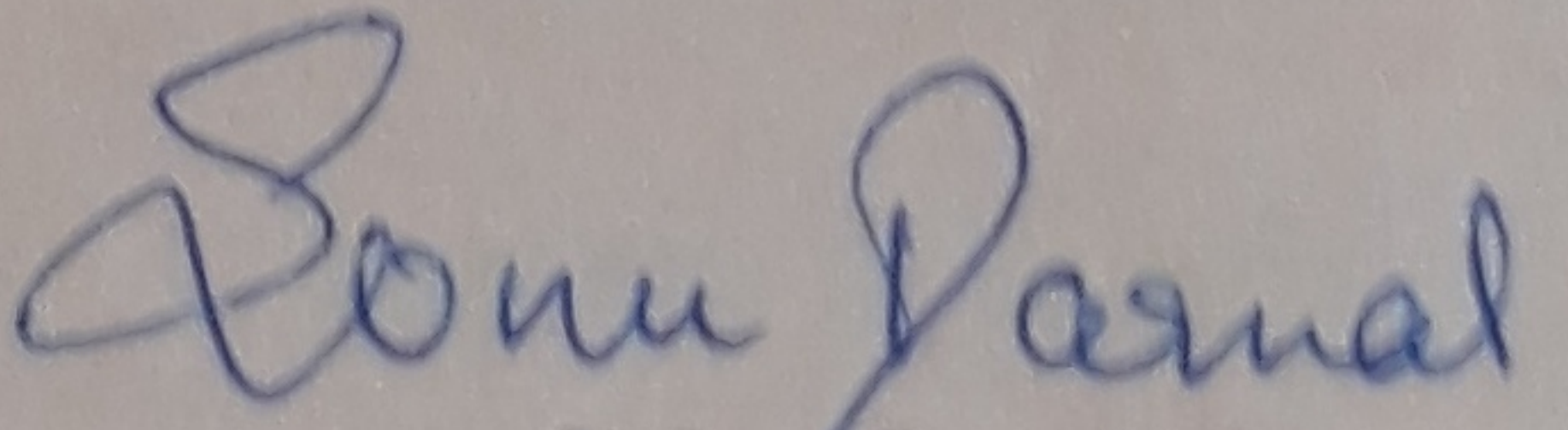
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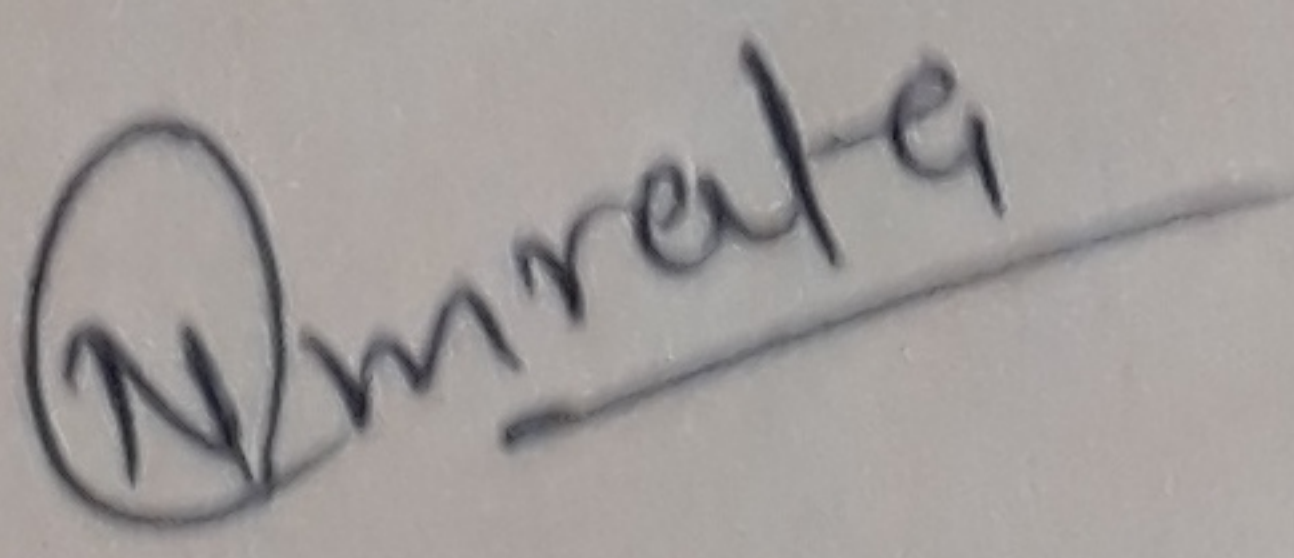
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**Stress, Coping, and Psychological Wellbeing among Parents of Children with
Autism Spectrum Disorder**

Submitted by **Ms. Sonu Darnal** under the supervision of **Namrata (PhD)**, Department of Psychology, School of Human Sciences, Sikkim University, Gangtok, 737102, India.


Signature of the Candidate


Signature by the Supervisor

6th माइल, सामदुर, तादोंग -737102
गंगटोक, सिक्किम, भारत
फोन-03592-251212, 251415, 251656
फैक्स -251067
वेबसाइट - www.cus.ac.in



सिक्किम विश्वविद्यालय
SIKKIM UNIVERSITY

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(A central university established by an Act of Parliament of India in 2007 and accredited by NAAC in 2015)

Forwarded by

Dr Satyananda Panda

Head of the Department

Associate Professor

Department of Psychology

Sikkim University

Dr. Satyananda Panda
Associate Prof. & Head
Department of Psychology
Sikkim University, Gangtok

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Abstract

Autism Spectrum Disorder is characterized as social, communicational and behavioral impairments. Evidence shows that parenting a child with Autism can disturb the whole family life and result in several physical, social and psychological problems. The wellbeing of those parents, therefore, is at risk. The present study examined stress, coping and psychological wellbeing of parents of children with autism spectrum disorder. Mixed method approach was adopted to examine this phenomenon. The study further examined the relationship among stress, coping and psychological wellbeing across child's age, degree of autism and parent's gender. 49 participants, mother (n=34) and father (n=15) completed the questionnaires for stress- Autism Parenting Stress Index (2012), coping- Ways of Coping Questionnaire(1895) and psychological wellbeing- The Ryff Scale of Psychological Well-Being(1989). Qualitative data was collected using semi structured interview schedule. Results highlighted that parents of children with moderate symptoms of autism experienced higher stress compared to parents of children with mild autistic symptoms. Parents used maximum coping styles and had better psychological wellbeing while rearing a older child with autism. Further, it was found that mothers of children with ASD used more coping styles compared to fathers. The results identified in the qualitative analysis were found to be in support of the quantitative results. The present study recommends for the development of programs and services for families for children with Autism in remote areas.

Introduction

The following chapter deals with definition and different theories on stress coping and psychological wellbeing. Section 1.1 discusses on the definition, symptoms and prevalence of autism. Section 1.2 defines primary theories on stress. Theories on coping styles is discussed in section 1.3 and definitions on psychological wellbeing is discussed in section 1.4

1.1 Autism

The DSM-III debuted in 1980, introduced the new category of Pervasive Developmental Disorders (PDD). This term was developed as an umbrella term for developmental disorders of childhood onset and included infantile autism. In the Diagnostic and Statistical Manual, Third Edition, Revised (DSM-III; APA, 1987) the name of infantile autism changed to Autistic Disorder. Additionally, the criteria of autism changed so that a person had to demonstrate 8 out of 16 criteria, with a certain number of endorsements in each of three core areas of impairments (i. e. social, communication and restricted activities and interests; APA, 1987). Overall the DSM-III-R had no doubt widened the diagnostic criteria of autism, but the new evidence from empirical research and in attempts to form an agreement with International Classification of Disease, Tenth Edition (ICD-10, 1992) led to refinement of the diagnostic criteria for autism in the Diagnostic and Statistical Manual, Fourth Edition (DSM-IV; APA, 1994). Thus, according to the DSM-IV, an individual had to meet at least 6 criteria must be met, with a certain number of endorsements in three areas of impairment (social, communication and restricted activities and

50 interests). Age of onset was re- instated in new diagnostic manual to 36 months of age (APA, 1994). As stated in DSM-IV-TR (APA, 2000), a diagnosis of Autism requires endorsement of at least six items from the socialization, communication, and restricted, repetitive, and stereotyped interests, activities or behaviour domains. At least two item endorsements must come from the socialization domain, and at least one item endorsement must come from communication domain, and the restricted, repetitive and stereotyped domain. Items in the socialization domain include: (1) impairment in non verbal behaviours, (2) impairments in the development of peer relationships, (3) deficits in sharing achievements, feelings or interests with others, and (4) impairments on emotional or social reciprocity. Items in the communication domain include: (1) lack of or delay in verbal communication, (2) deficits in initiating or sustaining conversation if the individual has the ability to speak, (3) repetitive and stereotyped language, and (4) deficits in spontaneous make believe play. Items in the restricted repetitive and stereotyped domain include: (1) abnormally high intensity or frequency in regard to preoccupation with a topic, (2) inflexibility in regard to nonfunctional rituals or routines, (3) repetitive and stereotyped motor movements, and (4) preoccupation with parts of objects. Furthermore, there must be delays or impairments before the age of three in at least one of the following areas: (1) social interaction, (2) communication, or (3) imaginative or symbolic play.

The term autism is derived from the Greek word *autos*, meaning self (Sharma & Sharma, 2016). According to DSM-5, Autism spectrum disorder is defined as describing a group of neurodevelopmental disorders including Autism, Asperger's Disorder, Pervasive Developmental Disorder not otherwise specified (PDDNOS) and Child Disintegrative Disorder. ASD is characterized by social, communicational and behavioural impairments (American Psychiatric association, 2013). Autism is a lifelong a neurodevelopmental condition, a developmental

disorder that typically occurs during the first three years of life. Autism is known for its spectrum of disorders because ranges from mild learning and social impairment to severe multiple disabilities (Sharma & Sharma, 2016). Though children with ASD share characteristics with the wide range of social, communicational, and behavioural impairments, still their uniqueness lies in the degree these impairments are present in each ASD individual. The most common and noticed symptoms of ASD include avoiding eye contact, difficulty reading non-verbal cues, and dependency on routines. Children with ASD have difficulties with the quality of their social and communication skills and relationships, as well as ritualistic practice of restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities. The symptoms may also include difficulty in interactive play, display behaviors not typical of their peers and respond to sensory stimuli by screaming or reacting strongly to light, sound, or motion (Sicile-Kira, 2004; Kendall, 2014).

One and a half million of United Nations States population is affected by ASD. One in 150 children in States is diagnosed with this developmental disorder and it is recorded that boys are four times more likely fall within the spectrum of ASD as compared to girls (Autism Society of America, 2006; Augar, 2013). In India, however, estimates are higher than the United Nations States and its increasing in an alarming rate. Just three years back as reported by Kendall (2014) in his study, approximately 2 million people have some form of ASD. According to statistics by the Centre for Disease Control and Prevention (CDC), (2010) one in every 88 children today is born with autism spectrum disorder (ASD) in India. Whereas, according to Centre for Disease Control and Prevention (CDC), 2012, it is estimated that one in every 68 children are autistic. Confirming to the earlier records, boys continue to be diagnosed with autism at greater rate as compared to girls. One in every 42 boys is considered to fall under the spectrum of autism. Still

it is difficult to accurately assess the true prevalence of the disorder as it is often under-diagnosed and under-reported. There are evidences stating that the reason why the prevalence of ASD among children has risen up in last 30 years is because it is now being diagnosed under Diagnostic Statistical Manual for Mental Disorders (DSM) which identifies ASD as a specific disorder, having specific diagnostic criteria. Another possible reason for its increasing recognition could be the wide diagnostic criteria, well established and standardized diagnostic instruments and increased level of awareness about ASD in general population (Sharma & Sharma, 2016; Wing, 2015). However, to date, no preventive strategies have demonstrated consistent benefits and no treatments have proven widely efficacious in treating the core symptoms of ASD. As a result, ASD causes lifelong disabilities for affected individuals and significant burdens to their families.

There is altogether varied range of challenges faced by Indian parents who have to raise a child with disability. Through the intense literature review in the related area it was found that there are limited resources that have looked into parental conditions after the diagnosis of the child, especially in Indian culture. Researches indicate that the parents whose children are diagnosed with ASD go through a lot of social, emotional and personal challenges that requires external support and interventions. It is also noticed that in India there is a delay in reporting the child's conditions related to ASD as compared to western countries (Desai et al, 2012).

1.2 Stress

After a rigorous review of present literatures it can said that the stress experienced by the parents of children with ASD is higher compared to the stress experienced by the typically growing children or children with other developmental disorders (Pisula, 2011; Ogston, 2010; Mancil,

Boyd & Bedesem, 2009; Tehee, Honan & Hevey, 2009; Hastings, et al., 2005). There are evidences that parents of children with ASD go through a lot of psychological and social stress, lesser quality of life, more depression, and greater pessimism about future as compared to parents with other disabilities (McHugh, Osborne, Reed, and Saunders, 2008; Pathappillil, 2011; Pushpalatha & Shivakumara, 2016; Bashir, Khurshid, & Qadri, 2014; Neff & Faso, 2014). The initial diagnosed of the child with autism, itself becomes the precursor of stressors for the parents- starting from acquiring the knowledge from diagnosis, searching for an appropriate intervention, bearing the charges of the costly interventions, its repercussion on the marital life of the parents, social challenges and coping with social stigma, parent's experience with the social support system and so on and on (Haisley, 2014; Sharma & Sharma, 2016). In addition it is found that parental relationship suffers and there is a family dysfunction in parents of a child with ASD (Gour & Pandey, 2016).

The physical, social, and environmental changes that are perceived as harmful having potentiality to perceive stress is termed as stressor. The stress caused by these situational changes produces either physical or psychological (anxiety, depression, hopelessness) responses (Morgan, King, Weisz, & Schopler, 2015). We come across number of stressors in everyday life that are termed as hassles like exam pressure, death of a closed one, poverty, and major life changes. Work load or work pressure could be one of the frequently and widely experienced stressor in present day life. Though it is believed that work is done better under pressure but when it comes to work that demands new ideas, innovation and creative, pressure may have negative effect. Another possible stressor could be when there less predictability and uncontrollability in the situation. The predictability in a situation gives us a sense of safety, comfort and assurity that things are under our control (Baron, 2007; Ciccarelli & Meyer, 2008).

Walter Cannon in 1920s was the first psychologist to give a detailed scientific understanding of what happens when we are faced with a stressful situation. He explained that when faced with a stressful situation the body is either prepared to confront the danger and defend oneself or to run away from the situation. This Cannon called the fight or flight response. Later, Shelley Taylor and her colleagues came up with a theory that suggested that there exists a difference in the pattern of response to stress in male and female. The female in fact experience tend-and-befriend response. They interpreted that the females first tend to the needs of their offspring, then befriend themselves from the others members of the group with the intension to further protect their progeny (Gerrig & Zimbardo, 2006). But both these theories did not fare well in long run and there came the widely accepted theory by Selye.

