

**PERCEIVED STRESS AND COPING STRATEGIES IN PARENTS  
OF CHILDREN WITH AUTISM SPECTRUM DISORDER**

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**Dissertation submitted in partial fulfilment of the  
requirements for the award of the degree of  
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**December 2018**

## DECLARATION

I hereby declare that this dissertation entitled “**Perceived stress and coping strategies in parents of children with Autism Spectrum Disorder**” is a bonafide record of my original research. It has not been submitted to any other university or institution for the award of any degree or diploma. Information derived from the published or unpublished work of others has been duly acknowledged in the text.

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## **CERTIFICATE**

Certified that the dissertation titled **“Perceived stress and coping strategies in parents of children with Autism Spectrum Disorder”** is a record of the research work undertaken by Ms. Prinu Jose, in partial fulfillment of the requirements for the award of the degree of ‘Masters of Public Health’ under my guidance and supervision.

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## **GLOSSARY OF ABBREVIATIONS**

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ASD	Autism Spectrum Disorder
ADOS	Autism Diagnostic Observation Schedule
CARS	Childhood Autism Rating Scale
CLW	Community Level Workers
DALY	Disability Adjusted Life Years
DSM	Diagnostic and Statistical Manual
ICD	International Classification of Diseases
ID	Intellectual Disability
ISAA	Indian Scale for Assessment of Autism
NDD	Neurodevelopmental Disorders
PDD	Pervasive Developmental Disorder
PDD-NOS	Pervasive Developmental Disorder-Not Otherwise Specified
PSS	Perceived Stress Scale
RBSK	Rastriya Bal Swasthya Karyakram
SCDC	Social and Communication Disorders Checklist
WHO	World Health Organization

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## ABSTRACT

**Background:** Parenting, children with Autism Spectrum Disorder (ASD) can be a state of high stress. Certain factors at individual, family and society levels offer succour to handle stressors and cope with it. This study aims to assess stress, factors associated with stress and coping strategies in parents of children with ASD.

**Methodology:** This was an institution based cross sectional survey done in five institutions catering to children with disabilities in Trivandrum. The accompanying parent of children under care for ASD from any of the selected institutions during the study period were interviewed using a structured interview schedule to assess stress, associated factors and coping strategies. PSS-10 was used to find the perceived stress scores. Fisher exact test, Mann- whitney u test and Kruskal wallis test were used for bivariate analysis and binary logistic regression for multivariate analysis.

**Results:** There were 110 participants (99 mothers) for the study. All subjects had moderate to high levels of stress, with 39% reporting high perceived stress. Parents with high anxiety were four times (adjusted odds ratio (AOR) 4.38, 95% CI 1.38-13.93) more likely to have high perceived stress. Never avoiding social gatherings was protective (AOR 0.12, 95% CI 0.026-0.63). Regarding coping strategies, proportions of parents with high stress were lower in those with positive reinterpretation, high religious faith and high emotional support.

**Conclusion:** All parents of children with ASD are likely to be stressed particularly if coping strategies are not favourable or in co-existence with other states like high anxiety. High stress levels in parents of children with ASD and needs to be identified and addressed. Sensitizing society about importance of creating an inclusive environment for children with ASD and identifying and facilitating factors that help parents socialize without restraint may be helpful in alleviating high stress.

## CHAPTER 1

### INTRODUCTION

#### 1.1 BACKGROUND

The term “infantile autism” was coined by a child psychiatrist Leo Kanner in 1943. He described the children as having certain traits of reduced instinct to interact with outside world, need for sameness and difficulty in managing a change of routine (Silberman 2015). According to American Psychiatric Association, “*Autism spectrum disorder (ASD) is a complex developmental disorder that can cause problems with thinking, feeling, language and the ability to relate to others. It is a neurological disorder, which means it affects the functioning of the brain*” (Lai et al. 2015). The DSM-IV classified autism as one of five development disorder in the group of Pervasive Development Disorder (PDD). Others disorders included are Asperger’s Syndrome, Rett’s Disorder, Childhood disintegrative Disorder, and if full criteria for one of the above disorders is not met, a child may be diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) (Barua 2012). Due to poor reliability of multi categorical system, DSM-V introduced single diagnostic dimension namely “Autism Spectrum Disorder”. DSM-V changed the three domain based diagnosis to only two domains such as impairment in social communication and interaction are required for the diagnosis of ASD.

Parenting a child is an emotionally fulfilling experience. Having a child with disability introduces a parent into new stressors and vulnerabilities. Parenting a child with development disabilities is often accompanied with high levels of stress and

negative psychological outcomes (Schieve et al. 2007). The physical and emotional wellbeing are at significant risk for parents of children with disabilities (Greenberg et al. 1993).

Parenting a child with ASD is additionally distressing as people with ASD might present with triad of issues namely “wing’s triad”. (Liao & Gendler 2018). This includes problems in social competence, communication, and imagination (Happé 1994); (Wing & Gould 1979). They usually engage restrictive or repetitive activities (Carpenter et al. 2005); (Happé 1994); (Rogers et al. 2005); (Wing & Gould 1979). A study done to assess mothers of preschool children with autism and Development Delay(DD) reported higher mean level of parental stress and psychological distress in mothers of children with autism compared to other group (Estes et al. 2009) (Dabrowska & Pisula 2010). While comparing psychological wellbeing of parents of children with ASD, autistic children’s parents reported more depressive symptoms than parents of typically developing children (Lai et al. 2015). Different factors of stress operate in multiple domains for parents of children with ASD. In an individual level, management of stress exercise as coping strategies.

Coping strategies are attempts from an individual in a crisis situation. In parents of children with ASD, utilization of coping strategies can either mitigate or elevate stress levels. In study which compared parents of children with intellectual disability and Autism Spectrum Disorder found that parents of children with autism experience more stress and was seeking more social support than the other group (Somasekhar 2017).

## **1.2 Rationale of the study**

Parenting a child with disabilities is a unique experience. Parents who experience higher levels of stress interact differently with their children, and they respond differently to their child's problematic behavior (Hayes & Watson 2013). This might have a negative impact on the functioning of child with developmental disorder. Factors like ASD severity, impaired social skills and other child characteristics are positively associated with caregiver stress (Beck et al. 2004). This might also dependent upon other contextual factors (Murray et al. 2009). In the process to overcome the stress, these parents might voluntarily or involuntarily utilize certain coping strategies.

In India basic, intermediary and speciality level services are available for children with ASD. But there is a dearth of accessible high quality ASD management facilities. Parents are the *'first therapist'* for their child. They are an integral part of treatment team for their child with ASD. Therefore, the next phase of management for a child with ASD would be considering parental issues and concerns.

### **1.3 Research question**

- What are the levels of stress and factors associated with it in parents of children with ASD?
- What are the coping strategies used by parents of children with ASD?

### **1.4 Research objectives**

#### Primary Objectives

- To assess the level of stress in parents of children with ASD
- To examine the factors associated with stress in parents of children with ASD
- To find the coping strategies used by parents of children with ASD

#### Secondary objective

- To assess the psychometric properties of perceived stress scale 10-Malayalam version

### **1.5 Chapterization plan**

Chapter one of dissertation gives a background and rationale for the study, research question and objectives. Chapter two describes on relevant literature that was reviewed for the topic. Chapter three describes the methodology of the study including study design and setting, tool for data collection, study variables, data analytical methods and ethical considerations. Chapter four gives the results including descriptive tables and results of open ended questions. The discussion, conclusion and policy recommendations are included in chapter five.