History of stress laid down its initial stone way back in the year 1936, when Hans Selye defined stress in his work as, “the nonspecific response of the body to any demand made on it.” Later, he structured his theory as, “a state manifested by a specific syndrome which consists of all the nonspecifically induced changes within the biological system” (Rice, 2012, p. 23). In a simpler term stress can be defined as physical, emotional, cognitive and behavioral responses to events that are perceived as threatening and challenging (Ciccarelli & Meyer, 2006). The theory given by Selye fell under the wide umbrella of stress-response theory, which later became the fundamental pillar for other prominent and functional theories on stress. He termed the stressors (that causes distress) demanding physical reaction as general adaptation syndrome (GAS). GAS consists of three stages, namely 1) the alarm reaction, 2) the stage of resistance and 3) the stage of exhaustion. In the first stage the body enters the alarm phase of temporary shock and prepares itself to face the stressor right away, where as if the stress continues to persist, the body develops a condition called resistance. If the stressor still persists, the body wears and tears out physically

and psychologically, causing the final stage, the stage of exhaustion (Myers, 2004; Morgan et al., 2015). GAS is assumed to explain the reason why stress causes and exaggerates most of the physical diseases.

From the theory laid by the Selye, McEwen and Mendelson and McEwen expanded the theory on stress by stating that the state of homeostasis is disturbed by the neuroendocrine response of the brain to the psychological stressors like fear and anxiety. These reactions from the brain may lead to the psychosomatic reactions like gastric ulcers, immunosuppression and also depressive symptoms. Thus, they believed that the first mediator of GAS was psychological in nature. In regard to the present study the model given by Selye has been applied. The initial diagnosis of the child's disorder brought in parents a state of arousal which in a way prepared them to face the situation and then the state of resistance, followed by the state of exhaustion where the parents experienced greater degree of stress because of the continuous exposure the stressful situation (i.e., child's disorder).

1.3 Coping Styles

Studies identify that there are different strategies that may be used by parents to cope with varied stressors. In the initial stage, the parents may try to enhance their knowledge about the disorder from varied sources like, seeking professional help, browsing internet, and talking out with other parent facing similar situation; by seeking for support from the family and friends; reaching out to the autism support groups; taking structured parenting classes that will help the parents to deal with the children with ASD, religion; or look out for professional help to confront about the challenges faced at every step so that the professional can orient them to confront those issues with positive attitude and with ease. Based on the disposition of resources and their cost, the

parents finally decide which coping strategies they prefer to opt. At the same time the adaptation of the various coping strategies may be affected by the numbers of factors like their religious beliefs, level of education, financial status, cultural norms, and living in a rural vs. urban area (Sharma & Sharma, 2016).

There are different modules of coping strategies that are laid down from the early 1960s and 1970s. For the present study the 66 item questionnaire designed by Lazarus and Folkman (1984) was used. Lazarus applied the process theory in the construction of Ways of Coping scale. In an article, *Coping Theory and Research: Past, Present, and Future*, 1993, Lazarus has further laid down some of the generalizations of process approach. He assumes that coping may change over period of time. In the studies conducted by Lazarus and his colleagues, it was found that if a person uses social support as coping strategy in one stressful encounter, he using the same coping style in another situation may depend on the availability of the social support system. Whereas if an individual employed positive reappraisal in one stressful situation there is more likelihood that he would apply the same in the encounter of another stressful situation.

As defined by Lazarus and Folkman, (1984) coping is an, “ongoing cognitive and behavioral efforts to manage specific (external and/or internal) demands that are appraised as taxing or exceeding the resources of the individual” (Mitrousi, Travlos, Koukia, & Zyga, 2013, p.131). The above psychological definition given by the authors is widely accepted and studied upon. The definition puts the decision making responsibility on the individual facing the situation as how she/he chooses to deal with the situation. One of the early researches on coping focused on the role of defense in most of the psychopathology. It was believed that obsessive compulsive disorder was a result of defense mechanism called intellectualization. Likewise it was assumed that psychopathology was related to the defense mechanism. Secondly, the trait

approach pointed out that there is a personality trait that decides how the body reacts physiologically and psychologically to the stress. But this approach fails to reveal the process that is used in dealing with the stressor (Mitrousi et al., 2013).

One of the first models that described the process that takes in the dealings of stress and coping was given by Lazarus and Folkman. This interactive model works in two levels, first is to identify how the stressor is related to an individual. And second is to find the measures to deal with the same. The individual cognitively assesses the situation and gives it's a label, as saddening, emotional, significant, or insignificant. Once labeled, the individual then seeks the resources available to him at that particular time and place and makes uses of the most feasible and appropriate coping style do deal with the situation (Mitrousi et al, 2013). The interactive model was based on the model found on the work of Boakaerts, (1996) the describes the whole stress-coping cycle, i.e., a) the stress prone situation, b) available coping skills, c) assumed outcome of the coping, d) evaluation of the situation, e) the intent to cope, f) the particular strategy adopted. The Lazarus and Folkman further included the social group circle which says that the group in which the individual belongs is the plays an important role in dealing with the stress. Even the stress stimulating situation is a product of group rather than an individual concern (Mitrousi, et al., 2013). Lazarus and Folkman could expand the coping strategies into eight groups; they are self-controlling, confrontative coping, seeking social support, distancing, escape-avoidance, accepting responsibility, positive reappraisal and planful problem-solving.

Further in the study conducted by Folkman and Lazarus (1984) it was found that participants who employed planful problem solving and positive reappraisal, there was more chances that the emotional to the stressful encounter would change from negative to less negative or even positive. But the participants who had used distancing or confrontive coping had

opposite emotional changes that are more negative and more distressing. Thus, it can be said that some of the coping styles provided positive output whereas others failed to do so. There are number of coping strategies identified by the psychologists that are being in different situations. One of them is repressive coping. In this coping style the individual deliberately makes an attempt to not think of the situation that is stress prone rather they try to cover their story of life with unrealistic positivity. In the practice of this coping style the person falls into the pit of avoidance where their main aim is to avoid every possible situation that may bring stress.

Though initially this coping may seem helpful but researchers have found that in long run this coping style may be harmful. The challenges and situations in life are to be understood and problems are to be worked upon, this is general idea of rationally coping style. Rational coping is opposite to the previous coping style as it deals with facing the stressful situation rather than avoiding it. It working in three steps, a) acceptance- accepting that there is a presence of stress in one's life, b) exposure- being available to the stress, thinking about it and if needed even seeking it out. c) understanding- it is an attempt to understand the meaning of stress in one's life. Thus, better understanding of the problem and its meaning in one's life will definitely help in avoiding long term negative impact. Another coping strategy commonly used is reframing. Sometimes people find positive and innovative way of looking at the situation that help them to reduce their stress and at times also makes feel positive about it (Schacher, Gilbert, & Wegner, 2009).

1.4 Psychological Wellbeing

The degree of stress the parents go through and the different strategies the parents sought in order to overcome these stressors plays defines and also determines their psychological wellbeing. "Psychological wellbeing is a mental condition characterized by pleasant feelings of

good health, exhilaration, high self-esteem and confidence, often associated with regular physical activity” (Velsamy, 2016, p. 333). Studies support that raising a child with ASD does impact the psychological well being of their parents. In most cases male parent (father) is said to have better psychological wellbeing as compared with to the female parent (mother), (Velsamy, 2016). Another factor that may affect the well being of the parents is the sense of they may for not having the so called ‘control’ over the child’s behaviour. As autism is accompanied by the physical markers, most of the social situations the child is simply assumed to be misbehaving. Such judgment from the society is often taken as a self blame for failing to be an effective parent (Fernandez & Arcia 2004; Mak & Kwok 2010).

Ryff had started working on psychological welling 20 years back and she was one of the first professors to come up with a systematic model of psychological wellbeing which has been widely accepted in the parts of the world. Carol Ryff firmly believed that psychological wellbeing cannot be restricted to biological definition because it indeed headed to the purposeful meaning of a good life. She further went through the different philosophical theories by Aristotle, John Stuart Mill, Abraham Maslow and Carl Jung. The philosophies of these thinkers provided Ryff with the foundation ground on which she laid her model on psychological wellbeing. Ryff’s model differs from the previous models on the ground that psychological wellbeing is not merely a concept of happiness and positive emotion rather it is multidimensional which embraces different aspects of wellbeing (David, 2014).

The most widely accepted model of psychological wellbeing is Ryff’s Six Factor Model of Psychological Wellbeing. Carol Ryff’s model of welling dwells under six dimensions, namely autonomy, environmental mastery, personal growth, positive relation with others, purpose in life, purpose in life and self acceptance. Further defining each of these areas, Ryff states that the high

scorer on Self-acceptance has a positive outlook towards oneself. The individual accepts all facets of one's self which includes both positive and negative side of personality. Further the individual feels positive about one's past life and hopefully reaches out to future. While positive relationship the individual is loving, empathetic, caring, and understanding. She/ he do not face difficulty in maintaining a healthy relationship with others and understands and respects the presence of others in their life. In the area of Autonomy an individual is strong and determined in one's mind. She/ he practices control over self from within and does not easily give up to the social pressure. An individual who scores high on autonomy is most independent and self-determining. Environmental mastery is another dimension where the individual is competent in making an effective use of the surrounding opportunities. They are capable in managing the environmental (external) extremities and are able to identify the arena of their needs and comfort. Purpose is the next dimension in the model of psychological wellbeing where an individual feels a sense of purpose in his life and lives a life with aim and objective. Individuals who score low in this area basically lack a sense of directedness and have few objectives in life. They are mostly dependent and need frequent motivation from others to keep them driven in life.

Individuals who score high in Personal growth view themselves as growing and expanding with each experience, exploring their potentials. They are not closed to new experiences in fact they welcome them with jest and enthusiasm which would add to their knowledge on the world and as well as understanding of the self (Ryff & Keyes, 1995).

Thus, under this backdrop, the objective of the present study is to measure and identify the stress, coping strategies, and psychological wellbeing of parents' raring children with ASD. The study further extends its objects to identify if there is difference in the level of stress, coping

strategies, and wellbeing in parents of children with high functioning or mild autism and parents of children with low functioning or severe autism.

Review of Literature

This chapter contains the different studies on autism in regard to parental stress, coping styles used and their psychological wellbeing. Section 2.1 discusses on the symptoms of autism and its diagnosis. Section 2.2 deals with the studies conducted on the parental stress experienced by the parents of children with ASD. Section 2.3 focuses on the studies that deal with different coping styles used by these parents to deal with their daily stressors. Further, section 2.4 contains the studies that look into the psychological wellbeing of parents of children with ASD.

2.1 Studies related to Autism

The main deficits of ASD fall under the head of social life, communication, behavioural problems and emotional issues. It is the second common developmental disorder today after intellectual disability (Reffert, 2008). The reason why autism is known be a spectrum of disorder is because there is a wide variety and range of symptoms under ASD. For example, two individual diagnosed with ASD may vary in their range of behaviours and their degree of severity may vastly differ.

In India, psychology and psychiatry made its entry through colonialism. Autism was first recognized as child showing schizophrenic behaviours, in the year 1959 (Desai et al, 2012). Ever since number of studies are done in the field of autism. Though autism as a disorder have existed from a long, but its prevalence seems to have increased in the course of time. The possible reason behind this increase in the statistics could be the change in diagnostic criteria and increasing awareness and recognition (Hwang, 2008). The parents of the children of ASD have to face a lot

of difficulties while raising them. Autism as a disorder has no biological marker which further makes it difficult for parent to detect and understand their child's condition at an early age.

As defined earlier autism is an amalgamation of spectrum of disorders, ranging from mild to severe. Most commonly seen symptoms of autism are social, emotional and communicational impairment. One of the first social attention impairment in autism is the lack of normal "Social orienting," namely, the tendency to spontaneously orient to naturally occurring social stimuli in one's environment (Dawson et al., 1998). The typically developing infants devote particular attention to social stimuli, including faces, voices, and other aspects of human beings (Striano & Rochat, 1999). In fact by 6 months of age, typically developing infants will effectively orient (i.e., turn head and/ or eyes) to novel stimuli, particularly social stimuli (eg, being called by name; Trevarthen, 1979). Children with Autism, however, exhibit early impairments in social orienting. Home videotape of infants later diagnosed with autism (Osterling & Dawson, 1994; Osterling, Dawson & Munson, 2002) revealed social attention impairment, including a failure to look at others and orient to their name in 12 months old. Besides this disorder is marked with emotional impairment which deprives the parents of the basic love and attachment of parenthood. The parents of children with ASD may feel deprived of the few parental rewards, as the child is not able to form a healthy and normal relationship with their parents. This in turn adds to their degree of stress (Sunayan, 20014; DePape & Lindsay, 2014; Tehee, Honan & Hevey, 2009). These experiences in turn affect their physical and psychological wellbeing.

2.1 Studies on Stress

As Pisula (2011) claimed, the life of parents with developmental disorder child is much more challenging compared to the parents with typically developing child. As studies comprehend,

parents of children ASD experience higher degree of stress compared to parents with other disabilities or parents of typically growing children (Ogston, 2010; Mancil, Boyd & Bedesem, 2009; Tehee, Honan & Hevey, 2009). The primary stressors experienced by the family members with an ASD are mainly identified as, financial pressure to meet the treatment needs, family disharmony, child's behavioral problems, failure to procure social support, social isolation and child's future concerns (Mancil, Boyd & Bedesem, 2009; Bashir, Khurshid, & Qadri, 2014; Jones, et al., 2014; DePape & Lindsay, 2014; Dardas, 2014). Along with these the comorbid conditions (mostly maladaptive behaviors, other psychological disorders like ADHD, neurological disorders, like epilepsy and developmental delays) which are generally accompanied by the ASDs, could be the possible stressors for the parents.

Further, depending upon the degree of disorder the stress in parents increase as the child grows older. The common fear observed in parents is the child's future independence and social life. The parents feel persistently distressed and are in sorrow for the very fact of their child's unpredictable future quality. As the parents get older they also fear their child's life after the parents aren't there to take care of them (Mancil, Boyd & Bedesem, 2009; DePape & Lindsay, 2014; Ogston, 2010). Unavailability of medical facilities within the geographical reach could be one of the major stressors for the parents. Sometimes the diagnoses are prolonged and confusing. In some cases the child was diagnosed as deaf because he failed to respond to his name (Kuhaneck, et al 2010, DePape & Lindsay, 2014; Tehee, Honan & Hevey, 2009; Tunali & Power, 1993). Another potential stressor is the reactions from family, friends, and neighbors and from society in general. The parents many a time feel the absence of family, societal, spousal, informal and professional support (Bashir, Khurshid, & Qadri, 2014). These stressors affect the personal as well as the social life of the parents and family members of children with disabilities

like ASD, ultimately leading to social isolation (Tunali & Power, 1993). Further the uncertainty of child's degree of autism in their adolescence adds on to the parent's worry and despair (Ogston, 2010). Studies further indicate that mothers go through higher stress as compared to fathers of children with developmental disabilities. Less involvement of fathers in child's daily activities could be the reason for their lower level of stress, though this area needs further exploration (Hastings, 2003; Sunayan, 2014; Velsamy, 2016; Tehee, Honan & Hevey, 2009; Bashir, Khurshid, and Qadri, 2014; Pathappillil, 2011).

While the parents are going through these challenges, it is very important that they are made aware of the various social and educational facilities that are available to the child and the family. Apart from the special educators and health care professional, who are the primary support system and the society, has its own significant role as a principle social support for the family faced with ASD (Sharma & Sharma, 2016). As per the literature, the commonly used coping strategies to deal with these stressors in the daily life are support from family and society, faith in God, appropriate support government and policy makers (Sharma & Sharma, 2016). All brings a positive attitude and needed support for the family to deal with daily challenges.