## CHAPTER 2

### REVIEW OF LITERATURE

This review attempts to research existing literature on stress and coping strategies of parents of children with Autism Spectrum Disorder (ASD). A detailed literature search was conducted on search engines and online databases like PubMed, Google scholar and Wileys online library. The key words used were “stress”, “children with disabilities”, and parents of autistic children”, “coping strategies and India”. Information was obtained through personal communication with parents of children with ASD and experts in similar field.

#### 2.1 Definitions used in this review

Stress can be defined as *“a negative emotional experience accompanied by predictable biochemical, physiological, cognitive, and behavioural changes that are directed either towards altering the stressful event or accommodating to its effects”* (Baum 1990) (Patnaik 2014).

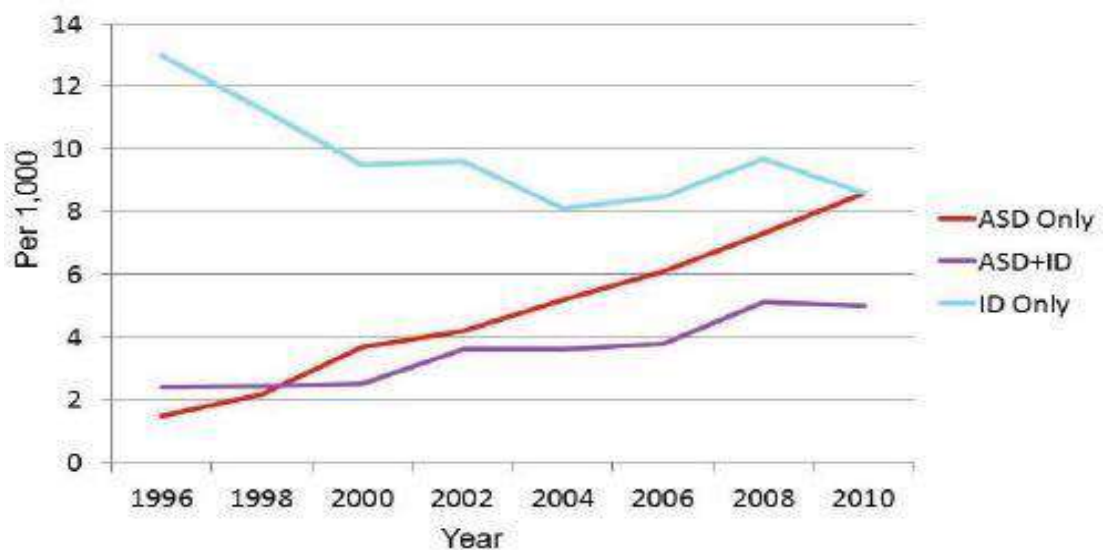
Parental Stress- Stress that parents experience not only because of childrearing, but also due to their social and environmental circumstances, responsibilities, and everyday life (Belsky 1984).

Coping Strategies- Coping strategies refer to the specific efforts, both behavioural and psychological, that people employ to master, tolerate, reduce, or minimize stressful events (MacArthur SES & Health Network | Research 1998)

## 2.2 Epidemiology of Autism Spectrum Disorder (ASD)

**Global scenario-** According to World Health Organization 2017 factsheet, 1 in 160 children have ASD (WHO 2017). The Global Burden of Disease 2010 estimated 52 million cases of ASDs around the world, equating to a population prevalence of 7.6 per 1000 that is, 1 in 132 people. Autistic disorder was three times more common in males (3.6 per 1000, 95% UI 3.4–3.9) compared with females (1.2 per 1000, 95% UI 1.2–1.3). ASD accounts for 7.7 million DALYs in 2010 (Baxter et al. 2014).

Figure 2.1 Contrasting trends in the prevalence of ASD and ID (Braun et al. 2015).



Main reasons for this increase can be partly due to heightened awareness of the disorder, different criteria for the diagnosis of ASD, an actual increase in individuals being diagnosed with ASD, or a combination of these factors (Diagnostic and Statistical Manual of Mental Disorders 2013)

**National-** A study done in North East India in a selected population of 11,849 school-children in India showed weighted prevalence of positive scores (for broader

autism spectrum, ASD, autism) as 0.23 % ( 0.07–0.46%) (Rudra et al. 2017). This study utilized social and communication disorders checklist (SCDC) followed by social communication questionnaire (SCQ). SCQ-positive children were administered the Autism Diagnostic Observation Schedule (ADOS). The prevalence rate was somewhat lesser at 0.09% in a community based study conducted in North West India (2017) reporting a higher prevalence in rural areas (Raina et al. 2015). This study utilized Indian Scale for Assessment of Autism (ISAA) which is based on Childhood Autism Rating Scale (CARS). ASDs usually coexist with other neurological problems. In a multisite population based survey on prevalence of Neurodevelopmental Disorders (NDD) it was found that among children diagnosed with ASD, intellectual disability (72.7%) and epilepsy (27.3%) were the major common coexisting NDDs (Arora et al. 2018)

**Local-** A study done in the Child Development Centre, Kerala in 2018, where trained Community Level Workers (CLW) administered Trivandrum Autism Behaviour Checklist (TABC) in Thiruvananthapuram endorsed a prevalence of 1.8 per 1000. Here, positively screened children were assessed by a developmental therapist with Childhood Autism Rating Scale (CARS). The male to female ratio was reported as 4:1 (George et al. 2018). A study in Kerala which was performed by administering Modified Checklist for Autism in Toddlers – Revised (M-CHAT-R) to mothers reported that prevalence of toddlers at risk of ASD were found to be 5.5% (Jaisoorya, et al. 2018).

Difference in prevalence estimates can be influenced by two factors: In the community based studies, only children who were present at the day of survey were selected and there were no secondary visits. Institutional based studies were done

with the help of teachers and parents in institutions and therefore probability of children with ASD being identified might have been better. Also there were differences in case definition in all studies. The diagnostic tools or criteria used might have influenced the prevalence estimates.

### **2.3 Biomedical model of ASD**

According to WHO, Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (WHO 1948). ASD is a condition that spans the mental and social dimension of health. According to the International Classification of Diseases – 11 (ICD-11) ASD includes a set of conditions “characterised by persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication. The exact time of onset of the disorder is not clear and is possibly very early, but diagnosis usually happens when the child with their limited social abilities is unable to meet the social requirements as they grow up. The current study also acknowledges that being a parent of a child with ASD can have a profound effect on all dimensions of health and subsequently wellbeing. ASD does not have a single cause. Certain studies have shown that ASD is caused by a combination of genetic (Marshall et al. 2008) and environmental factors (Davis & Carter 2008). Even now controversies regarding Measles Mumps Rubella (MMR) vaccine and ASD exist. But there is no empirical evidence suggesting any relationship between MMR vaccination and ASD (Dyer 2010). The diagnosis of ASD is usually clinical and based on a battery of cognitive tools that need to be appropriate for the populations they are applied to. In India, diagnosis of ASD is primarily by utilizing Childhood Autism Rating Scale (CARS),

DSM IV and DSM V, INCLIN Diagnostic tool for Autism Spectrum Disorder (Zachariah et al. 2017).

### 2.3.1 Severity levels of Autism Spectrum Disorder

As the name implies, the condition is not a concise entity but a spectrum with near normal individuals at one end to very severe forms at the other.