DePape and Lindsay (2014) analyzed 31 articles using constant comparative approach to explore the experience of parents in rearing a child with ASD. During this analysis the authors came up with six broad themes of experiences, they are: prediagnosis, diagnosis, family life adjustment, navigating the system, and moving forward. Some parents reported that their children grew typically in their early years where as some parents complained that there was something in their child from the very beginning. This atypical development of their child made the parents search for the reason for their different nature. After the diagnosis the parents reported to have felt relieved as they could identify the reason for their child's atypical

development. This sense of relief was soon followed by the sense of devastation for some of the parents as they were confronted with the long term diagnosis and changes in daily life schedule. The parents also experienced financial burden in meeting child's regular medical needs and therapies. At the same time the parents may also have to go through social humiliation because of their child's condition. Parents also show their dissatisfaction with the social support group and school system that fails to fulfill the child's and parent's need (DePape & Lindsay, 2014, Bashir, Khurshid, & Qadri, 2014).

A study was conducted by, Bashir, Khurshid, and Qadri, 2014, with aim to assess the degree of awareness among parents of children with ASD about the disorder, and also to study various challenges faced by parents of these children. Five mothers of children with ASD participated in the study, selected through random sampling. The participants were subjected to the interview schedule which was structured under five broad heads. The results indicated that 60% of the parents had financial issues because of which they faced problem meeting medication needs of the child and other household expenditures. Responses from the participants indicate that the state of their child affected their psychological wellbeing, especially mothers, because they had to face all responsibilities for the child's state, including inequity in the division of household work and in addition to it, the undesirable societal pressures (Velsamy, 2016; Tehee, Honan & Hevey, 2009; Pathappillil, 2011). 60% of the parents reported that the medication and treatment did not bring any changes in the condition of the child, as it did not make the child self sufficient to lead an independent life (Kuhaneck, et al 2010, DePape & Lindsay, 2014; Tehee, Honan & Hevey, 2009). Majority of the parents reported a constant worry of what would happen to the child after them (DePape & Lindsay, 2014; Ogston, 2010). Most of the parents with ASD even opted to have second child with a belief that their child with ASD will have someone with

them after their parent's death. The study also indicates that 60% of the participants were not aware of the interventions and the available resources for their child that can help, if not overcome, but deal effectively with their impairments.

Pathappillil (2011) worked on the topic entitled, *Through Our Eyes: A Qualitative Study of Indian Mothers and Their Perceptions of Autism*. The purpose of this qualitative study was to investigate the perceptions, awareness and knowledge of Indian mothers on raising a child with autism. Semi structured interview was conducted on eleven Indian mothers settled in United States. Three participants had direct exposure to children with autism spectrum disorder and rest had known Indian children with autism. The research results indicated the lack of awareness among Indian population about the disorder autism and its symptoms. Due to high stigmatization in Indian society, families, especially mothers, of children with any form of disability face a lot of social and emotional strains (Velsamy, 2016; Tehee, Honan & Hevey, 2009). The lack of acceptance of these atypically growing children in the society could be one of the reasons behind their reluctance in seeking the little resources that is available for the children with autism and their family. Thus, Indian mothers' rearing children with autism experience whole lot of more stress, responsibility and social isolation.

Silverman (2008) says, "Individuals with autism whose life histories suggested the most resilience and best overall quality of life were often those who, rather than being independent, benefitted from accommodations in their surroundings and a complex network of social and family supports" (p.328). The author said that in many scenarios, it is social, economic and cultural factors, even more than innate cognitive, psychological, or developmental deficits that make experiences with ASD so difficult to manage. In India as a whole, and certain regions in particular, the challenges of ASD are exacerbated by a number of social factors. The author

further adds that the disability is a social problem. It is a problem of stigma, a problem of lack of awareness, and a problem with the lack of available and accessible resources.

The parents of ASDs are seen to have more stress as compared to other parents when the child starts going to the school. Their general areas of concern are mostly on how far the child will be able to follow the instructions at school, form social relations, communicate their need, and do the required school work. Some may have the pre academic skills, but they have difficulty applying those skills, lack social skills, and have difficulty in maintaining attention for required amount of time (An Atlantic Partnership Education in Autism, 2015). Though there can be lot of stress both for the child with ASD and their families, but with proper transition planning this primary change can be a platform for new opportunities which will help them learn and develop newer skills and form healthier social relations (Vicker, 2009).

Another study titled, *Stress, Burden and Coping between Caregivers of Cerebral Palsy and Autism Children* was conducted by Pushpalatha and Shivakumara (2016). As it is clear from the title of the study, the purpose of the study was to see if there was notable difference in the experience of stress, burden and coping strategies among the care givers of ASD and CP. The study was conducted on total of 60 participants, 30 care givers of CP and 30 care givers of ASD. The Parenting Stress Index (Short Form), by Abidi was used to assess stress in both the groups, Schedule to Assess Burden by Pai and Kapur, was used to measure the degree of burden felt by the caregivers due to the child's disability and Coping Checklist by Rao, Subbakrishna and Prabhu, was used to identify the different coping strategies used by the participants to cope with their daily stressors. 't' test was used to identify the significant difference between the two sample groups. As a result, the parent caregivers of children with ASD experienced greater level of stress as compared to care givers of CP, where as the care givers of CP experienced

comparatively greater degree of burden as compared to the caregivers of ASD. Both sample groups used different forms of coping strategies depending on the daily life situations.

In the study conducted by Tehee, Honan & Hevey (2009), parents of 24 children with autism participated in the study which examined the stress and coping strategies of these parents. 23 mothers and 19 fathers were part of the study. The age group of the children marked from 3-18 years of age. The parents had to fill number of questionnaires, from social demographics to The Perceived Stress Scale-10 item, The Family Stress and Coping Questionnaire, and The Support Questionnaire. 300 Questionnaires were distributed in the schools and other institutions with instructions and information about the study, out of which only 42 filled questionnaires were returned. When looked from gender perspective, it was found that mothers experience greater stress, and were more involved in child caring than fathers. The mothers also reported to have felt overburdened with the household responsibilities. The study found a positive correlation between support system and information/ education. It was identified that mothers reach out more to the social support system when compared to the fathers.

Studies indicate that parents who reach out for social support, practice emotional regulation, make use of different coping skills and indulge oneself into more positive thinking have reported to having positive daily mood, less stress, and decreased level of depression (Sharma & Sharma, 2016; Tehee, Honan & Hevey, 2009). Whereas parents who adopt blaming, worrying, and withdrawal as coping strategies reported to have a negative outlook towards every situation, higher levels of daily stress, and increased feelings of depression and sadness (Sharma & Sharma, 2016). In the study conducted by Sharma and Sharma 2016 the main objective of the study was to explore the stress experienced by the parents whose child was diagnosed having ASD. The study further extended its objective by trying to identify the various coping strategies

adopted by these parents to deal with the stressors in daily life. For the stated purpose, five parents with ASD child were taken, who had at least one another child apart from the child with ASD. These samples were interviewed on the basis of interview schedule consisting of 38 items specifically made for the study. The interview schedule questions were focused under the broad heads of their reaction when the child was first diagnosed with the disorder, if the diagnosis brought any changes in their life, if the stress was experienced, and if so what were different strategies the parents adopted to deal with those stressors. The result from this qualitative study stated that autism is life altering to parents in many ways, from changes their intra personal identity, to their social life, their important career decisions, and it also hampers the relationship with the spouse and other family members. All most all the parents reported to have gone through the phase of adjustment after the diagnosis of their child. Different coping strategies were adopted based on their availability and degree of accessibility. Some who had greater resilience had better state of mind which made them resourceful and increased their ability to cope up with their situation. Study was conducted by Jones and colleagues (2014) to see if psychological acceptance and mindfulness had any positive implication on distress in parents caused by the child's behavior problems. It was found that the psychological acceptance helped the parents to deal with their daily stressors. Along with this general mindfulness and parenting mindfulness was seen to have a positive effect in relation to parent's level of stress, anxiety, and depression.

Though studies have been identified that attempts to measure the stress and identify the coping strategies, but least is the work done in the area of designing the educational and counseling programmes that would help the parents to deal with these stressors (Mancil, Boyd & Bedesem, 2009). Access to social support and families of other children with ASD tends to be

the means to share and reduce the stress experienced by the family members. Thus, the practitioners could help the families make access to the social support groups and well planned educational and counseling sessions for both the parents and children with ASD (Mancil, Boyd & Bedesem, 2009). Some of the common and most used coping strategies that are the used by the parents include social and family supports, professional supports and services, support groups, and religion. It is found that religion and support from the spouse and few the most effective coping strategies (Kuhaneck, et al 2010).

2.3 Studies on Coping Strategies

In order to deal with the daily stressors the parents need coping strategies that is appropriate and also accessible. Six major maternal coping strategies were identified, namely, (a)“me time,” (b) planning, (c) sharing the load, (d) knowledge is power, (e) lifting the restraints of labels, and (f) recognizing the joys. As rearing a child with ASD is indeed a time and also energy consuming, it was reported that the mothers of children with ASD needed the ‘me time’ that would fill them with new energy for the upcoming task. Some of the ‘me time’ comprised of their morning exercise, meeting up with their friends, and spending quality time with their other children. Planning much ahead and in abundance helped the mothers as well as the child. The mothers further reported that it is effective to warn the child before hand for the transition in activities as it prepared the child for the next task and also mellowed down her/his tantrums. At the same time having a partner who is supportive and also understanding turned to be an emotional and practical support system to the mothers. The mothers reported that their knowledge about the child’s disorder and to know the resources available to them became an important instrument to deal with their daily stressor. Giving the child enough space to grow with the typically growing

children helped the child to develop and become expressive of their feelings (Kuhaneck, et al 2010).

In a paper titled, *Parental Stress and Autism: Are There Useful Coping Strategies?*, number of articles were reviewed that looked into the stress and coping strategies that were adopted by the parents of children with ASD to deal with the stressors. The review primarily focused on the research results and methodologies implemented in the studies, and aimed to identify and present various guidelines and implications for the researchers and practitioners who deal directly with ASD and their parents. After making a thorough search, 19 articles were selected which met the predetermined inclusion criteria. The most common stressors that affected the lives of parents of ASD were child related stress, social isolation, frustration, and marital relationship issues. Whereas the most commonly identified coping strategies were social and professional and spousal support (Mancil, Boyd & Bedesem, 2009).

Grey (2006) conducted a longitudinal research on the experience of parents of children with ASD in regard to the coping strategies. The aim objective of the study was to identify if there is change in the coping styles used by the parents of children with ASD over a decade (approx.). The study was conducted on 29 parents, 19 mothers and 9 fathers. The qualitative method used in this study was ethnography and data was collected through in-depth interviews and participant observation. The results from the study indicated that there is change in the selection of coping strategies by the parents over a period of time. The parents reported lesser emotional disturbances and lesser usage of coping strategies in the later phase of the study. Grey reported that there was a shift from problem focused coping style to adoption of emotion focused coping style where parents paid attention to the good qualities of the child and showed more inclination to religion.

In a pilot study, the author included parents as well as the siblings to understand the, *Coping Mechanisms and Parental Relationship in the Families of a Child with Autism Spectrum Disorder*, Gour and Pandey (2016). The researcher interviewed the parents and siblings of autistic children with the aim to identify their coping mechanisms, and to investigate into the relationship between the parents and siblings of ASDs. The study was conducted in the National Capital Region (NCR) of India, spanning New Delhi, Gurgaon, Noida and Greater Noida. The sample included 10 families and 4 members from each family which made the total sample size of 40. Each participants, mother, father, and the typically growing sibling were interviewed separately. The data thus collected was transcribed in word document, and then content analysis was done in order to identify the themes, using phenomenological psychology to interpret the data. The results from the study suggested that almost every parent experienced stress in their marital life after the diagnosis of ASD in their child (Sharma & Sharma, 2016). But with early intervention and general optimism, the relationship gradually became complementary with the reduction of stress. To cope with varied stressors, when the parents sought for the household support or gathered knowledge from the internet sources, this instead added to their stress rather serving as coping mechanism. Acceptance of the diagnosis, seeking early professional help, and learning parenting styles, were found to be the best coping styles. Interestingly, the relationship between the sibling and the ASD child was found to be close. In cases where sibling was elder, especially female, at times took up the maternal role in taking care of the younger sibling with autism.

One of the coping measures could be self-compassion, “which involves being kind to oneself in times of difficulty, recognizing the shared nature of human suffering, and being mindfully aware of negative thoughts and emotions” (Neff & Faso, 2014, p. 1). The result of a

study, *Self-Compassion and Well-Being in Parents of Children with Autism*, by Neff and Faso (2014), pointed out that self compassion could have a significant role in positive psychological wellbeing in parents of children with autism. The study was conducted with the aim to identify and measure if self-compassion had any relationship with other psychological aspects, such as, life satisfaction, hope, goal reengagement, depression and parenting stress. To measure these psychological aspects the following tests were used, namely: Self Compassion Scale (SCS; Neff 2003), Satisfaction with Life Scale (SWLS; Diener et al. 1985), Adult Hope Scale (Snyder et al. 1991), a subscale of Goal Disengagement and Goal Reengagement Scale (Wrosch et al. 2003), Center for Epidemiologic Studies Depression Scale (CES-D; Radloff 1977), Parenting Stress Index-Short Form (PSI-SF; Abidin 1995), respectively. For the mentioned study, the author included 51 parents (40 mothers and 11 fathers) of children with ASD. Severity of autism in the children of these parents was identified using Gilliam Autism Rating Scale 2nd edition (Gilliam 2006). The study came up with the results that self compassion invariably had positive correlation with life satisfaction, hope and goal reengagement and negative correlation with depression and parental stress.

2.4 Studies on Psychological Wellbeing

The psychological wellbeing of these parents gets affected in dealing with their life stressors. When looked into the quality of life (QOL), the existing researches suggest that parents of children with ASD had poor QOL as compared to the parents of typically growing children or with other disabilities. The core symptoms of ASD being social deficit and maladaptive behavior might hinder the parent's access to social support system. This may gradually lead to social isolation in parents effecting their QOL and psychological wellbeing (Eapen & Guan, 2016). Velsamy, in the year 2016 conducted a study where the author wanted to test the psychological

wellbeing among parents of children with ASD. The author hypothesized that there is no significant difference between father and mother of children with autism in anxiety, depression, positive wellbeing, self control, general health and vitality. The study was conducted on 25 upper middle class couple, parents of children with ASD, from the city of Chennai, Tamil Nadu. To obtain the said objective, the Psychological Well Being Index by Harold Dupuy (1984) was used. This questionnaire contains 22 statements on 6 dimensions and is ranked under 6 point scale. The acquired data was then analyzed using t test. The scores indicated that fathers of children with ASD have less anxiety and depression, better positive wellbeing, general health, and vitality as compared to mothers (Tehee, Honan & Hevey, 2009). Mothers, on the other hand were seen to have better self control as compared to fathers.