Table 2.1 gives a simple classification of the spectrum based on the severity.

<b>Severity and Support level needed</b>	<b>Social communication</b>	<b>Restricted, Repetitive behaviours</b>
Level 1 Requiring support	<ul style="list-style-type: none"> <li>- Difficulty initiating social interactions</li> <li>- Decreased interest in social interactions</li> </ul> <p>For example: failed to and fro conversations</p>	<ul style="list-style-type: none"> <li>- Inflexibility of behaviours which causes difficulty in functioning</li> <li>- Difficulty in switching between activities</li> <li>- Issues in planning and organizing which causes difficulty in independence</li> </ul>
Level 2 Requiring substantial support	<ul style="list-style-type: none"> <li>- Marked deficits in verbal and nonverbal social communication skills</li> <li>- Limited initiation of social interactions</li> <li>- Restricted or abnormal responses to social overtures from others.</li> </ul>	<ul style="list-style-type: none"> <li>- Inflexibility of behaviour</li> <li>- Difficulty to change routines</li> <li>- Restricted/repetitive behaviors which interfere with functioning in different context</li> <li>- Difficulty/distress in changing focus or a definite action</li> </ul>

*Table continued..*

<b>Severity and Support level needed</b>	<b>Social communication</b>	<b>Restricted, Repetitive behaviours</b>
Level 3  Requiring very substantial support	<ul style="list-style-type: none"> <li>- Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning</li> <li>- Very limited initiation of social interactions</li> <li>- Minimal response to social overtures from others</li> <li>- Responds to only very direct social approaches</li> </ul>	<ul style="list-style-type: none"> <li>- Inflexibility of behavior</li> <li>- Extreme difficulty coping with change</li> <li>- Restricted/repetitive behaviors markedly interfere with functioning</li> <li>- Great distress/difficulty changing focus or action.</li> </ul>

Source: (Diagnostic and Statistical Manual of Mental Disorders 2013)

#### **2.4 Parental stress and Autism Spectrum Disorder (ASD)**

Parenting is a wonderful and rewarding experience. But for parents of children with ASD, it is often accompanied by high levels of stress, because of difficulties and frustrations that they face during their everyday life (Blacher 2001). Normal parenthood calls for certain interpersonal, reflective skills and enlists caregivers' agential capacities for generating social bonds. Parents of children with ASD might have difficulty in performing this (Willett et al. 2016). A study done in Kerala recounts parental experiences of diagnosing of their autistic child. Parents usually felt something different in their child by the average age of 18 months or during preschool age. Lack of eye contact, language delay, self-stimulatory behaviours like sensitivity to certain noises, minimal social interaction and lack of play were usually identified (Mohan 2015). Similar experiences were reported in a study performed in Goa where parents identifies their child's incongruent behaviours while comparing to older siblings or same aged children caught their attention in first phase (Desai et al.

2012). After being diagnosed, a period of grief or loss was the first phase which was followed by self-blaming. Parents verbalised shock about their child's diagnosis and felt despair (Mohan 2015).

Certain studies have reported higher prevalence of stress in parents of younger children with ASD. This can be due to stress related diagnosis of the child and initiation of interventions (Davis & Carter 2008). Often transitions in stress levels are observed in these parents, whereby they face highest stress during adolescence and early adulthood of the child (Blacher 2001). Even among parents of children with ASD the stress levels are not uniform. Mothers of children with ASD reports higher amount of stress than fathers (Davis and Carter 2008);(Dabrowska & Pisula 2010). Ironically, when the child is young, both mothers and fathers experienced high stress (Davis & Carter, 2008). The causes of distress in mothers and fathers were also found to be different. For mothers, child problem behavior was associated with increased parenting stress while fathers had issues with the externalizing behavior of the child as these behaviours invited negative attention from public (Estes et al. 2009). Parents were often afraid that a stranger unaware of child's condition may misinterpret their child's behaviour (McStay et al. 2014).

Many studies have compared stress in parents of autistic children with parents of children with other disabilities. In a study which assessed mothers of preschool children with autism and Development Delay (DD) showed a higher mean level of parental stress and psychological distress among mothers of children with autism than mothers of children with DD (Estes et al. 2009) (Dabrowska & Pisula 2010). In a study which compared parents of children with intellectual disability and Autism Spectrum Disorder, it was found that parents of children with autism experience

more stress and was seeking more social support than mothers of Mental Retardation (Somasekhar 2017).

In India, parents of children with Autism Spectrum Disorder face lot of challenges not only because of a child with disability but the attitude of society which prevents the integration of a child with disability into the society (Barua 2012). Parents have deep concern about the life of their child after their death and also about absence of social scale security systems in India.

#### **2.4.1 Domains of stress**

**1. *Child's characteristics***- Disruptive behaviour of child was positively correlated with daily negative mood for parents (Pottie et al. 2009). In a study performed in Iran, which compared parental stress among fathers and mothers of children with ASD reported correlation between parenting stress of fathers and severity of ASD (Soltanifar et al. 2015). Another cause of stress due to child characteristics were problem behaviours like self-injury (Konstantareas & Homatidis 1989).

**2. *Economic and familial difficulties***- ASD can upset the rubric of financial and familial situations of affected households. Autism is considered as an “expensive disorder”. The total annual societal per capita cost of caring for and treating a person with autism was estimated to be \$3.2 million (Ganz 2006). Even though ASD is a childhood disorder, the cost related to the disorder can reflect in adulthood (Ganz 2007). Parenting a child with autism is a challenging task which can have significant effects in marital life. In a study which compared 391 parents of children with ASD and matched sample of parents of children without disabilities, it was found that prevalence of divorce was significantly higher in parents of children ASD (23.5



percent). But this rate was lower as compared to divorce rates in U.S. during the period, 50 percent (Raley & Bumpass 2003). The risk of divorce remained higher in the childhood, during adolescents and early adulthood of autistic child (Hartley et al. 2010).

**3. Family and social support-** Studies suggest that high levels of psychological distress and levels of reported distress are associated with low levels of informal support within the family (Bromley et al. 2004). Having supportive family members can reduce parental stress considerably (Boyd 2002). In a study done in West Australia, it was found that families were more stressed if parenting a child with autism prevented them for socializing from others (Sim et al. 2017). Providing emotional support had positive benefits on the mood and psychological wellbeing of parents.

Parents of children with ASD are usually amidst of constellation of difficulties due to overlap of multiple domains of stress. A phenomenon called *stress proliferation* can occur for these parents. Stress proliferation occurs when one or multiple stressors in a life domain spill over other situations of life (Pearlin 1997). An example of stress proliferation in autistic child can be: increased child care demands can lead to less concentration at work, subsequent professional and financial constraints.

### **2.5 Family adaptation for raising a child with ASD**

Each family of children with ASD is unique and ways of adaptation to stressors will be different. As per the ABC-X model described by Hill 1953, characteristics of family stressor (A), family's crisis meeting resources (B), how family define

stress(C) interact with each other to contribute to either prevent or precipitate family crisis (X). McCubbin and Patterson 1983, described the Double ABC-X model, which incorporated the impact of accumulated life stressors in the life time on family adjustment (McCubbin & Patterson 1983). For parents of children with ASD, similar model of adaptation can operate whereby an interaction of parental cognition of stress and familial resources occur which can either aid resolve or exaggerate the stress. The impact of stress varies if parents are living amidst of constellation of difficulties. Here, resilience of family/individual plays its role.

## **2.6 Coping Strategies: Problem Based Coping and Emotion Based Coping Strategies**

Coping strategies are thoughts or actions which people perform when they are under stress. Problem focused coping strategy mainly focuses on resolving the problem or removing the source of stress while, emotion-focused coping strategy is based on managing the emotional distress which is the result of stressful situation. Although people use both of these coping strategies, utilizing problem focused is considered more constructive as this focuses on resolving the root problem. Certain examples of problem focused strategies are active coping, planning, suppression of competing activities, seeking of instrumental social support and emotion focused are seeking of emotional social support, positive reinterpretation, acceptance, or denial (Carver et al. 1989). According to Folkman and Lazarus (Lazarus & Folkman 1984), positive reappraisal can be defined as efforts to create positive meaning by focusing on aspects like personal growth, finding new faith, rediscovering the important things in life, and being inspired to be creative. Well documented evidence of parents of

children with ASD utilizing positive reappraisal as their coping strategy exists. (Dardas 2014).

Seeking social support' was one of the most used coping strategy in parents of children with Autistic Disorder. (Gray 2006) (McCubbin & Patterson 1983). Supportive family members and interacting with other parents of children with autism can decrease parenting stress (Boyd 2002). Creation of peer support groups by bringing together parents of children with ASD can alleviate the physiological and emotional distress of parents to a considerable level (Bray et al. 2017). According to previous researches parents who use active avoidance like denial or distraction reports more stress (Sarriá & Pozo 2015). Compared to parents of typically developing children, parents of children with ASD used active avoidance coping which is a maladaptive coping strategy (Lai et al 2015).

Certain studies have shown the involvement of moderators between stress and distress. In a study conducted in Florida Autism Society and Autism Societies of America found that stress was not directly related to negative outcome but social support and coping style were acting as moderator (Dunn et al. 2001).

## **2.7 Role of Gender in ASD and its effects on stress and coping strategies**

Traditional gender roles still exist in society. Mothers were generally the primary caregiver for autistic children (Mouridsen et al. 2007). Researchers have found that women exhibit higher psychological distress than their male counterparts (Thoits 1995). Also, more than men women are more likely to appraise events as stressful (Ptacek et al. 1992) (Tamres et al. 2002). From a feminist perspective, generally

women are made to surrender their agency. This extends to parenthood as well. As mothers, society expects women to bring up a normal child (Willett et al. 2016).

Women disproportionately take more responsibility on household and childcare than men. When a member of the family is disabled the burden caring them falls on the mother and this can even restrict her career (Gray 2003). Women are more vulnerable to certain specific stressors like events to their loved ones or in their social network while men are more vulnerable stressors which are job related or economic stressors (Conger et al. 1993). Furthermore, coping strategies have shown differences according to one's gender. Eventhough there are exceptions in literature on gender differences in utilization of coping strategies, men usually have inexpressive way of responding to a stressor while a women are more expressive and emotional (Milkie & Peggy1993).Women are more likely to use emotion-focused coping strategies, including avoidance (Ptacek et al. 1994). Gender differences may also manifest in care seeking practices - mothers of children with ASD were also depending on community resources and took professional help for managing their stress.

## **2.8 Management of ASD**

### **2.8.1 Clinical approach**

ASD cannot be completely "cured". Chronic management of an individual focuses on reducing core deficits of ASD, attaining independence in performing daily living skills and alleviation of stress in family. Children who receive behavioural intervention at a younger age have shown substantial improvement in achievement of language and adaptive skills (Myers & Johnson 2007).

*Educational intervention* aims to provide habilitative therapies and manage behavioural issues. It incorporates social and communication skills, daily living skills and management of maladaptive behaviours. *Applied Behaviour Analysis* methods are based on principles of learning derived from experimental psychology which focuses to improve and maintain the adaptive behaviour and reduce maladaptive behaviour. A functional behavioural analysis is usually performed to understand a specific maladaptive behaviour. Here, problem behaviour is described which include its nature and frequency. The reinforcing factor and consequence is studied. Accordingly new adaptive skills are formulated. TEACCH (*Treatment and Education of Autistic and Communication related handicapped Children*) method developed by Schopler and colleagues also called as “structural learning”. It helps autistic children to improve their skills and modify the environment according to their deficits. Organisation of physical environment, structured activity system, visually structured activities, predictable routine and visual schedules are the main components. *Speech and language therapy, occupational therapy (OT) and sensory integration therapy* can help children in developing their communicational, self-care and academic skills. Medications in ASD are restricted to management of certain comorbidities like epilepsy and sleep disturbances. This can eventually help them in benefitting from other interventions (Myers & Johnson 2007).

### **2.8.2 Inclusive approach and derived parental roles**

People with ASD might have issues with participating in social activities. Even a simple touch or a smell can be highly aversive for them. In this case changing the ‘*neurotypical*’ majority might not be possible. This might cause additional stress in these parents as a responsibility is added with existing ones here (Wasserman et al.

2015). V.R. Krishna Iyer described 'Rehabilitation' as philosophy rooted in capabilities of an individual rather than things which they are not capable of. Abilities of individuals should be given priority rather than their inabilities (Iyer 1982). People with autism have difficulty in understanding mental states of other individuals. But unlike people with psychopathy, individuals with ASD can behave morally. In spite of their generally less mind reading abilities, they can respond on the distress of people. This aspect is a positive ability for autistic individuals (Stueber 2018).

Management of children with ASD should focus on the strengths of each child rather than weakness. A review by Scott.M.Myers et al, points out that inclusion of family in autistic child's treatment is an essential component of early intervention program. For better inclusion for people with ASD in society, the parents should take up the major role. They are the immediate care givers and first agents of change (Wasserman et al. 2015).

As "first therapist", parents can assist in identification of their child's skills and frame tailor-made interventions. For better inclusion with neurotypical majority, parents have to work for physical and social modifications with normal care related burden. This might cause additional stress in these parents as a responsibility is added with existing ones here (Wasserman et al. 2015). Therefore, integrating management of parental stress and issues in the treatment of child with autism is crucial.

## **2.9 Theoretical approaches to autism and parenting**

### **2.9.1 Emerging theories on neurocognition**

Cognition is being increasingly seen as something beyond merely the brain. Embodied cognition considers that cognition depends upon an individual's body rather than just the brain. In theories on embedded cognition and extended cognition, physical and social environment of the individual plays a predominant role. Some theorists consider these theories as separate ones, while others think that these theories overlap. The message from these theories is that certain parental and social aspects (like gender and education) can help in modulating child's condition (Grandgeorge et al. 2009). The concept of embedded and extended cognition of children with ASD places their parents or caregivers firmly in the response to treatment (Wilson & Foglia 2017).

Improvement or deterioration in cognitive development can lead to changes in parental stress levels which can further affect the cognitive development of the child. Moreover, social or environmental stressors in individuals can influence the biological expression of bodily functions and responses. Thus envisaging a body-mind-society continuum will be helpful in conceptualizing ASD and related situations.