A recent study (Ogston, 2010) was conducted to see the experience of hope and worry in the parents of children with ASD and Down syndrome. The study was conducted on two hundred and fifty nine mothers of children with autism spectrum disorder (n= 199) and Down syndrome (n= 60). The study identified two broad themes through qualitative study. Under theme of child and family, the worries were focused on child's health, well being, school related worries and child's ability to live an independent life. The main points under the self centered worries are: worries regarding daily life stressors and work pressure, financial concern, child's concerns after the death of the parents, wellbeing, and health and sleep issues. The study had used both qualitative and quantitative approaches to understand the role and presence of hope and worry in parents of children with autism. Quantitative data was collected online using different questionnaires on worry and hope, whereas, the qualitative responses were derived through semi structured interviews. The qualitative data was analyzed thematically after the transcription of the interviews. It was found in the study that mothers who had high hopes worried less and

could make efficient plans to meet their child's and their own personal demands. Education qualification of mothers had positive correlation with hope and also with their socio economic status.

In the Indian study conducted by the authors Perumal, Veeraraghavan, and Lekhra (2014) found that parents of children with autism spectrum disorder show significant impairment in all the four domains of wellbeing i.e., Physical, Psychological, Social and Environmental, when compared to the parents of children with physical disability or typically growing children. At the same time no significant difference was seen in QoL in terms of degree of their child's autism. The study was conducted on 140 Indian parents that comprised of 73 mothers and 67 fathers. These were the parents of 54 children with autism, 38 children with physical disability, and 48 typically growing children. The instrument used to assess autism was Indian Scale for the Assessment of Autism (ISAA), whereas WHO Quality of Life BREF (WHO QoL-BREF), Hindi version was used to measure the quality of life in these parents.

Study was conducted in one of the Arabian countries, Jordan. The study aimed to explore the stress, coping strategies and quality of life of parents rearing a child ASD in a country like Jordan where the most of the families are already affected with low or middle socio economic status and financially unstable household conditions. The scales used to measure the three variables, stress, coping strategies and quality of life were, The Parenting Stress Index- Short Form (PSI-SF), The Ways of Coping Checklist-Revised (WCCF), and The World Health Organization Quality of Life Assessment-Bref WHOQOL-BREF self-administered instrument. WHOQOL-BREF was translated in local language which was validated with a pilot study. 184 parents participated in the study whom the author met individually and in group, explaining and instructing the participants about the study and guidelines to fill the form. The findings of the

study stated that in most of the cases mothers were the primary care givers of the child which is in sync with of the previous findings (Tehee, Honan & Hevey, 2009). It was also found that the parents of children with ASD experienced significant amount of stress, though no difference in stress was found between the male and female parent. In case of coping strategy, it was found that majority of the parents adopted positive reappraisal as coping mechanism to their daily stressors. The developmental condition of the child hampered the parent's quality of life affecting their social, physical, psychological and environmental health domains.

Studies dealing with stress experienced by the family of children with developmental disabilities have gained its importance in recent years. Along with this, time has witnessed changes in the ways stress has been defined and redefined. The most recent and widely accepted definition is the evaluation of stressful situation in terms of availability of resources to deal with the stress which takes the traditional theories to next level. Thus, the availability of the resources directly affects the stress experienced in a situation (Tunali & Power, 1993). As seen in the above studies, in most of the cases parents were unaware of the resources available and even if they had access to the resources they weren't satisfied with the services provided (Bashir, Khurshid, & Qadri, 2014). In the above literature review it is seen that there are in fact number of studies conducted on the experiences of parents having a child with autism. These studies have looked into the various psychological aspects, starting from depression, stress, burden, coping strategies, well being, quality of life, to the parental awareness, perception and knowledge, about autism, different challenges faced by the family, and parental relationship which might get affected because of autism. Most of these studies have focused on the negative aspect of having a child with ASD, but very limited effort is made in exploring the positive changes that might have taken place in the life of the parents after the diagnosis of the child with

autism. Some studies report that the child's autism has improved the live of the individual (mostly parents) by increasing the level of their tolerance and patience. The parents have improved in the relation by being more understanding and supportive, emotionally and practically (DePape & Lindsay, 2014).

In most of the articles reviewed above, the limitation lied in the adaptation of methodologies. Most of the studies have adopted either qualitative or quantitative approach to study the above mentioned phenomena which indeed requires a very detailed, in depth and at the same time a scientific approach. Majority of the studies focused on the experience of mothers, while undermining the possible psychological effects on male parent of children with ASD, who is additionally burdened with meeting the needs of his family. Though some of the studies have tried to include the male parents in their studies, but due to the small sampling size the results acquired from those studies cannot be generalized. Studies were identified that had limited sampling (3-5), and also included participants who did not have direct exposure to autism. The results from these studies were generalized on parents' awareness of the disorder, their level of stress and social challenge and stigma. Most of the studies have failed to look into the socio economic demographics of the family in concern with the study, which directly affects the experience of parents of ASDs. A huge bulk of researches is done in the western nations the results of which cannot be generalized on the Indian population. Most of the studies done in the area of autism in India are centered around the metro Politian cities, like Chennai, New Delhi, Srinagar, Goa, and other place. Thus, body of researches must rise in India so that it would be a direct benefit to the Indian population in terms of identifying the appropriate coping strategies for the parents as well child that would help them deal with daily stressors. Quality research needs to be done on Indian population which includes the rural sample living with ASD, so that

the practitioners, policy makers and resource providers can be aware of difficulties faced by of these areas and can further make plans and avail resources that can be practically and efficiently put to practice.

The Present Study

3.1 Rationale of the study

It has been observed that the prevalence of autism has increased in the recent years. After a thorough review of literatures, it was found that there are limited resources available in the field of autism, especially in the Indian context. Number of study is done in the western countries that looked into the various psychological aspects related to autism and their family. However, Indian studies on autism are fewer in number compared to the researches done in western countries. Indian studies that are done on autism are conducted in and around the metro Politian cities, like Chennai, New Delhi, Srinagar, Goa, and other place. The present study was conducted in the small district of West Bengal, Siliguri. Though number of studies have been conducted that looked into the experiences of parents having a child with autism on different psychological aspects, starting from depression, stress, burden, coping strategies, well being, quality of life, to the parental awareness, different challenges faced by the family, and so on. Most of the studies had adopted either qualitative or quantitative approach to study the above mentioned phenomena. Thus, in the present study, the parental stress, coping and psychological wellbeing was studied using both qualitative and quantitative approaches which indeed shall provide with an in depth and also scientific understanding. Thus, mixed method approach shall help in the comprehensive understanding of the phenomena, strengthening the present body of available resources. Majority of studies have focused on the experience of mothers, while undermining the possible

psychological effects on male parent of children with ASD, who is additionally burdened with the financial needs of his family. Thus, keeping in mind all the practical challenges, the present study has included the male parent in the participant group. This has further helped in understanding if there laid any difference or similarity in the way mother and father perceive stress.

Statement of problem: As per the review of related literature, it is found that parents of children with ASD face a lot challenges and has a greater degree of stress as compared to parents of children with other disabilities. Thus, the present study, under the title, “Stress, Coping Strategies and Psychological wellbeing among parents of children with Autism Spectrum Disorder,” aims to measure and identify the stress, coping styles, and psychological wellbeing of parents’ raring children with ASD and also to discern if there lies any difference in the level of stress, coping, and wellbeing in regard to child’s age, degree of autism and parent’s gender.

3.2 Research Questions

Under this backdrop, the present study poses following research questions:

- 1) How do parents of children with autism experience stress in their daily life?
- 2) What are the coping strategies frequently used by parents of children with autism?
- 3) In which area do the parents of children with ASD have better psychological wellbeing?
- 4) Do parents (mother and father) differ in their experience of stress, usage of coping styles, and psychological wellbeing in dealing with their children with ASD?
- 5) How do parents of children with ASD experience stress, coping and psychological wellbeing across, child’s age and their degree of autism?

3.3 Objectives of the study

The study has following objectives:

- 1) To study the status of stress, coping styles, and psychological wellbeing of parents with ASD.
- 2) To examine the relationship among stress, coping strategies, and psychological wellbeing of parents of children with ASD.
- 3) To investigate stress, coping, and psychological welling across various groups of child's age, severity of autism, and parent's gender.

Methodology

The present chapter deals with the discussion of the methodological concerns in the present study. This chapter consists of eight sections. 4.1 is the section of methodological considerations, in which the methodology used in social science will be defined. Section 4.2 shall deal with the different research designs used in the social sciences and also discusses the overall research design of the present study. Next section, 4.3 deals with data collection, techniques used, and participants in detail. Section, 4.4 introduces the different data collection instruments that has been developed and used in this study. Before conducting the study all the ethical concerns were met by the researcher which will be dealt in detail in section 4.5. The above mentioned data collection methods were implemented in the main study and section 4.6 shall deal with this part in detail under the head of procedure. Section 4.7, data analysis, discusses on how the data collected though both qualitative and quantitative method were analyzed.

4.1 Methodological concerns

In the most common term researches must sought to understand a problem and find a solution to it. In the field of social sciences, researches are done in order to understand the social phenomenon as a whole. Thus, while formulating a research problem, a social researcher always pays attention to the group than at an individual issue. This is because what is true for an individual may not be true for a group but what is applicable to a group may be applicable to most of the members in the group. Social research is a method of studying, analyzing and conceptualizing social life in order to verify the abstracted knowledge (Raiyani, 2012). Thus we

see that social research makes use of the scientific as well as the systematic framework that is used to expand our knowledge on social life and facts.

If methodology is to be defined in the traditional term, it indicates to the process in which the answers are shot for the framed questions, measurements are recorded, the phenomena under observation are described and then the experiments are conducted. In the words of Kaplan, the aim of the methodology is, “to describe and analyze these methods, throwing light on their limitations and resources, clarifying their presuppositions and consequences, relating their potentialities to the twilight zone at the frontiers of knowledge. It is to venture generalizations from the success of particular techniques, suggesting new applications, and to unfold the specific bearings of logical and metaphysical principles on concrete problems, suggesting new formulations” (Cohen, Lawrence & Morrison, 2005, pp. 45). Thus, in terms of Kalpan, research methodology tries to focus more on the process of the study than its product.

Social scientists conduct research following a systematic plan that is provided by the methodology. There are two families of social sciences research method; they are qualitative and quantitative methodologies. While one looks into the social phenomena through the lens of quantifiable evidence and depends on the statistical analysis, the other relies on direct observation, communication and subjective interpretation of the same phenomena (Social research, n.d). Though the methods have been divided into qualitative and quantitative, most of the methods contains the elements of both.

In order to fulfill the objectives of the present study mixed method approach was used that implements of both qualitative and quantitative measures for data collection and data analysis.

4.2 Research Design

In general terms, research design is said to be the blue print or a detailed plan of how the research will be carried out. It covers the complete framework of the research covering sample, sample size, tools used in collecting data, the procedure followed, and analyzing data. Research design is the detailed step by step plan on how a research study will proceed, where everything is well structured and defined.

There are different types of research designs used in social sciences based on the method chosen by the researcher, i.e., qualitative or quantitative. The quantitative research designs can be broadly classified into three heads by examining them from three different perspectives: 1) the number of contacts with the study population 2) the reference period of the study and 3) the nature of the investigation. On the basis of the number of contacts, a quantitative study can be designed in three different ways, i) cross-sectional studies, ii) before- and- after studies and iii) longitudinal studies. Based on the reference period, studies can be categorized as i) retrospective, ii) prospective and iii) retrospective-prospective. Further, the study design based on the nature of investigation can be designed as i) experimental research, ii) non- experimental research and iii) quasi or semi-experimental research. In the present day scenario another possible quantitative research is online survey method that is mostly used on large sample size. Commonly used study designs in qualitative study are case studies, oral histories, focused group/ group interviews, participant observations, and community discussion forum (Kumar, 2014).

Through literature review, it was recognized that some studies have used the qualitative method by administering interviews or case studies to understand the level of stress that is experienced by the parents of children with ASD. Some other studies have used only questionnaire to understand the same phenomenon and also the coping strategy and

psychological wellbeing. While others have very diligently made use of both the qualitative and quantitative method which gave an objective and as well as an in-depth understanding of stress, coping strategy, psychological wellbeing and also the relationship between these variables.

As per the need the present study, mixed method approach was used. Data was collected using both the qualitative and quantitative methods. The quantitative data was collected using different questionnaires that measured stress, identifies different coping strategies, and levels their psychological wellbeing. The qualitative data was collected through in-depth interviews with the parents of children with ASD.

Creswell and Clark (2007) define mixed methods research as ‘the combination of quantitative and qualitative approaches which provides a better understanding of research problems than either approach alone’ (pp. 8-9). As stated above, using mixed method approach gives a better and in depth understanding of the phenomena under study which may not be possible by using the single approach alone. Mixed method approach strengthens the research results, as the same phenomenon is examined in different ways. Through this method data can be drawn from different sources, limiting the chances of researcher’s biases (Hwang, 2008). There are different types of mixed method given by different authors in different disciplines. In the field of evaluation, mixed method is defined by Greene, Caracelli and Graham (1989) with five types namely, initiation, expansion, development, complementary and triangulation. There are four major types of mixed method designs used in social science; they are the triangulation design, the embedded design, the explanatory design and the exploratory design (Creswell and Clark, 2007). Triangulation design is the well-known and commonly used design. In terms of Morse (1991) the triangulation method is used, “to obtain different but complementary data on the same topic.” Thus, this method is used when the researcher wants to validate and enhance

her/ his research finding using different sets of data that are complementary to one another. In triangulation design, result consists of the interpretation based on both qualitative and quantitative findings.

Thus, keeping in mind the objectives of the present study, mixed method approach was used to have an in-depth understanding of stress, coping and psychological wellbeing of parents of children with ASD. The researcher used the triangulation design where the interpretation was based on both qualitative and quantitative findings. The study concerns with the experience of parents rearing a child with ASD. The study looked into the three main areas, namely the level of stress experienced by the parents, the various coping strategies adopted by these parents in order to deal with their stress in day to day life. And also to measure their psychological wellbeing that is likely to get affected because of their child's condition.

Firstly, stress, coping styles and psychological wellbeing of parents of children with ASD were measured using different questionnaires. These evaluative tools are discussed in detail in section 4.5. Later qualitative data was collected using semi-structured interview schedule on 10 parents (6 mothers and 4 fathers).

4.3. Population

Research population is generally defined as a large collection of individuals or objects, who share the common characteristics that is the main focus of the scientific query. There are two types of population, target population and accessible population. The target population is the entire group of individual or object to which the researcher is interested in generalizing the result of her/ his study. It is also known as a theoretical population. Whereas accessible population is the definite group of population on which the researcher can apply their conclusion. The

accessible population is also known as study population. But the population itself at times is so very large that it becomes inconvenient for the researcher to investigate each individual. Thus, the sampling technique comes into the scene which makes the task easier. Thus, from target population the accessible population is derived and from it comes the sample (Banerjee & Chaudhury, 2010).

In the present study, the target population is the parents of children with autism spectrum disorder in West Bengal. The conclusion drawn from the study is applicable to this sample alone. As per the objective of the present study, the participant consists of the parents of children with autism spectrum disorder who are already diagnosed as per the ICD-10 diagnostic criteria. The study included only the parents of children with mild and moderate autism. Both the parents were included in the study. It was strictly noted that the children of these participants fall under the age group of 3-10 (childhood) and 11- 18(adolescent) years. In order to be sure with their age group, the researcher verified it with the child's birth certificate. For the present study sample was collected from Siliguri, West Bengal, India.