### **2.9.2 Theory of embodiment**

Nancy Kreiger's concept of embodiment (Krieger 2005) clearly embarks on explaining how the social environment affects the individual's biology. *“Embodiment is, by definition, a multilevel phenomenon, as it necessarily entails the interplay between bodies, components of bodies, and the world(s) in which the*

*bodies live*”. The physical or psychological issues of an individual can be a biological expression of the environmental stressors. Stress and morbidities of parents with an autistic child, is not only because of the child’s problematic behaviour related autism. Their socioeconomic and familial condition also has influence on stress. As an example, poor socioeconomic condition can cause reduction in the health facility visit that can eventually lead to the higher severity in symptoms in child. Higher severity of symptoms is related to stress in parents with autism (Hastings & Johnson 2001). A vicious cycle of events is followed in these parents which eventually results in stress and probably stress proliferation.

In a study done on Chinese mothers of preschool children with ASD, lifetime prevalence of having any psychiatric disorder was 39.7 percent. Major depressive disorder was the most common psychiatric disorder in these parents (Yu et al., 2016). A study which compared the psychological wellbeing of parents of children with ASD and typically developing children found that autistic children’s parents reported more depressive symptoms than the other group (Lai et al., 2015)

## **2.10 State response for disabilities including ASD**

The constitution of India assures every citizen of India fundamental rights which includes right to equality (Article 14 to 18), right to freedom (Article 19 to 22), right to life and personal liberty (Article 21), right to education (Article 21 A), right against exploitation (Article 23 to 24), cultural and educational rights (Article 29 to 30), right to freedom of religion (Article 25 to 28) and right to constitutional remedies (Article 32). The Constitution clearly provides that ‘*the state shall not deny to any person equality before law or the equal protection of law within the territory*



*of India.*’ Right to life and personal liberty clearly earmarks right to live a dignified meaningful and complete life free from exploitation. With the 86<sup>th</sup> constitutional amendment in 2002, Right to education was added which provides free and compulsory education for children in age group of 6-14 years (Constitution of India 1950).

Attaining constitutional provisions by children with ASD remains daunting. Both central and state governments have introduced different programmes and policies for people with disabilities and their families. While some schemes are exemptions from taxation, concessions for travel etc, some schemes extend to directly address the needs of the intended beneficiaries.

### **2.10.1 Kerala State Schemes for persons with disabilities by Department of Social Welfare**

Department of Rural Development is providing State Disability pension for person with disabilities according to the degree of disability. For more than 80% disability, pension of INR 700 per month and degree of disability below 80%, INR 525 per month is provided. The pension scheme is funded by centre and state equally. Educational scholarship for student with disabilities till class 12<sup>th</sup> is given through their respective schools. Kerala government also provides marriage assistance of Rs.10,000/- for differently abled woman of BPL families (“Kerala State Schemes for Persons with Disabilities by Department of Social Welfare | EYEWAY,” n.d.). The tendency of some schemes to facilitate people fulfilling normative roles is evident.

A new initiative called “State Initiative on Disability - Prevention, Detection, Early Intervention, Education, Employment and Rehabilitation” was implemented by

Department of Social Justice with close association with Department of Health and Department of Education. Prevention, early detection and screening, early intervention, education, employment and rehabilitation are the major components of this initiative. The approach is in line with the RBSK (given below) through establishment of District Early Intervention Centres (DEIC) and training of Anganwadi workers for detection of development delay are part of action plan (“Special Assistance to Specially Abled - Government of Kerala, India,” n.d.).

### **2.10.2 “Spectrum project” under Social Security Mission**

The Social Security Mission, Government of Kerala has introduced “Anuyatra programme” for management of disabilities. “Spectrum project” is a new initiative for comprehensive development of autism sector in Kerala under Anuyatra programme launched on 15 November, 2018. The existing therapy centres in the state will be registered under the Right of Persons with Disabilities (RPWD) act. Infrastructure development and institutional capacity building is major strategy envisaged in this project. A parallel empowerment programme is planned to create awareness and training for the parents of affected children with Autism Spectrum Disorder (“Spectrum project for development of autism sector gets a boost,” n.d.).

### **2.10.3 Rashtriya Bal Swasthya Karyakram(RBSK)**

As a part of implementation of Rastriya Bal Swasthya Karyakram, District Early Intervention centres (DEIC) were established at the district Hospital level across states in India. The purpose of DEIC is mainly to intervene early and minimize disability to children detected with developmental delays and disabilities primarily for children up to 6 years of age group. DEIC’s will also provide referral support. Core services includes medical services, dental services, psychological services,

occupational therapy and physical therapy, speech and audiology, cognitive services (“Rashtriya Bal Swasthya Karyakram (RBSK),” n.d.). Supplementary services of DEIC include family support services. These services aim to help children who need chronic support in home setting or natural environment. A family- centered approach will be utilized for training the child with disability. Even though parent associations are a part of services rendered by RBSK, no information about this component is available at present.

Sarva Shiksha Abhiyan; “Education of Children with Special Needs” links Ministry of Human Resource Development, Department of School Education & Literacy. Inclusive education and support for children from 6-14 years is given with the help of trained special educators. Also on need basis, home based education interventions are to be provided for children (“SSA - Functional Areas | Inclusive Education For CWSN (Children With Special Needs” n.d.).

#### **2.10.4 National trust for welfare of persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999**

The National trust for welfare of persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 was formed to empower persons with disability to live as independently and as fully as possible within and as close to the community to which they belong. The trust provides support the person with disabilities and their families by strengthening the existing facilities. Also, if the person do not have a family support or if there is any event of death of caregivers, trust will take measures for promoting care of protection.

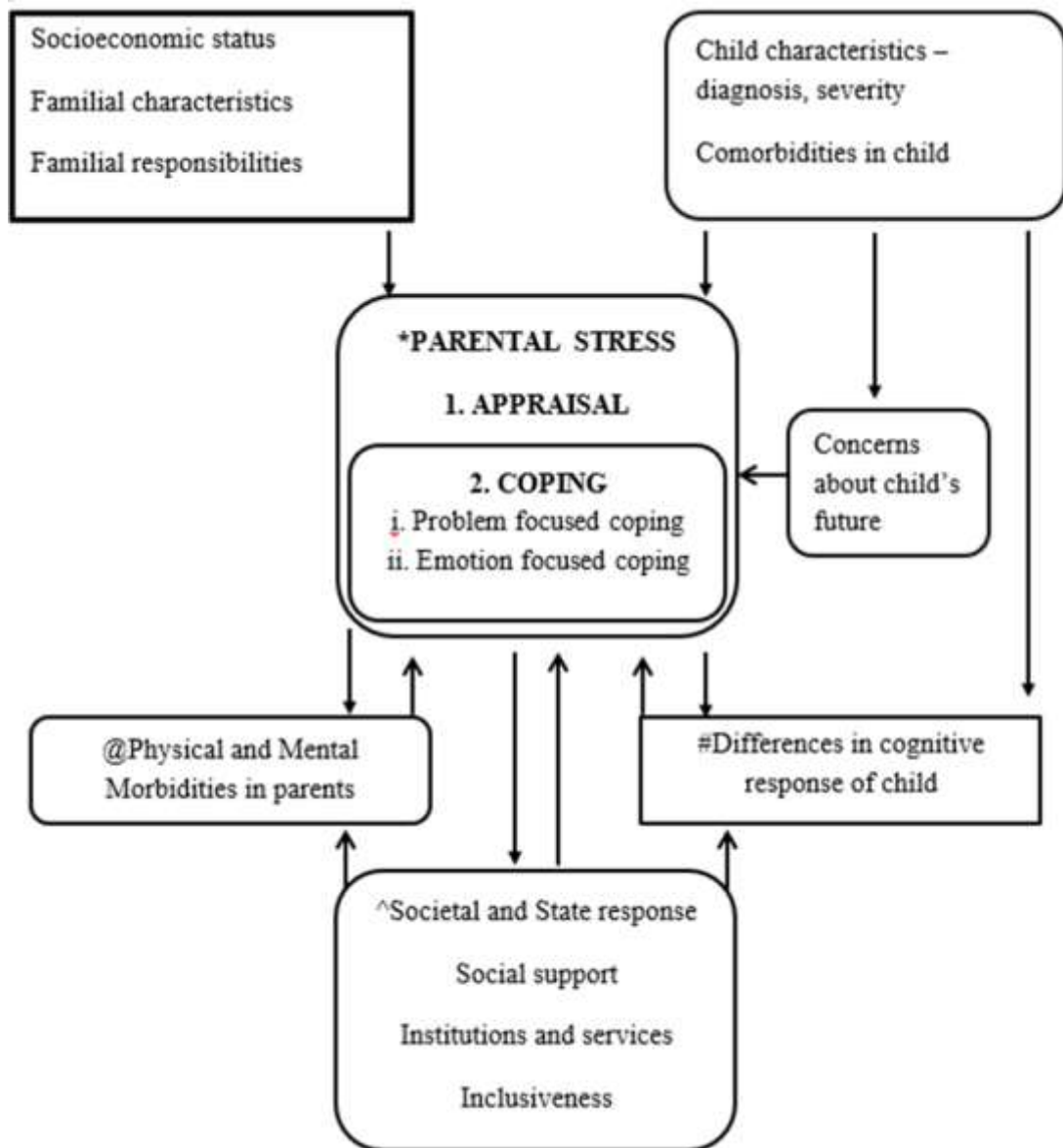
Gharaunda scheme under the act provides home and other services including basic medical care for people with disabilities. It provides pre vocational activities

and training by setting up Gharaunda centers. Many of the training schools do not provide services for people with disabilities after 18 years. In this scenario, this scheme is boon as it aids in making them capable of earning for a livelihood (“National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act,” n.d.).

#### **2.10.5 Rights of Persons with Disability Act 2016**

The Rights of Persons with Disabilities Act, 2016 stress to “ensure people with disabilities, enjoy the right to equality, life with dignity, and respect for his or her own integrity equally with others”. The types of disabilities have been increased from existing 7 to 21 categories which includes Autism Spectrum Disorder (ASD), Speech and language disability. The act calls for provision of inclusive education, skill training programmes for persons with disabilities including people with ASD. Surveys are to be conducted every five years to find children with disabilities and assess their needs. Clauses regarding guardianship and reservation are also included in the Act. In every government establishment, not less than four per cent of the total number of vacancies in the cadre strength in each group of posts meant to be filled with persons with benchmark disabilities of which, one percentage each shall be reserved for persons with autism, intellectual disability specific learning disability and mental illness. This was a significant step as providing specific per cent reservation for each disabled category is essential for their enrolment. RPWD, 2016 was a paradigm shift in perception about disability from a social welfare concern to a human rights issue (RPWD Act 2016).

**Figure 2.2 Conceptual Framework**



Theoretical underpinnings:

\* Psychological stress theory – Lazarus, Folkman and Lazarus; Feminist theory – differential exposure to stressors, response and coping

@ Embodiment – Nancy Kreiger's theory of embodiment

# Theories of cognition – Embodied, embedded and extended cognition

^ Sociological theory – Structure and agency

Psychological stress theory by Lazarus delineates two concepts: appraisal and coping. Appraisal is the assessment of significance of a life situation and coping is an individual's actions to manage specific demands (Krohne 2001). Stress is a transaction between an individual and their environment. *Coping* is closely connected with stress and hence relevant to person- environment transactions (Folkman & Lazarus 1980) Problem-focused coping attempts to alter causes behind negative emotions or stress. While emotion-focused coping attempts to change the appraisal of a crisis situation or reduce a negative emotional state (Krohne 2001)

Caring for a child with disability is a challenging task. Parents of children with ASD face different domains of challenges in their everyday life. The main factors associated with stress in parents of children with ASD are socioeconomic status of the family, familial characteristics which includes number of children in the family and birth order of the child. Child characteristics like age of child, level of care needed for the child and comorbidities can have a profound effect on the healthful living of an autistic child's parent. Caring for other children and family members, arranging money for treatment are certain familial responsibilities which are possible causes of distress. Anxiety of parents about life of the child after death of parent can also affect their stress levels.

Social theories of structure and agency define structure as "*recurrent patterned arrangements which influence or limit the choices and opportunities available*". Agency is the "*capacity of individuals to act independently and to make*

*their own free choices*” (Structure and agency | World Library - eBooks | Read eBooks online,” n.d.). In the context of stress in parents of children, the inadequacies in existing policies and programmes from government are structural level problems. According to the embedded cognition theory, the agency of a parent (for example: education and gender) can alter the cognitive development of child. The child’s existing symptoms might be affected positively or negatively. Negative effects on child’s neurocognitive situation can increase parental distress. Theory of embodiment by Dr.Nancy Kregier explicitly explains the impact of stress in the physiological wellbeing of individuals (Kregier 2005).In the current context, the stress might be manifested as medical conditions and comorbidities in parents which in turn worsens stress, thus forming a vicious cycle of events that may cause stress proliferation during the course of their life.

## **CHAPTER 3**

### **METHODOLOGY**

#### **3.1 Study design**

The study design was an institution based cross sectional study. This design was selected as there was no common ASD registry for Kerala and limited time was available for data collection.

#### **3.2 Study setting**

The study was conducted among parents of children with ASD who have a child taking treatment in institutions namely: Child Development Center (CDC), National Institute of Speech and Hearing (NISH), Sree Chitra Tirunal Institute for Medical Sciences and Technology (SCTIMST), Central Institute on Mental Retardation (CIMR), Buds school Venganoor and Malayalamkeezhu. CDC, NISH and SCTIMST are the three pioneer institutions in Kerala where specialized teams diagnose and treat children with developmental disorders. Kudumbashree initiated Buds school is a disability mainstreaming program started in 2004. The first BUDS institution was started at Venganoor Panchayat with the policy focus on basic inclusive and integrated education for mentally challenged children and empowerment of mothers of such children. CIMR is a national level Non-Governmental Organisation (NGO) in Kerala, founded in 1980. It is one of the first institutions for education, training, development and rehabilitation for mentally challenged. It works closely with the families of the mentally challenged, professionals and various governmental agencies.



### **3.3 Study population**

Target population: Parents of children with ASD in Trivandrum

Study population: Parents, who have a child taking treatment or training in any of selected institutions

### **3.4 Time frame**

The data were collected by principal investigator between June 15, 2018 and August 31, 2018

### **3.5 Sample size**

No fixed sample size was considered. The previous month institutional records of five selected institutions were reviewed and approximate numbers of children from each institution was recorded. The anticipated sample size was 100. A total of 110 subjects participated in the study.

### **3.6 Sample selection**

#### 1. Selection of schools

Three institutions providing treatment for autistic children and two schools were selected for the study assuming that most of the children with ASD in Thiruvananthapuram, Kerala were taking either treatment or care in these institutions.