4.3.1 Sample

Bogardus defines sampling as, "Selection of certain percentage of group of items according to the predetermined plan" (Ramamurthy, 2014, pp. 84). Thus, from the stated definition it can be said that sampling technique to be used in the study depends on the aims, objectives, and methodology of the study. Sampling basically means the population one tends to involve in her/his study. There are number of sampling techniques available for the researchers through which they can segregate their sample from the general population. There are two broad methods of sampling- 1) Probability Sampling and 2) Non-probability Sampling.

Probability sampling technique is the commonly used sampling techniques in social sciences in which the probability of selecting each item in the sample is known. Probability sampling contains some form of random sampling. This sampling technique is further divided into five categories. They are: A) Unrestricted sampling- in this method each member in the target group has an equal chance to be a part of the sample group. This technique is free from biases where everybody stands an equal chance. B) Restricted sampling- this technique is somewhat restricted and complex compared to the unrestricted sampling. C) Systematic sampling- in this sampling the researcher randomly selects the first and then the nth person after that. This technique may include some form of bias. D) Stratified sampling- here the sample is decided after dividing the target group into different strata or sub groups. This sampling is considered to be the most efficient probability sampling technique. Stratified sampling is further divided into proportionate stratified sampling and Disproportionate stratified sampling. E) Cluster Sampling- in this method the entire population is divided into clusters or small groups and then the sample is selected on the basis of random sampling (Bhattacharyya, 2006; Ramamurthy, 2014).

In case of researches where the target population is an anonymous group such as, alcoholics, widows, or in case of the present study, the parents of autistic children, probability sampling might not be possible. Thus, in such cases non probability sampling technique has to be used. There are five techniques under non- probability sampling technique. They are: A) Quota sampling- this sampling technique is a form of stratified sampling with a difference that in this case the sample is selected on the basis of 'quota' fixed by the researcher. This technique works best in case where the researcher wishes to study the characteristic trait of a particular group from the whole population. B) Convenient sampling- this technique is also known as accidental

or haphazard sampling. Under this method the researcher selects the respondents on the basis of their easy and convenient accessibility. C) Judgment sampling- here the sample is selected on the basis of the researcher's judgment. The results collected from this technique may not be generalized as the data collected fails to represent the whole population. D) Purposive sampling- this method is a form of judgment sampling where the researcher selects his respondents to fulfill the purpose of the study. E) Snowball sampling- in this case researcher reaches out to the respondents through references. The researcher first starts with the respondents who are available to him and those respondents further suggests the names of the other participants who fulfill the criteria of the research (Ahuja, 2007; Ramamuthy, 2014).

Keeping in mind the aim and objectives of the present study, purposive sampling technique was used. In this technique the researcher starts with the purpose in his mind and selects only those respondents who fulfill the purpose of the study, excluding the rest. Though this form of sampling is similar to judgment sampling the difference can be laid on the emphasis of fulfilling the purpose of the research. There is high chance that the researcher's subjectivity may hamper the sample selection. However, this technique incurs less time and cost (Ahuja, 2007; Ramamuthy, 2014).

Due to time constrain, the present study focused on the parents of children with ASD residing in West Bengal. Sample size consisted of 49 parents (15 fathers and 34 mothers) of children with autism spectrum disorder.

Table 4.1

Sample distribution

	Childhood		Adolescent	
	Mild	Moderate	mild	moderate
Mother	10	8	12	4
Father	4	3	7	1
Total		49		

4.4 Tools used

For the present study, the following tools are used.

4.4.1 Autism Parenting Stress Index (APSI)

APSI was developed by Silva & Schalock, (2012). It is a 13 item scale and the items fall into three categories: the core social disability, difficult-to-manage behaviour, and physical issues. The APSI indicates how much stress parents are experiencing and what factors are causing this stress. The Autism Parenting Stress Index is a parent-report questionnaire that assesses parenting stress specific to ASD symptoms and comorbid conditions (e.g., sleep problems, bowel problems). Reliability cronbach's alpha is 0.827. Parents were asked to rate how each item might cause stress to them and/or their family on a 5-point Likert scale (0 = Not stressful, 1 = Sometimes creates stress, 2 = Often creates stress, 3 = Very stressful on a daily basis, and 4 = So stressful we feel we can't cope). The questionnaire deals with the statements like, the child's ability to communicate, child's social development, self-injurious behavior, child's diet, sleep problem and so on. The parents were asked to mark the degree of stress that they experience on

the mentioned statements. Higher overall APSI scale score indicated higher levels of parenting stress. The reliability of APSI in the present study is .70 (Cronbach's Alpha).

4.4.2 Ways of Coping Questionnaire (WCQ)

WCQ has been extensively used to assess coping styles in the clinical or non-clinical context. This was designed by Lazarus and Folkman (1985) as a measure of coping processes used in a particular stressful encounter (and not of coping style or traits). The Ways of Coping (Revised) is a 66-item questionnaire containing a wide range of thoughts and acts that people use to deal with the internal and/or external demands of specific stressful encounters. The subject responds on a 4-point Likert scale (0 = does not apply and/or not used; 1- somewhat used, 2- used quite a bit and 3 = used a great deal). The scale has eight subscales which deal with different coping styles. They are: Confrontive Coping, distancing, Self-Controlling, Seeking Social support, Accepting Responsibility, Escape-Avoidance, Planful Problem-solving, and Positive Reappraisal. The test consists of items from all the eight dimensions in varied sequence. Some of the items that indicate the coping strategy used by the subject are: made light of the situation; refused to get too serious about it, went on as if nothing had happened, didn't let it get to me; refused to think too much about it, tried to forget the whole thing, and many more. According to Folkman and Lazarus, (1988) reliability coefficients for these subscales ranged from .68 to .79 (Pisula & Kossakowska, 2010).

WCQ has been used in a number of studies that aim to identify the coping strategies used in different and difficult life situations. A study was conducted by Folkman and others in 1986, to identify the dynamics of stressful encounters. The study was conducted on seventy-five married couples for a period of five months. Every month the couples would be interviewed and asked about the most stressful situation faced in the week. In the process, they were asked to fill

in the WCQ questionnaire to indicate the coping strategies used by them to deal with the situation. In the same line, another study was conducted by Folkman, S. & Lazarus, R. S (1985) titled, "*If it changes it must be a process: Study of emotion and coping during three stages of a college examination.*" In the study 108 college students had to fill the WCQ three times as a part of studying stress during the examination. Reliability of WCQ in present is .70 (Cronbach's Alpha)

4.4.3 The Ryff Scale of Psychological Well-Being

The Ryff's scale of psychological wellbeing (1989) is widely used to measure the psychological well-being. It was designed to measure all the specific areas of psychological wellbeing, such as, self-acceptance, the establishment of quality ties to other, a sense of autonomy in thought and action, the ability to manage complex environments to suit personal needs and values, the pursuit of meaningful goals and a sense of purpose in life and continued growth and development as a person. For this study, Ryff inventory of 18 questions (short form) will be used. The forms consist of a series of statements reflecting the six areas of psychological well-being: autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance. Respondents rate statements on a scale of 1 to 6, with 1 indicating strong disagreement, 2 = somewhat disagree, 3 = a little disagree, 4 = don't know, 5 = a little agree, 6 = somewhat agree, and 7 = strongly agree. The scale consists of the items like, I like most parts of my personality, in many ways I feel disappointed about my achievements in life, I am good at managing the responsibilities of daily life and others similar statements. As per the study conducted by Bayani, Koocheky, & Bayani (2008) the test-retest reliability coefficient of RPWBS was found to be 0.82. The subscales of Self-acceptance, Positive Relation with Others,

Autonomy, Environmental Mastery, Purpose in Life, and Personal Growth were found to be 0.71, 0.77, 0.78, 0.77, 0.70, and 0.78 respectively, which were statistically significant ($p < 0.001$).

The Ryff's scale of psychological wellbeing has been extensively used in the studies that aim to assess the psychological wellbeing of the subjects/ participants. In some cases, the scale is used as a whole where as in some studies the subscales are used that suits the purpose of the study. In the study conducted by Leann and others in the year 2008, the personal growth subscale which consisted of six items, from the Scales of Psychological Well-Being (Ryff, 1989) was used to measure positive psychological wellbeing. Similarly, in another study, two subscales of Ryff's Psychological Wellbeing, namely environmental mastery and the positive social relationship was used to reflect on the sense of control and social relationship which is regarded as an integral part of psychological wellbeing (Winefield et al., 2012). In the present study Cornbach's Alpha reliability of Ryff's Psychological Wellbeing scale is .90

4.4.4 Indian Scale for Assessment of Autism (ISAA)

In order to measure the degree of autism, the Indian Scale for Assessment of Autism was used. This is especially designed for the Indian population by the expert committee which consisted of professional working in the autism and related developmental disabilities. This committee was formed by the Ministry of Social Justice and Empowerment, Government of India. Initially, 437 items were generated by the government and non-government professional working in the field of autism. 57 items were further scrutinied by the experts.

And finally, 40 item are selected for ISAA on the basis pilot study results. The scale is rated on five-point scale (1=never to 5=always) and has six domains: social relationship and reciprocity, emotional responsiveness, language and communication and behaviour patterns,

sensory aspects and cognitive components. The items in the domain of social relationship and reciprocity consist of statements like, has poor eye contact, lacks social smile, unable to take turn in social interactions. Similarly, in the domain of emotional responsiveness, the items are shows inappropriate emotional response, lacks fear of danger, etc. The alpha coefficient of ISAA was 0.93 which shows that the scale has a higher degree of internal consistency (Deshpande, 2008).

4.4.6 Semi-structured interview schedule

A semi-structured interview schedule was constructed to collect the data from parents of children with Autism Spectrum Disorder. The questions focused to identify the challenges faced by the parents of children with autism. For this purpose, 6 mothers and 4 fathers were interviewed in detail. Questions for the interview were based on the literature related to parents and children with autism.

4.5 Ethical Concerns

Consent was taken from the participants regarding their willingness to participate in the study. No participant was forced into study. They had all rights to leave the study at any point of time. The participants were informed in brief about the present research before the commencement of the study. Only after the participants were ready they were provided with the questionnaires. After filling the questionnaires, interview was conducted by the researcher on one to one basis. The participants were assured that their information shall be kept confidential. The participants were also assured that the information provided by them will not be used elsewhere without their permission. With the participant's permission proceedings of the interview was recorded in

mobile phone. Prior permission was taken by the researcher to transcribe the interviews conducted.

4.6 Procedure

Children with autism spectrum disorder and their parents were approached through special schools, clinics and hospitals. There were almost 5-6 special schools in and around Siliguri out of which only four functioned on regular basis. Most of the schools had their set of rules and regulations according to which they would not disclose the information about the inmates of the schools and also about their parents. Thus, the data could be collected from only three special schools. The researcher first visited a special school that was funded by the state government. This particular school, along with the principal and the staff was quite cooperative from the very first day. The principal, through her teaching staff arranged meeting with autistic parents from the very next day of visit to the school. Next was a private sector school in which the researcher had to wait for almost three weeks to just get an appointment with the principal. The schools were particular about the number of children (their parents) they would provide for the research. Because of which the researcher could not get access to the larger sample. In one of the schools though the principal was very much positive about the study, but it seemed impossible for her to involve and convince the parents for their participation. The researcher visited the school three times on the days when the meeting was arranged with the parents. In all these days the parents did not turn up.

However, the researcher could collect data from 49 parents of children with ASD. Initially, consent was taken from the school authorities and then meeting was arranged by the school authorizes with parents of children with ASD. In few cases were the parents could not come to the school the researcher visited their home with prior consent of the parent involved and also the

school authority. After giving informed consent to the parents, they were asked to complete demographic characteristics (i.e., gender, age, education, income, language). Before handing the questionnaires to the participants, they were briefed about purpose of the study. After the participants filled the questionnaires, interviews were conducted on one to one basis.

4.7 Data Analysis

The following statistical analysis was performed using software named, Statistical Package for Social Sciences (SPSS), version 21. Descriptive statistics such as mean, standard deviation and Pearson's correlation was used to find the relationship between the variables i.e., stress, coping strategies and psychological wellbeing. t-test was computed to find the difference between the groups. Data collected through interviews was transcribed and analyzed thematically.

Correlation coefficient is used to measure the association between the two variables. However, the correlation does not tell us about the cause and effect relationship. There are different types of correlation, positive, negative, simple, partial, multiple, linear and non-linear correlation. Further, there are different methods in which correlation can be studied. One of the most popular methods of studying correlation is Karl Pearson's method, commonly known as Pearson's coefficient correlation. Pearson's correlation is denoted by the symbol r (Gibbs, 2013; Gupta, 2014). Thus, in the present study Pearson's correlation was used to measure the relationship between stress, coping and psychological wellbeing in parents of children with ASD. In addition, t test was computed to make a comparison among stress, coping and psychological wellbeing, across child's age, degree of autism and parent's gender.

Qualitative research helps in understanding the phenomenon in a holistic way. Meaning, it gives an overall and in depth understanding of the research query. It helps in understanding person's behavior, belief, and attitude, through in depth interviews, observations or narrations from the participants. Qualitative analysis plays an important role in the field of psychology as it does not seem justifiable to measure human behavior just on the basis of numbers (Pathak, V., Jena, B., & Kalra, S). In order to analyze the qualitative data of the present study thematic method was used. At present thematic approach is the most commonly used method to analyze the qualitative data. This method is used to identify the themes from the qualitative data base. Terms such as indices, codes, categories or themes are used in identifying one or more passages in the text that are found in the quantitative data like, interviews and narrations. The themes in the qualitative analysis are mostly identified using codes and categories in the text. There are different ways to arrive at thematic analysis. They are inductive, deductive, semantic, latent, realist or essentialist and constructionist approach. In the present study inductive approach was used in which coding and themes derived are directed by the content of the data. Thus, in order to arrive at the general themes that are explicit in data collected through interviews, thematic analysis was used (Gibbs, 2013).

RESULTS AND INTERPRETATIONS

5.1 Introduction

This chapter provides presentation, analysis, and interpretation of the data. Along with descriptive statistics, data were analysed using t-test and Pearson Correlation. a t-test was used to make comparisons between child's age, the severity of autism, and parent's gender with respect to stress, coping style and psychological wellbeing. Pearson Correlation was used to examine the relationship between stress, coping style and psychological well being and their subscales. Qualitative data were thematically analysed.

This chapter is divided into six sections. Section 4.2 discusses the sample profile of the participants. Section 4.3 deals with the descriptive statistics of stress, coping style, and psychological wellbeing. Section 4.4 analyzes the relationship between stress, coping and psychological wellbeing. Section 4.5 describes the comparison between groups using t-test. Section 4.6 deals with the qualitative analysis.

5.2 Sample Profile

The sample was collected from the West Bengal. The total sample consisted of 49 parents including both mother and father of children with ASD, the severity of autism (mild and moderate), and child's age (childhood and adolescent).

Table 5.1

Demographic profile of participants (n=49)

Variable	No. of respondents	%
<i>Parents</i>		
Mother	34	69.4
Father	15	30.6
<i>Child's age</i>		
Childhood (3-10 yrs)	25	51.0
Adolescence (11-18 yrs)	24	49.0
<i>Severity of Autism</i>		
Mild	33	67.3
Moderate	16	32.7

Table 5.1 showed that out of total sample 49 participants, mothers were 34 (69.4%) and fathers were 15 (30.6%), parents of children according to the severity of autism ranged from mild 33

(67.3%) to moderate 16 (32.7%). As per the child’s age, parents of children with autism of childhood included 25 (51.0%) and adolescence included 14 (49.0%).

In addition to this, for collecting qualitative data, 15 parents were interviewed using semi-structured interview schedule. Out of 15 parents, 7 were of childhood and 8 were of adolescence age group.

5.3 Descriptive Statistics for Stress, Coping and Psychological Wellbeing

There were three variables stress, coping, and psychological wellbeing in the study. To measure stress, The Autism Parenting Stress Index was used. It had three dimensions named as core social disability, difficulty to manage behaviour, and physical issues. Ways of Coping Scale was used to measure coping styles, which had eight dimensions confrontative, distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, painful problem solving and positive reappraisal. The Ryff Scale of Psychological Well-Being had six dimensions positive relation with others, self- acceptance, autonomy, personal growth, environmental mastery and purpose in life. Mean and SD for all the scales along with their dimensions are given in the table below.

Table 5.2

Mean and SD of Stress and its dimensions (n=49)

Scale/Dimension	Mean	SD
Stress	18.53	6.78

Core social disability	9.59	3.92
Difficult to manage behaviour	5.32	3.62
Physical issues	3.61	2.42

Table 5.2 showed that core social disability had the highest level of stress (M=9.59, SD=3.92) followed by difficult to manage behaviour (M=5.32, SD=3.92) and physical issues (M=3.61, 2.42). Result also showed that participants had scored low on the overall scale and its subscales.

Table 5.3

Mean and SD of Coping Style and its dimensions (n=49)

Scale/Dimension	Mean	SD
Coping	95.22	18.44
Confrontive	10.28	3.22
Distancing	8.46	2.55
Self-controlling	12.26	2.65
Seeking social support	10.91	3.64
Accepting responsibility	4.73	1.66
Escape-avoidance	15.97	4.37
Planful problem solving	16.30	4.06
Positive reappraisal	16.26	3.98

Table 5.3 showed that highest coping styles used by the participants were planful problem solving (M=16.30, SD=4.06) and positive reappraisal (M=16.26, SD=3.98), followed by escape-avoidance (M=15.97, SD=4.37), self-controlling (M=12.26, SD=2.65), and seeking social support (M=10.91, SD=3.64), confronted (M=10.28, SD=3.22), distancing (M=8.46, SD=2.55), and accepting responsibility (M=4.73, 1.66).

Table 5.4

Mean and standard deviation (SD) of psychological wellbeing (n=49)

Scale/Dimension	Mean	SD
Psychological Wellbeing	82.02	9.20
Positive relations with others	12.81	3.25
Self-acceptance	12.32	2.12
Autonomy	4.34	2.21
Personal growth	4.46	.75
Environmental mastery	3.95	2.30
Purpose in life	14.10	2.12

Table 5.4 showed that participants' psychological wellbeing was highest for personal growth (M=14.46, SD, 2.75), autonomy (M=14.34, 2.21), and purpose in life (M=14.10, SD=2.12), followed by environmental mastery (M=13.95, SD=2.30), positive relations with others (M=12.81, SD=3.25), and self-acceptance (M=12.32, SD=2.12).

5.4 Relationship between Stress, Coping Style and Psychological Wellbeing

From the (5.5) it is understood that SD1 and CD6 has a positive correlation at .260. Similarly SD1 has positive correlation with PD6 at the 0.05 level at .280, where as SD1 has a negative correlation with PD2 at 0.05 level (-.274). Meaning that parents who feel higher stress in child's core social disability uses more of escape-avoidance coping style and has purpose in life, but has lesser self acceptance. SD2 has negative correlation with CD2 (-.262), CD3 (-.323), CD7 (-.316), PD1 (-.281) at 0.05 level. The parents who feel higher stress in managing child's behavioral issues might have difficulty in planful problem solving, in self- controlling and having positive relationship with others. SD3 has no correlation with either of the scales. The matrix further does not show any internal correlation between the different dimensions of stress.

PsywD1 has a strong positive correlation with PsywD2 and PsywD4 (.343 and .351) at .01 significant level. Similarly PsywD2 has a significant positive correlation with dimension 3, 4, and 5, of the same scale (.308, .297 and .321, respectively). On the same line significant positive correlation has been seen among the different dimension which shows a strong internal correlation of psychological wellbeing scale, namely, Positive relations with others, Self acceptance, Autonomy, Personal growth, Environmental mastery and Purpose in life. When correlated with other scales, PsywD2 had positive correlation with CopeD3, Cope D4 and CopeD8 with the numeric value of .328, .297 and .246 at 0.5 significant level, which means that self acceptance is higher in the parents who uses self control, seeks out for social support and practices positive reappraisal as their coping style in dealing with their stressors. Similarly, PsywD3 had a significant positive correlation with Cope D7 at .01 significant level (.418).

Dimension 6 of the psychological wellbeing scale was found to be strongly correlated with the dimension 5, 6, 7 and 8 of coping scale at .01 significant level. Purpose in life among the parents

is higher when the parents are more accepting of their responsibilities, planfully solves their problem and uses escape avoidance techniques as their coping styles. Thus, it can be said from the above interpretation that parents who uses maximum of coping strategies as per their need have better psychological wellbeing in varied areas.

From the table (4.5) it is found that ways of coping scale has a significant positive correlation among its dimensions at both .01 and .05 significant level. To quote some, CopeD7 had strong positive correlation with CopeDs 1 and 3, at .01 significant level (.714 and .678, respectively). On the same line CD8 was positively correlated with CopeD4 at .764 at .01 significant level. As mentioned earlier SD2 has negative correlation with CD2 (-.262), CD3 (-.323), CD7 (-.316), meaning that the parents experiences higher level of stress when to they fail reach out to different coping strategies. This can also be the case when the parents have no access to proper resources that are needed to deal with daily stressors while raising a child disability, especially autism.

5.5 Comparison between Child's Age, Severity of Autism and Parent's Gender on Stress, Coping Style and Psychological Wellbeing

This section examined the comparison between child's age, the severity of autism, and parent's gender with regard to stress, coping style, and psychological wellbeing. To compare these groups t-test was computed.

Table 5.6

Mean, SD and t-test for Child's Age on Stress, Coping Style and Psychological Wellbeing

Variable	Mean	SD	t
<i>Stress</i>			
Childhood	19.60	6.67	1.12
Adolescence	17.41	6.85	
<i>Coping Style</i>			
Childhood	88.28	16.24	
Adolescence	95.22	18.10	2.88**
<i>Psychological Wellbeing</i>			
Childhood	79.08	8.21	
Adolescence	85.08	9.34	2.39*

* $p < .05$; ** $p < .01$

Table 5.6 showed that there was no significant difference between childhood and adolescence on stress ($t=1.12$, $p > .05$). Regarding coping style, childhood and adolescence groups significantly differed on stress ($t=2.88$, $p < .01$). In other words, parents of adolescent age group had a higher level of coping styles ($M=95.22$, $SD=18.10$) in comparison to childhood ($M=88.28$, $SD=16.24$). Similarly, childhood and adolescence significantly differed regarding their psychological wellbeing ($t=2.39$, $p < .05$). In other words, the psychological wellbeing of parents of adolescent age group ($M=85.08$, $SD=9.34$) was better than childhood ($M=79.08$, $SD=8.21$).

Table 5.7

Mean, SD and t-test for Severity of Autism on Stress, Coping Style and Psychological Wellbeing

Variable	Mean	SD	T
<i>Stress</i>			
Mild	16.36	6.01	3.54**
Moderate	23.00	6.19	
<i>Coping Style</i>			
Mild	94.45	19.89	
Moderate	96.81	15.51	.21
<i>Psychological Wellbeing</i>			
Mild	81.81	8.36	
Moderate	82.43	11.02	.41

* $p < .05$; ** $p < .01$

Table 5.7 showed that for stress, mild and moderate groups significantly differed ($t=3.54$, $p < .01$). In other words, parents of children with a moderate level of autism had a higher level of stress ($M=23.00$, $SD=6.19$) in comparison to mild level ($M=16.36$, $SD=6.01$). However, there was no significant difference between mild and moderate groups regarding their coping style ($t=.21$, $p > .05$) and psychological wellbeing ($t=.41$, $p > .05$).

Table 5.8

Mean, SD and t-test for Parent's Gender on Stress, Coping Style and Psychological Wellbeing

Variable	Mean	SD	T
<i>Stress</i>			
Father	18.53	5.62	.02
Mother	18.52	7.31	
<i>Coping Style</i>			
Father	86.06	14.52	
Mother	99.26	18.72	2.43*
<i>Psychological Wellbeing</i>			
Father	83.06	9.66	
Mother	81.55	9.10	.52

* $p < .05$; ** $p < .01$

Table 5.8 showed that there was a significant difference between father and mother regarding their coping style ($t=2.43$, $p < .05$). In other words, mothers of children with autism used more coping styles ($M=99.26$, $SD=18.72$) in comparison to fathers ($M=86.06$, $SD=14.52$). However, no significant difference was found between father and mother regarding stress ($t=.02$, $p > .05$) and psychological wellbeing ($t=.41$, $p > .05$).

5.6 Qualitative Analysis

This section analyzed the primary data collected through interviews with parents of children with autism to understand the parental stressors, ways of dealing with stressors and their psychological wellbeing. The semi-structured interview schedule allowed parents to express their insights about various issues related to parenting a child with autism. Interviews enabled participants to discuss their interpretations of the world where they live and to express how they regard situations from their own point of view. It also allowed in-depth questioning and flexibility. Data collected from the interviews were transcribed and organized into various themes and categories that emerged out of data analysis. Direct quotes and narrative descriptions that subjects revealed were used in the presentation of the result. This section is divided into two sub-sections, the first deals with parental stress and their psychological wellbeing, and the second sub-section offers results related to the ways of coping that was used by these parents.

5.6.1 Parental Stress and Psychological Wellbeing

From the interviews, it was found that the parents experienced stress on a daily basis. The common stressors experienced by the parents were understanding the autism (lack of knowledge/awareness about autism), social life, and future concerns for the child. All these stressors were the indicators of parents' low level of psychological wellbeing.

Some of the parents reported that they noticed the atypical symptom in their child from the early age of seven months. The most common symptom visible at that early year was the child's inability to communicate (verbal and non-verbal). Most of the parents reported that initially, their child developed like any other typically growing child. The child spoke words like mama, daddy, didi etc, but soon that was replaced by complete muteness. Some of the parents

also reported that the child would sing, respond to the sound of the vehicle and TV ads, but would fail to respond when called by their name. This failure to respond to the social clue depicted their impairment in social life. Child's core social disability was reported to be one of the major areas of stress for parents. A parent reported:

“Initially my child would sing, but when called by his name he would not respond. When there is his favourite ad or song on TV he comes running from the other room but if we ask him anything he does not even look at our face. It seems like he does not hear...”

Another mother described,

“She will talk whatever comes in her mind... when someone asks her name or anything, she will not answer, rather she will go on talking something else or will just not respond and look away. It feels like she isn't interested in talking to us...”

Because of the impairment in communication, the parents reported that many times they failed to understand the needs and problems faced by the child. The child may simply throw tantrums or engage in self-stimulating behaviour for the reason which is not apprehended by the parents. A father explained,

“Sometimes it happened that he cried all day...and we don't know what would have happened... we keep guessing and asking if his stomach is paining or his tooth is hurting or if he is upset with something, or if he wants anything... we have to go on making guesses. At times his mother makes the right guess and we are able to help him and at other times both of us (child and parents) have to bear with it throughout.”

One of the problematic symptoms that accompany autism is the child's insensitivity to pain and their inability to communicate the same. Because of their emotional and communicational deficit, the parents failed to understand what causes them pain or if the child is hurt. One of the parents narrated,

“Once she got hurt in school which I wasn’t aware of. Later I noticed that her foot was swollen and had a mark on it. When I touched it she pulled her foot back. Till then she did not tell if it was hurting, neither did she cry... for a child 8 years it must have been very painful but she cannot say anything. This was one thing that I noticed but there could be so many other hurts that she endures and I am aware of it. ”

Another mother described,

“Once his father took him on a bike ride. Somehow his feet touched the silencer which was very hot. Later when they came home his foot had a big patch of burn....and all the while he did not speak a word or show any form of discomfort the burn would have caused him”

Thus, due to the symptoms of coming along with autism the child fails to understand and also communicate their needs and conditions to the parents. Largely the parents view this as incompetence on their part in comprehending their child’s need and the reason for their sudden outburst. To see their child suffer without being able to help them, cultivated the feeling helplessness among the parents.

Poor infrastructural facilities were another issue faced by the parents. A mother came up with an issue that most of the parents with disability face while going outdoors. The public toilet facilities in the malls or cinema halls are available only for male and female, it becomes challenging for a mother with 16-year-old son who needs her assistance while using the toilet. Neither she can take him to the male toilet which will be awkward for her nor can she take him to the female area which will be awkward for other ladies in the washroom. Giving another example the same parent said:

“We have big malls and many counters with really long queues. And I have an autistic son who is also hyper. Will it be possible for me to stand in that long for an hour...? Can’t they have one

counter in the huge mall for a special person or for parents of special children and veterans? The society is still not ready to accommodate us.”

The poor infrastructural set up in the most of the places makes it inconvenient for the parents with special children to visit the social forum. This, in turn, makes the child and also the family less social. The inadequacy of the social setting could be the main reason why the special children are not seen in much of the social places even when the parents want to expose their child to the environment around. This limitation to the world of the child and also the parents could be a significant stressor in their daily life.

Social reactions faced by the parents are another important stressor in their life. The parents reported having experienced both positive and negative responses from their relatives and neighbours. For some, the family members, relatives, neighbours were supportive and accepted child's condition. But on the other hand, the societal reaction became the main source of parental stress.

“The neighbours are fine till he creates any fuss... if he is at their home and makes noise or touches their things, which most of the typically growing children also do, they have a problem. Even if he just sits people will ask why is he sitting alone and not playing with others...if he plays still people will question why is he so hyper and always jumps around....so our child no matter what he does is always questioned, because people know that he is not normal.” says a mother stating that the society has laid conditions on the child.

At times the parents had to stand for the child and make the public realize that their child has a place in the society.

“We are too busy and we cannot take our child to field for cycling and in no ways can we leave him alone on the streets by himself...and he loves to cycle around. So I make him cycle on the terrace for sometime whenever I have time...and my co-inhabitants in the apartment had a problem with that... but I was strict enough I told my child is going to play here and that's all.

What do I do..they are not ready to accept our situation... I have to fight for my child till I am alive, and I shall do that” says a mother with courage and also a concern.

When asked if the parent felt that the child is being accepted in the society, a mother confidently says,

“Society will not accept, that’s a known fact.”

It was reported by the mothers that they have to create a space for their child where they can grow, and be happy because the society is not going to do that for them. Thanking the new inventions a mother says,

“My son has a problem with noise, he gets irritated and then he cries and shouts. And there is a lot of crackers being burnt during Diwali and my neighbours will not understand mine or my son’s problem. Then I got to know about ear muffs. Now whenever we go out and he gets disturbed, I give him ear muffs and then he is fine. Thanks to Amazon,” she says with a relieved smile.

Thus, for some, the society acts a strong support group but most of the time society and the standards laid by them adds and also exaggerates the stress experienced by the parents of children with ASD. Lack of awareness regarding different disorders could be one of the possible reasons for the uncooperative nature of the society. As it is often said that till one’s place is served with neem they would not know how bitter the meal could be. The lack of experience with a disabled child in one’s family could be another possible reason for the ignorant attitude of society towards the disabled child and their family.