#### 2. Selection of study participants

##### Inclusion criteria

- Parents who have children with ASD and were taking treatment or care from any of the selected institutions

- The child should have got diagnosed with ASD from a health professional at some point of time

#### Exclusion criteria

- Parents who are not willing to participate in study
- Parents who are having a child of age above 18 years attending the concerned institution

### **3.7 Data collection techniques**

- Interview schedule which captures different domains of stress and coping strategies was administered to the participants. Perceived Stress Scale-10 item was used for assessing stress.
- For face validity 10 experts in the field of pediatrics, pediatric neurology, public health, social work and psychology was administered Perceived stress scale (PSS)-10 Malayalam version for evaluation and review. Out of ten experts, two experts were parents of children with ASD. Both of them were working for children with disabilities in the institutions which were selected for conducting the study

#### 1) Perceived stress scale-10 item

The Perceived Stress Scale (PSS) is a psychological instrument for measuring the perception of stress. It measures the degree to which situations in an individual's life are appraised as stressful in previous month. Questions in PSS probe on the

frequency of feelings or thoughts about a specific life situation. Items are designed to explore how unpredictable and uncontrollable respondents find their lives.

## 2) Questions on factors related to stress

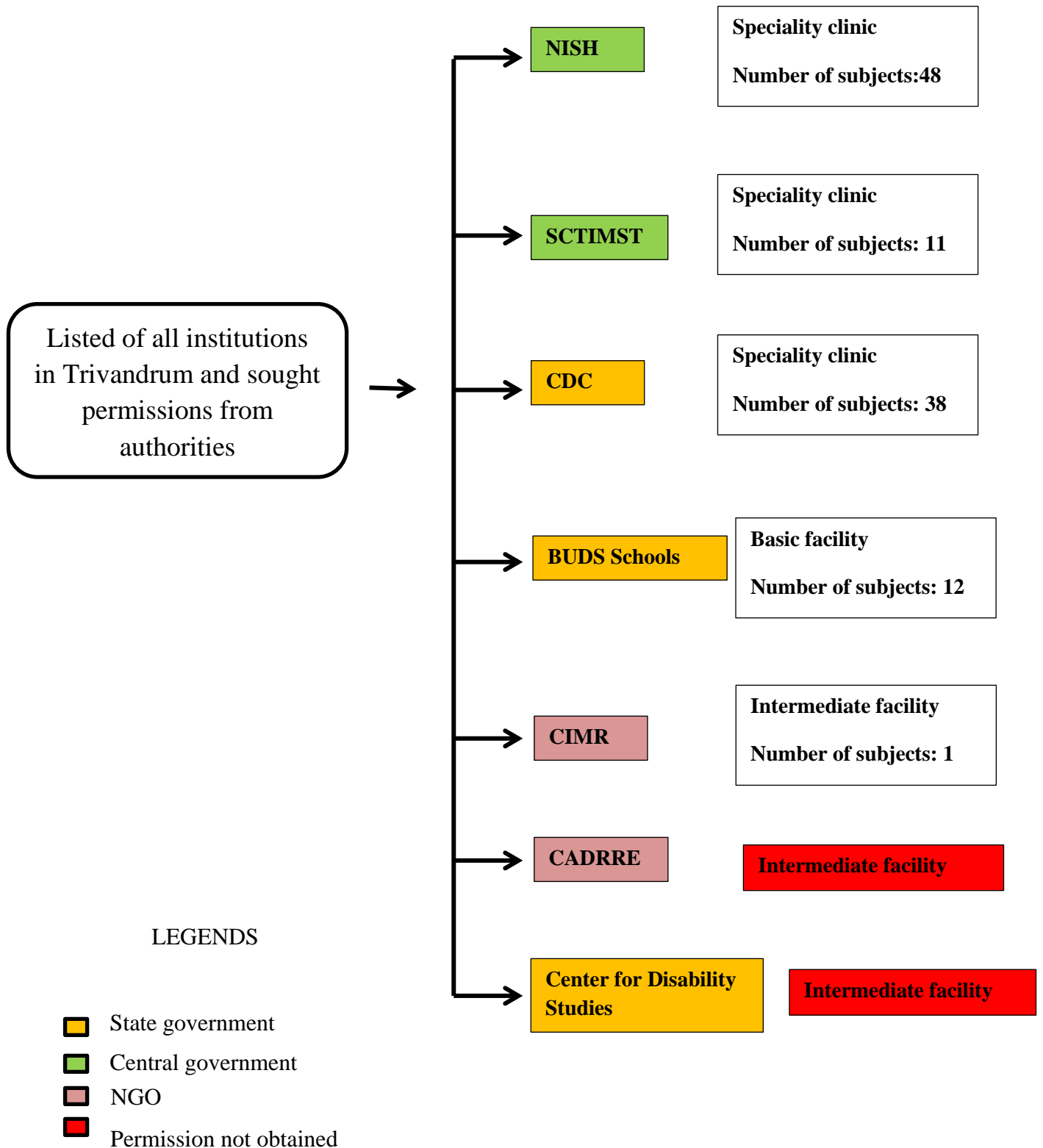
Interview schedule had questions on factors related to stress includes questions on sociodemographic information including family tree, child characteristics, and concerns about the child, social support/cohesion, family expenditure, family roles and responsibilities. One part of the interview schedule had open ended questions on parental perception about autism. These questions were included as they were expected to introduce the concept of stress to the parent and they would open up about the real factors associated with stress which will supplement the quantitative information collection in the interview schedule.

## 3) Questions on coping strategies

Coping strategies are divided into problem focused strategy and emotion focused strategy (Carver et al., 1989). Seeking support from an institution is a problem based coping strategy. Questions on coping strategies in this interview schedule focuses mainly on “emotion based coping strategies”. Emotion based coping strategy was chosen over problem based coping strategy for current study. This is because the sample was taken from different institutions catering for children with disabilities and parents were already seeking institutional support. Consideration of structural factors would expand the scope of the study and raise feasibility given the time constraints.

### 3.8 Data collection method

#### STEP 1: SELECTION OF STUDY PARTICIPANTS



## STEP 2: Contacting parents

Parents were contacted with the help of head of institutions. In treatment facilities, parents who accompanied their children for treatment were approached to participate in the study. Subject information sheet and consent form was given to the parent. If any parent was not willing to participate in the study, the next eligible child's parent was selected.

## STEP 3: Data collection

On receiving the consent, each question from the interview schedule were asked to the participant in the same order.

### **3.9 Data analysis**

Data cleaning and analysis was done by the principal investigator. In the current study, outcome variable was high perceived stress. Data entry was done in Microsoft Excel and analysed using IBMSPSS Version 21. For univariate analysis, sociodemographic variables and familial responsibilities were categorized across sex. Descriptive statistics was also done for sample characteristics. Family tree was analysed by deductive coding. The codes being: sex of the child, birth order of child, number of children presence of siblings, consanguinity and reported abortion/stillbirth. Crosstabulation was done for bivariate analysis. Potential associations were examined using Fisher exact test for stress level as dichotomous outcome, and Mann- Whitney U test when ranks of the actual stress scores were compared. For independent variables with more than two categories, Kruskal Wallis test was done. Correlations were examined using Spearman's rho. To analyse open

ended questions, coding was deductively done . Narratives on stress, factors associated with stress and coping strategies were analysed. Psychometric properties of PSS-10 were analysed using content validity index (item level and scale level) and cronbach's alpha.