It was found from the interviews conducted that the parents had almost no knowledge about autism till their own child was diagnosed with it. Other than the couple of participants, rest all reported,

“I had not heard term ‘autism’ before.”

In fact, the other parent said,

“Initially I could not even pronounce the term correctly. It was so new to us.”

One of the parents said that though she did not know about autism but had watched a TV serial named, ‘aapkiantara’ there the symptoms of the main character matched with her child. Some of the parents did not even know that their child had autism though the child had a disability card with autism on it. When the parents were enquired about the condition of their child, they said that they only knew that their child is not normal. A mother narrates,

“My child has less intellect. She does not understand things.”

Another mother said,

“The doctor just said my daughter has moderate autism, and nothing more. And we did not know what it was. This was the first time we had heard the term and also it was also the first time that we had to deal with such child. We didn’t know whom to talk to...”

To realize that their child had a disorder that they had not even heard of added to their state of confusion, leading to the high level of stress and even depression. Due to the lack of awareness of the disorder, the parents did not know of the resources, support system and coping strategies available to them. This indeed added to their level of stress and lower psychological wellbeing.

Most of the parents were not oriented about the cause of their child’s autism. Instead, they hold different notions of their child’s disorder. When asked about the possible cause of their child’s disorder, some parents reported that it was their fate that they have a child with autism.

“When he was young, he had fallen from bed a number of times. Almost 11- 13 times and every time he fell he hit his head, maybe that’s the reason for his condition,”

Said a mother, thinking the cause of her son’s condition is the fall from the bed. Most of the parents reported that it all started with a high fever and then epileptic attack. After that, there was delay in speech, atypical behaviour and so on. Some of the parents also reported that they felt themselves to be responsible for child’s condition.

“Maybe it was my bad karma that my child is born like this,” Said a mother expressing her grief.

“My daughter was playing and my mother in law said that I should check on my daughter or she would have a fall, she had come to an edge while playing. I thought let me finish the little work. But by the time I turned to her she had a bad fall. And after that, the problems started. So I feel I am responsible for my child’s condition, even my mother in law feels the same...” narrates a mother with tears in her eyes.

Thus, the lack of knowledge in regard to the real cause of autism adds to their stress, leaving the parents in doubt, guilt and hopelessness which in turn affect their psychological wellbeing.

The symptoms that come with autism along with the comorbid conditions tend to confuse and also misled the parents during the child’s early diagnosis. Some of the parents reported that their child’s condition was misunderstood as being hearing impairment or child’s misbehaviour. Almost half of the children of these parents were also reported to have severe episodes of epilepsy. Following this, the child was taken for the diagnosis of hearing impairment and neurological disorder. The diagnosis was mostly prolonged and tiring for both parents as well as the child. One of the parents reported,

“I took the child to Bangalore because everyone said it’s the best place for a neurological problem, but there was no improvement. We were there for almost a month... a lot of money was spent there. Later I took him to a doctor here in the town and from then he is fine.”

This particular child had regular episodes of epilepsy along with mild autism. But it was only after a couple of years did the parents realize that their child had some problem other than epilepsy. As most of the times, autism is accompanied by the comorbid symptoms; it was found that parents often misunderstood the autistic symptoms as the child being too hyper, disobedient, lack of attention and introvert. As the parent narrates,

“He was so hyper that we just felt he was too naughty. He would not pay attention to what we were saying !! all he wanted to do was jump around..”

These confusing symptoms and prolonged diagnosis created a lot of disturbance and helplessness in the parents, further adding to the level of stress experienced by the parents and in turn affecting their psychological wellbeing.

Parents reported having a mixed sense feeling during the first diagnosis of their child. Some parents disclosed their sense of relief because now they could understand why their child is the way s/he is. They communicated to have felt strong and safe for now they knew where to search for help and whom to approach with their problem. A parent says,

“We were very enthusiastic, we were young then and wanted to do anything that would help my child. At least we knew he has autism and is not confused anymore. I started to get myself educated on autism and learnt about different autism that would help child...”

Parents also had an emotional reaction to their child’s diagnosis. As a parent said,

“I cried a lot when the doctors told that my child may speak or may not...even normal education won’t be possible for him. I did not want to talk to anyone, I just wanted to cry.”

Some of the parents were in the state of denial. A mother narrated,

“I would think how can a doctor say that my child has some disorder on the basis of some questions and limited observation? Maybe there is something wrong with the diagnosis. But

sooner or later we had to accept that our child had some problem...” expressing her state of mind when her daughter was first diagnosed with ASD.

The arrival of a child in the family is always accompanied by new hopes and dreams. But all that falls apart with the realization that the child would not develop like the kids of their neighbour or go to the school just like other children of their relatives. The initial diagnosis of the child’s disorder marks the starter of stress experienced by the parents. Most of the parents take a lot of time accept the fact that their child is different from others. Some make references to different doctors and experts to cross-check the diagnosis and also to access better support for the child. The life-long and varying condition of autism is another trauma to parents. Some of the parents think autism to be a disease which would be cured by medication but to their dismay, they are bound to accept the fact that their child and they themselves will have to suffer the long-term condition of the disorder.

Another parental stress was related to the child’s future. There was a constant fear of what will happen to their children after the parent’s death such as who will take care of them, work and marriage were the major cause of stress experienced by all the parents. When asked about their child’s future, a father described,

“What will happen to the child after we are not there in this world is my biggest concern. And I am sure it is the concern for all the parents who have special children...” Another father said that *“the thought itself is so disheartening that I don’t even want to think about it...actually, I don’t even know what to think. I only leave me disheartened...”*.

Some parents said that they were looking for a place where they can put their child and where the child can learn, grow and also be safe. A mother reported expressing her concern for her growing autistic girl child:

“When she is grown up she cannot come to school. She will be at home and she is totally dependent on me. I have to go the work, who is going to take care of her? I cannot trust anyone, especially when the world is getting worst. Every day we hear some incident. That’s why I seek for a place where my daughter will be safe.”

The constant fear of child’s future after their parents was reported to be one of the biggest stressors in the life of the parents. Taking care of a special child is a challenge in itself. The parents fear and concern depended on the child’s degree of disorder and their level of dependency. Some of the parents even reported that they are saving some amount which they plan to give to the person who promises to take care of their child after them. Thus, it is observed that child’s future concern is indeed the major cause of stress in parent’s life and this constant fear and worry no doubt affected their psychological well-being too.

5.6.2 Coping Strategies of parents

From the interviews it was found that the coping strategies that were available and used by the parents were social support and professional help, painful problem solving, positive reappraisal, and confrontative coping. Some of the parents reported to have received a lot of information from the internet which was easily available to them at any given time. Thus, it was a new and most feasible coping style identified in this study.

Describing the response from her relatives, one of the parents said:

“She is the only daughter in the family and she is being loved more than needed. There was a time when I felt that my child has become disobedient and does not respond to our calls because she is being pampered so much.”

Another father mentioned:

“The neighbours love him and treat him well and I feel good about it. Sometimes he leaves the house without our notice, though we always keep our doors closed and look over him. Then the neighbours give us a call or sometimes they bring him back home. Other children try to play with him, but it’s him that he does not like to mingle with others”

Similarly, another father narrated with joy,

“Once my son just ran into the house of my boss when we were coming back home after his therapy sessions. I felt little awkward and asked for pardon, but the boss was happy and said, ‘look he was so confident to come home, you don’t worry, let him be here.’ I left good when he said so. It feels good to see my kid being loved and accepted.”

Thus, from the above narration it can be concluded that for some parents seeking social support from family members and neighbors was their main coping style. The support from the family members boosts the morale of the parents and also encourages the parents to accept their child’s condition. Support from family members provided the primary care takers with time where they could take some time off for themselves. This helped the care takers to reenergize themselves for better working in coming days.

Another important source of support parents seek for was the professional help. A mother of a child said:

“I got a lot of support from the school...I can call the school professionals at any hour and they are ever ready to listen to me. There was a time when I was absolutely low...my son must have heard someone call him mad and one afternoon he was running around the house saying, ‘I am a mad boy, I am a mad boy,’ I felt shattered...he does not even know what he was saying... that time school counselors came to help, I could discuss everything

with them and they would guide me how to deal with it... they have helped me come out of that terrible phase.”

Parents whose children went to a special school reported that they constant and selfless support from the school and also from the special educators. Some of the parents further reported the school and the parents of other children with special needs were like their extended families. They could share their worry and also the progress of their child with other parents of children with similar condition. In fact the parents reported that bond shared with the school was more than the bond with their family members. Further the school trained and provided them with enough information on the child’s condition that made them equipped in the dealing with their child.

Another parental coping strategy was confrontative style. One of the parents reported as:

“After having the knowledge about autism, we wanted to know how other parents deal with raising an autistic child. Initially, we were looking for other factors so that we could deny the symptoms of autism. Later when we realized that there is some serious problem and it’s now time to take action and intervene...”

Another parent reported:

“We took up the challenge and decided that we will deal with it. Although with the passes of time difficulty level was increasing, it was difficult to manage too. However, we had already prepared ourselves to face the challenge and let’s fight with it...we were enthusiastic...”

For some parents the diagnosis of their child's disorder was relieving, as now knew what actually caused their child's condition. They sounded enthusiastic and determined to help their child. The parents who were educated started their search from the very first day, fixed in their minds that they would not make any further delays. The parents even discussed their child's condition with other parents in the similar situation to get a better understanding of their child's condition and to figure out the effective and safe copings to deal with those conditions.

Planful problem solving is another coping style that was frequently used by parents of children with ASD.

As one of the parents reported,

“What we focus on is our next step...we follow all the instructions that are given to us. Some behavior technique that is useful to autistic child is not applicable to my child. So I have to be very careful and patient.”

Another mother reported,

“Whenever I have any doubt I ask the school instructors... then I plan how I should go about implementing it. With autistic children, it like, for days we do not see any improvements... but suddenly one day he follows my instruction. And next day he may not follow my instructions. But I have to keep on my work. And I have to manage other things...my other kid, family, husband... This requires a lot of planing and patience”

When asked about how deal with their problem in regard to their autistic child, most of the parents reported that they focus on the next task. Making adjustments and taking turns in their

work was practiced by these parents so that they could always be available to their child to take care of their needs.

Positive reappraisal was another coping style that was frequently used by the parents of children with ASD. It was particularly observed that parents of children with older age group made maximum use of this coping style. The parents made a point to appreciate the slight positive change that was observed in their child. This further helped the child themselves to make note of their positive behaviors and segregate them for their other behavior problems.

As a parent described,

“Before he would not listen to any of my instructions, neither would make an eye contact when he name was called. But now he follows my instructions...and also makes eye contact. He hardly makes fuss when I demand transition in his task..”

Another mother gave details saying,

“He loves to sing...we both sing together. He listens to what I say... at times we get up in the morning and do yoga...”

Internet seemed to be another important source of information and coping style that was easily accessible to the parents. A mother of a four-year child mentioned:

“Doctors told me that he has autism and nothing more. Then I searched on the internet and got to know more about it... I often browse the internet. It helps me know better of my child...”

Thus, social support and confrontative style were the two main coping strategies used by the parents to deal with the stressors along with the confrontative style. Results also showed that internet was also one of the important sources of information that helps in understanding the autism for parents.

Discussion

This chapter aims to discuss results in light of theoretical framework and literature discussed in previous chapters. It is divided into three sections. Section 6.1 deals with the level of stress, the most commonly used coping styles and the psychological wellbeing in parents of children with ASD. The relationship between stress, coping styles and psychological well-being has been discussed in Section 6.2 and difference across child's age, the severity of autism, and parent's gender has been discussed in section 6.3.

6.1 Status of Stress, Coping Styles, and Psychological Wellbeing of Parents

One of the objectives of the study was to examine the status of parental stress, coping, and psychological wellbeing in parents of children with ASD. The result showed that participants had scored high on the overall scale and its subscales indicating their high level of stress. There are number of studies that have proved that parents of children with ASD experience greater stress compared to parents of children with other disabilities or typically growing children (Ogston, 2010; Mancil, Boyd & Bedesem, 2009; Tehee, Honan & Hevey, 2009; Hastings, et al., 2005). In the study conducted by Pisula and colleague (2017), family functioning, stress and quality of life among the parents of children with ASD, was studied in comparison to the typically growing children. The study was conducted on 49 mothers and 49 fathers of children with ASD, and 52 mothers and 52 fathers of typically growing children. It was obtained from the study that mothers experience more stress in personal domain as compared to fathers of children with ASD and

overall the parents of children with ASD scored high in the stress scale when compared to scores of parents of typically growing children. The result also showed that parents' stress was high in 'core social disability' followed by 'difficult to manage behaviour' and 'physical issues'. The above finding is supported by the qualitative results, which states that parents face a lot difficulty because of child's social disability. Most of the times the parents fail to understand the need and requirements of the child because of their communicational impairment. Parents reported that because of their child's discomfort in social settings, the parents too had to avoid social gatherings.

The life of a family with a disabled child has always been filled with stress and worry. The very reason that their child is not alike other typically growing children is itself a prime stressor in the life of parents. One of the social impairment includes damage in child's communication skills. As indicated in the qualitative analysis the children with ASD many a time failed to communicate the needs and the reason for their sudden outbursts. The parents are left with confusion and worry. The children with ASD further fail to make friends and involve themselves in interactive conversation. This hampers in building their circle of friends (social circle). Parents are in constant worry of their child's social life and the inability to make friends in their entire life. Added to this the behavioral problems that accompany ASD is another vital concern for the parents. Thus, child's communicational disability, sudden behavioral outburst in the social setting, and additional behavioral impairment could be the possible reasons why the parents scored high in the stress scale.

Some of the themes identified in the present study that caused stress to the parents of children with autism were child's atypical development, initial and prolonged diagnosis, social, emotional and behavioral impairment. These qualitative findings were in line with the previous research

findings (DePape & Lindsay, 2014; Bashir, Khurshid & Qadri, 2014). Though not significant, but parents have more stress in dealing with younger children when compared to dealing with adult with ASD. The first encounter of the child's disorder, prolonged and delayed diagnosis, and lack of awareness could be the possible reasons for the higher stress in parents of younger children (Grey, 2006). As reported by the parents, most of the children lacked social orientation, like failure to respond to their names, whereas they would effectively respond to the ads in the television or sound of the vehicle. Research conducted on infants who were later diagnosed with autism revealed similar understanding of the symptoms observed at an early age (Osterling & Dawson, 1994; Osterling, Dawson & Munson, 2002). Due to the comorbid symptoms that come along with the symptoms of autism, the parents and in some cases the doctors are misled thinking that the child had hearing impairment. These findings of the present study were in line with the previous literatures (Kuhaneck, et al 2010; DePape & Lindsay, 2014; Tehee, Honan & Hevey, 2009; Tunali & Power, 1993).

There are different coping strategies that are available to the parents of children with ASD. As observed in the findings of the present study, the most frequently used coping strategy by the parents of children with ASD is planful problem solving and positive reappraisal. The stated result was found to be supported by the qualitative analysis. The parents mostly dealt with their children systematically by carefully planning their next step. Instead of their complaints in regard to their child's autistic symptoms, the parents were found to praise the little improvements in the child due to interventions applied at the school. The result seemed to be in sync with the earlier study conducted by Hastings and Taunt (2002) on 135 parents of preschool and school-aged children with ASD. The research findings indicated that parents who use positive reframing during stressful situation may help them deal with extreme stressors. Another study that looked

into the stress, coping strategies and quality of life among parents of children with ASD found that positive reappraisal was the most used coping style in the 184 Jordanian parents. The least used coping strategy was confrontive which is also in line with the present study results (Dardas, 2014). The parents who make use of different coping strategies, reach out to social support system and indulge oneself in positive thinking are seen to have better state of mind as compared to parents who are involved in negative thinking like self blame and excessive worrying, experiences higher level of stress and are more prone to depression (Sharma & Sharma, 2016; Tehee, Honan & Hevey, 2009, Ogston, 2010).

One of the least applied coping styles found in the present study was seeking social support. The reason for this variance could be the lack of social support that should be available for the parents rearing children with ASD. Thus, rather than looking for the support group outside, the parents possibly felt the need to take up the challenge by systematically thinking about the problem and by making positive alterations in their mind. The result of present study has found that parents had high psychological wellbeing in personal growth, autonomy, and purpose in life. These dimensions were followed by environmental mastery, positive relations with others, and self-acceptance. It was further found that psychological wellbeing among the parents of children with ASD seemed to be low in the areas like self acceptance, positive relation with others and environmental mastery. These findings are in sync with the findings of previous research (Dardas, 2014).

The above result is supported by the qualitative analysis. As reported by the parents, though the parents went through a lot challenges in their daily life, they also felt the positive change in themselves. Some of the parents reported that they felt positive change in their life in the form of increase in patience, increase in empathy as they now can understand the feeling of other parents,

and the overall development of a humane personality with the positive qualities of hope and faith. These could be the possible reasons for their high score in personal growth. As the parents do not get cooperation and support required, parents often are bound to be the child's sole rescuer and make decisions that are beneficial for the child and his surroundings. This could be the possible explanation why parents scored high in autonomy, where the parents are independent and have confidence in their decisions.

6.2 Relationship between Stress, Coping and Psychological Wellbeing

One of the objectives of the study was to analyze the relationship among the three variables, stress, coping and psychological wellbeing. It was found from the quantitative analysis that parents who feel higher stress in child's core social disability uses more of escape-avoidance coping style and have purpose in life, but have lesser self acceptance. In addition to this it was found that parents who feel higher stress in managing child's behavioral issues might have difficulty in planful problem solving, in self- controlling and having positive relationship with others. The disability in the area of social dimension could be the possible reason for their adaptation of escape-avoidance coping style. The child's sudden emotional and behavioral outbreaks in the public place, their lack of social communication skills, and their stereotyped atypical repetitive behavior could be the possible reason for their parents to avoid public places and situations which could be awkward for them and also for the child. There is a possibility that because the parents does not practice planful problem solving there is a difficulty in managing child's behavioral problem. Because in order to manage the child's behavioural problems like,

transition in activities, self injury, aggressive behavior, and tantrums or meltdowns, requires thought, skill and systematic planning.

It was further found that parents who use self control, seeks out for social support and practice positive reappraisal as their coping style in dealing with their daily stressors have better self acceptance. The social support system available at present to the parents of children with ASD are mostly available from school, the clinical counselors, special educators and support from family members, relatives and neighbors. The help provided by the special schools and clinicians are systematic in nature that helps the parents to deal with their stressor diligently. These support systems orient the parents about child's condition and about their responsibilities as a parent to a special child. This helps the parents to accept and understand child's condition and the situation the parents are placed in. This further helps the parents in the adaptation of positive reappraisal of stressful situations. Thus, the above discussion might explain possible reason for the higher self-acceptance in parents who use social support system and positive reappraisal as their coping style.

6.3 Stress, coping and psychological wellbeing across child's age, degree of autism and parent's gender

Another objective of the present study was to find relationship of stress, coping and psychological wellbeing across child's age, degree of child's autism and parent's gender. It was found that there is no difference between the stress experienced by the parents of younger and older children with ASD. Whereas, significant difference was found in the coping strategy and psychological wellbeing in regard to child's age. Parents of adolescent children with ASD used

greater coping strategies compared to parents of younger age group. In the same line parents of children older age group had better psychological wellbeing compared to the parents with younger age group. In the present study the parents of older children used greater number of coping strategies which lead to better psychological wellbeing as compared to the parents with younger age group. The above result is further supported by the qualitative outcomes. Parents of adolescent children with ASD reported that their child's condition had improved a lot compared to what it was when the child was first diagnosed with ASD. The parents of elder children reported that their child could follow instructions and communicate their needs which helped in improved communicational skills leading to better psychological wellbeing of parents. In the study conducted by Grey (2006) it was found that parent reported to have lesser emotional disturbances when their child was in adolescent stage compared to the phase when their child was young (childhood). Researches further indicate that professional support has positive impact on the wellbeing of mothers of children with ASD (MacMullin, Tint, & Weiss, 2011).

ASD as a disorder can be diagnosed as early as one to two years of child's age. During the initial diagnosis the parents are mostly in the state of shock and denial. But with time and situational demands the parents become aware and also reach out to the various support systems and adopt different coping styles. Thus, by the time the children are in the stage of adolescence the parents would have access to most of the support system and gained knowledge enough that would uplift their psychological wellbeing. Hence, the above discussion highlights the possibility for the parents of older children to use greater coping styles and have better psychological wellbeing compared to the parents of younger children. Previous studies indicate that that efficient coping strategies help in the better functioning of parents with ASD. MacMullin and colleagues (2011) conducted a study with the aim to see if there existed a relation between

professional support and parental gain among mothers of children with ASD. The study was conducted on 132 mothers. The correlation analysis of the data computed that positive gain significantly correlated with professional help.

There was no difference found in the level of stress experienced by the parents in regard to older and younger children. However, significant difference was found in the experience of stress in parents of children with moderate and mild autism. Parents taking care of moderate autistic child reported to have experienced greater degree of stress compared to parents who had to rear a high functioning autistic child. Considerable amount of stress is seen in parents who have children with moderate autism. These results were in sync with the qualitative analysis which showed that parents of children with moderate autism face greater challenges and experience higher level of stress rearing their child. The most probable reason of parent's higher stress in dealing with moderate autistic child is the concern for their child's ability to live an independent life. Further, the parents reported that it's troublesome to take the child in the social settings moreover when the infrastructure isn't efficient enough to accommodate the child. Such results are found in earlier studies too (Mancil, Boyd & Bedesem, 2009).

Child's future concern was one of the major stressors in the life of the parents of children with ASD. All the parents looked stressed, worried and distant when the question in concern to their child's future was put forth. This stress was higher for the parents who had children with moderate autism. Children with moderate degree of autism have higher severity in all the areas of social, behavioral and emotional impairment which in turn added highly to the parental stress. These children are greatly dependent on their parents and the parents constantly have to be there taking care of the child. Expressing their future concern the parents reported that they were saving money to give it away to the person who will take care of their child after them. The

concern for the child's independent future is the major cause of stress and worry in the parents of children with autism (DePape & Lindsay, 2014; Ogston, 2010). Though all the parents have consistent worry about their child's future, the parents of children with moderate autism and parents with girl autistic child seemed to have greater fear of their child being abused or neglected. The above finding is in line with the research conducted by Gupta and colleagues (2012).

In the present study, it was found that there is no significant difference between the stress experienced by the mothers and fathers of children with ASD. This finding is in line with previous studies. Hastings (2003) in his study found that there was no significant difference in the stress experienced by the father and mother of children with ASD. In the same line, in study titled, '*Autism Spectrum Disorder: Parenting Stress, Family Functioning and Health-Related Quality of Life*', the authors through descriptive statistics found that both the parents of children with ASD have moderate level of stress with no significant difference in stress between the male and female parents (Johnson, Frenn, Feetham, & Simpson, 2011).

It was also found that mothers of children with ASD used greater number coping strategies compared to fathers. The possible reason for this difference could be the mothers being the primary caretakers of the child, thus it seemed justifiable that they use greater number of coping strategies. It was further found in the qualitative analysis that almost 90% of the mothers were the primary caretakers of their autistic child. Mothers reported that they got help from the school, clinical psychologist, special educators, and by talking to other parents of children with ASD. Whereas, the fathers reported that they do not like to share their feelings, they mostly kept their feelings to themselves, and when the worry got too much they reported to have kept themselves engaged in other works. Mothers and fathers may use different coping strategies based on their

need and preference. Mothers have reported to have implemented more coping styles as compared to the fathers of children with ASD (Hastings, et al., 2005). Coping strategies are implemented based on their availability and usefulness to the situation. Mothers felt confident and prepared with planning made ahead of time that would help them and also the child to avoid or deal efficiently with the stress prone situation (Kuhaneck, et al., 2010). Findings of these studies are in same line with the results of the present results.

As identified in the qualitative results, some of the coping strategies available to the parents of children with ASD are social support from neighbors, family members and relatives, and professional guidance from clinicians and special educators. These findings are in line with the previous researches (Mancil, Boyd & Bedesem, 2009). It was found that the parents who reached out to the various support system and resources available to them had better state of mind when compared to parents who withdrew themselves from the social support system and indulged in excessive worry and tension. Further, it was found in the present study that parents of children with ASD got a lot more information on the disorder from the source of internet. This finding seemed to be new as well as a competent coping strategy that helped the parents feel equipped and well oriented about their child's disorder.

Summary and Conclusion

7.1 Summary

The present bodies of resources are filled with studies conducted on different psychological aspects of human beings. However, it was felt that there is dearth in studies conducted on the children with special needs, especially in the smaller and rural geographical locations. Most of the studies are conducted in big cities where the parents and the children have access to certain resources. Experiences of population from small towns are still unheard. In general Indian literatures are less in number compared to the western studies conducted in the field of autism. Moreover, when looked around in the social world, we hardly get to see atypical children from the huge umbrella of 'special' or 'differently able' group. Thus, this study was an outcome of the seer wonderment to find what could be the possible reason that keeps the families and the children with special need, autism in present context, from making access to the social world.

The study had two broad objectives, first to identify the relationship among stress, coping, and psychological wellbeing. And the second objective was to identify if there existed relation among stress, coping and psychological wellbeing of parents of children with ASD across child's age, degree of autism and parent's gender. The study was conducted on 49 parents (15 fathers and 34 mothers) of children with ASD, the residents of West Bengal. In order to achieve the said objectives, mixed method approach was used in which the quantitative data was collected using

the different questionnaires on stress, coping, and psychological wellbeing. Quantitative data was collected using a semi structure interview schedule, prepared while keeping in mind the aims and objectives of the study. Different psychological tools were used to measure stress, coping styles used and psychological wellbeing in parents of children with ASD. To measure stress in parents of children with ASD, Autism Parenting Stress Index (APSI) developed by Silva & Schalock (2012) was used. For identifying the different coping styles used by the parents, Ways of Coping Questionnaire, by Lazarus and Folkman (1985) was used. In order to measure the level of parent's psychological wellbeing, Ryff Scale of Psychological Wellbeing (1989) was used. Quantitative data analysis was performed using Statistical Package for Social Sciences (SPSS). Thematic method was used in order to analyze the qualitative data.

In order to achieve the first objective of the study, Pearson correlation was computed on SPSS. The results showed that parents who felt highly stressed in the area of child's social disability used escape avoidance coping. These parents further had lesser self acceptance but seemed to have purpose in life. Whereas, parents had better psychological wellbeing who sought out to social support, had self-control and practiced positive reappraisal of the situation as their copings styles. To fulfill the second objective t test was performed to see the comparison among stress, coping and psychological wellbeing across child's age, degree of autism and parent's gender. Different coping strategies was used by these parents where mothers were found to use more coping styles compared to fathers. Psychological wellbeing of these parents were found to be better when dealing with older children compared to parents who had to deal with younger children with ASD. Further, parents were found to use more coping strategies when dealing with older children compared to parents with younger children. The results further showed that degree

of autism in their child effected their level of stress. Meaning, that parents with moderate autistic child experienced higher of stress compared to parents with mild autism.

7.2 Conclusion

Based on the results, it can be said that parents of children with autism face greater challenges in their daily life. The possible factors that contributed to the parental stress were child's initial diagnosis, lack of awareness on the disorder, high treatment cost, social stigma, and child's future concerns. These stressors in due course have an effect on the parent's psychological wellbeing. In order to deal with these stressors the parents needs to have access to the different coping styles that are practical and easily available. It was found that coping styles that are accessible to the parents were social support, guidance from the school staff and professional help from the clinicians. This too was not available to the parents who were from remote and rural places. Thus, coping styles are to be made available to the parents who lack their access. Parents further need to be oriented on the various coping styles that are available to them. Apart from this, there is an urgent need to spread awareness among the parents in regard to the child's autistic condition. Most of the parents reported to had heard the term for the first time when their own child was diagnosed with autism. Thus, there is a need of mass awareness to the old and new parents on autism so that parents are able to identify the symptoms at an early age. This shall help in the early intervention which is beneficial to both parent and the child.

7.3 Limitations of the study

No research is complete in itself. Likewise, this study too has its limitations. The size of the sample is the first limitation that could possibly be identified in the study. Due to the challenges faced during data collection and also because of time constrain, the researcher could not reach out to the maximum number of participants. Within this limited sample, male parent participants were too less in comparison to the female parents. It was difficult to encourage male parent's participation as they had to attend to their office. However, with much challenges the researcher could involve only limited male participants in the study. This variance in the composition of the sample is one of methodological limitations of this study. Further, due to time boundaries the study was confined to a small geographical location. The research conducted in different areas could have given an understanding of stress, coping and psychological wellbeing in parents of children with ASD across the geographical locations. But the study could not be extended to a wider geographical area because of time limitation. The study could examine only the limited psychological factors like stress, coping and psychological welling in parents, whereas other factors like anxiety, depression, quality of life, positive emotion involved in having a child with autism, and the experience of siblings and other family members could not be included. For the analysis of qualitative data, ethnographic approach could have been used that involved in depth interview, researcher's participation and detailed observation of the participants.

7.4 Implications

Apart from creating awareness among the parents of children with ASD, there is a general need to spread awareness amidst the common population so that they can be more awakened and mindful on the disorder. The population who directly deal with children with ASD needs to be made aware of the different support systems and coping styles that are available to them.

Different interventions in the areas of behavior, communication and emotion are to be made available to the parents and children with ASD through government sectors. Most of the equipped special schools and therapeutic centers are situated in the urban town whereas the needs of the families in the rural areas are left undermined. Thus, changes and improvements in the policies are to be made where the resources are practically available to children and also parents.

Changes in the social infrastructures are to be made that is more inclusive, accommodating the needs of the special children and their families.

7.5 Recommendations for Future Research

For the future recommendation, researches can be conducted on a larger sample so that the results thus found can be generalized. Moreover, though it might be challenging but effort must be made to include more of male (father) participants. Studies that include different geographical locations will help to get a varied understanding of different psychological factors that are part of life of parents of children with ASD. This would further enrich the existing body of resources.

Different psychological and socio-economic factors like anxiety, depression, experience of other family members, occupation of parents, education, and family background that could not be added in the present study can be taken up in the future undertakings. Longitudinal studies can

be conducted to see if there exists a difference in stress, coping and psychological wellbeing in parents of children with ASD over a period of time. Different forms of methodological approaches in qualitative analysis can be adopted that will help in understanding the stated phenomenon in detail.

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