### **3.10 Ethical considerations**

The study was carried out only after review and approval by the Ethics Committee of Sree Chitra Tirunal Institute for Medical Sciences and Technology (Ref number: SCT/IEC/1209/MAY-2018). Study was approved by ethics committee of CDC and research review board of NISH. Participation in the study was made purely voluntary. Parents were assured that services that the child has been receiving from the institution will not be affected in anyway. There were no direct benefits for the study participants from the study. This was mentioned in the information sheet provided to participants. Trained professionals were made available in selected institutions for counselling parents in case of distress. In addition, a social worker who was experienced in working with families with children with developmental disorders and life limiting illness was also available for help. Personal identifiers were not used for analysis or at any stage of the study. Collected data were strictly kept confidential.

### **3.11 Study variables**

#### **Outcome variable**

High perceived stress:

The Perceived Stress Scale was utilized for assessing stress in parents of children with ASD. PSS score of twenty-seven to forty was considered high stress.

## **Predictor variable**

Predictor variables are classified into five categories- Sociodemographic variables, child characteristics, expenditure on child's treatment, familial roles and responsibilities, concerns about the child, social support/cohesion and coping strategies

- a. Sociodemographic variables - Profile of study subjects
- b. Child characteristics- Age of child, age at diagnosis, level of care needed for child and medical morbidities for the child
- c. Expenditure on child's treatment- This includes average monthly expenditure and monthly expenditure for child's treatment in the last month, availability of financial assistance from government.
- d. Familial roles and responsibilities- Effect of ASD diagnosis in child on employment status, role of subject/family members in household responsibilities and accessed services like counselling or medical aid
- e. Concerns about the child- Parental anxiety about child's future
- f. Social support/cohesion- This includes presence of significant others in different life situations, difficulties parents face while interacting and frequency of avoiding a social gathering.

### **3.12 Data storage**

The investigator bears responsibility for interview schedules, consent forms and transcribed data. This contains data on effects of autism on parents. The data will be preserved for a minimum of three years as per ICMR guidelines.

### **3.13 Dissemination of the study to participating institutions**

A summary of the study results will be submitted to Kudumbashree State Mission office, Child Development Center and CIMR. This is to inform possible interventions for handling issues of parents of children with ASD.



## CHAPTER FOUR

### RESULTS

This chapter briefly describes the outcome of data analysis in concordance with objectives of the study. There were 110 participants in the study. The first part of this chapter describes sociodemographic characteristics of study subjects. This part also includes characteristics of child with ASD, expenditure for child's treatment, family roles and responsibilities of parents, concerns about the child and social support or cohesion for parents. Statistical testing was undertaken to compare different variables in the study with the outcome. This part includes sections on bivariate analysis with high perceived stress as dependent variable. The actual stress scores were also used for non-parametric comparisons of ranked stress scores to explore any potential associations not evident when stress is handled as a categorical variable. The second part includes description of open ended questions, which explores narratives on parental stress, factors related to stress and coping strategies. The chapter concludes with assessment of psychometric properties of Perceived Stress Scale-10 (PSS-10) Malayalam version.

#### **4.1 General characteristics of study subjects**

Out of 110 participants 99 (90 percent) were mothers of children with ASD. Majority of the participants were married and among them 12.7 percent were in consanguineous marriages. Eighty seven per cent of parents belonged to 25-44 years age group. Mean Age of the participants was  $33.91 \pm 6.93$  years with median age of 33 years. The mean age of the spouse was  $37.89 \pm 6.23$  years. Half of the total

participants had education up to diploma/graduation or above. Among the participants 69 (62.7 percent) were homemakers and 40 (36.3 percent) were employed. While considering educational and occupation of spouses, almost half had diploma/graduation and were private employed. Only 5.5 percent of the spouses were homemakers. Subjects were divided into four categories according to their ration cards: Above Poverty Line (APL), Below Poverty Line (BPL), antyodaya and no ration card. Seventy one (64.5 percent) of participants was from APL category, 27.3 percent and 2.7 percent from BPL and antyodaya respectively.

Table 4.1 Distribution of sociodemographic characteristics across sex of parents

<b>Variable</b>	<b>Fathers N = 11 n (%)</b>	<b>Mothers N=99 n (%)</b>	<b>Total N=110 n(%)</b>
<b>Age group</b>			
19-24 years	0(0%)	4(4%)	4(3.6%)
25-44 years	8(72.73%)	88(88.9%)	96(87.3%)
45-64 years	3(27.27%)	7(7.1%)	10(9.1%)
<b>Marital status</b>			
Married	11(100.0%)	97(98.0%)	108(98.2%)
Divorced	0(0.0%)	1(1.0%)	1(0.9%)
Separated	0(0.0%)	1(1.0%)	1(0.9%)

Table 4.2 Distribution of socioeconomic characteristics across sex of parents

<b>Variable</b>	<b>Fathers N = 11 n (%)</b>	<b>Mothers N=99 n (%)</b>	<b>Total N=110 n(%)</b>
<b>Education status</b>			
Primary	2(18.2%)	10(10.1%)	12(10.9%)
Secondary	1(9.0%)	10(10.1%)	11(10%)
Diploma/Graduation	4(36.4%)	52(52.5%)	56(50.9%)
Post-graduation or higher	4(36.4%)	27(27.3%)	31(28.2%)

*Table continued..*

<b>Variable</b>	<b>Fathers N = 11 n (%)</b>	<b>Mothers N=99 n (%)</b>	<b>Total N=110 n(%)</b>
<b>Educational status of spouse</b>			
Primary	1(9.1%)	19(19.2%)	20(18.2%)
Secondary	1(9.1%)	14(14.1%)	15(13.6%)
Diploma/Graduation	7(63.6%)	47(47.5%)	54(49.1%)
Post-graduation or higher	2(18.2%)	19(19.2%)	21(19.1%)
<b>Occupation</b>			
Govt. employed	2(18.2%)	12(12.1%)	14(12.7%)
Private employed	3(27.3%)	15(15.2%)	18(16.4%)
Self employed	4(36.4%)	2(2%)	6(5.5%)
Daily wages	0(0.0%)	2(2%)	2(1.8%)
Homemaker	1(9.05%)	68(68.7%)	69(62.7%)
Unemployed	1(9.05%)	0(0.0%)	1(0.9%)
<b>Occupation status of spouse</b>			
Govt. employed	0(0.0%)	17(17.2%)	17(15.5%)
Private employed	3(27.3%)	55(55.6%)	58(52.7%)
Self employed	2(18.2%)	20(20.2%)	22(20%)
Daily wages	0(0.0%)	5(5.0%)	5(4.5%)
Homemaker	6(54.5%)	0(0.0%)	6(5.5%)
Not applicable	0(0.0%)	2(2%)	2(1.8%)
<b>Social group</b>			
APL	7(63.6%)	64(64.7%)	71(64.5%)
BPL	3(27.3%)	27(27.3%)	30(27.3%)
Antyodaya	0(0.0%)	3(3.0%)	3(2.7%)
No ration card	1(9.1%)	4(4%)	5(4.6%)
Do not know	0(0.0%)	1(1%)	1(0.9%)

## 4.2 Child Characteristics

Among children with ASD, 77.3 percent were male. Majority of children in the present study were in 1-3 years age group. The mean age was  $5.77 \pm 4.55$  years and range was between 1.5 years to 18 years. The average number of children in the family was 1.59. More than three quarters of children in this study got their diagnosis in between 1-3 years of age. Among children with ASD, 1.8 percent had siblings

with neurodevelopmental or language disorders. Twenty six per cent (29) of autistic children in the study reported medical comorbidities.

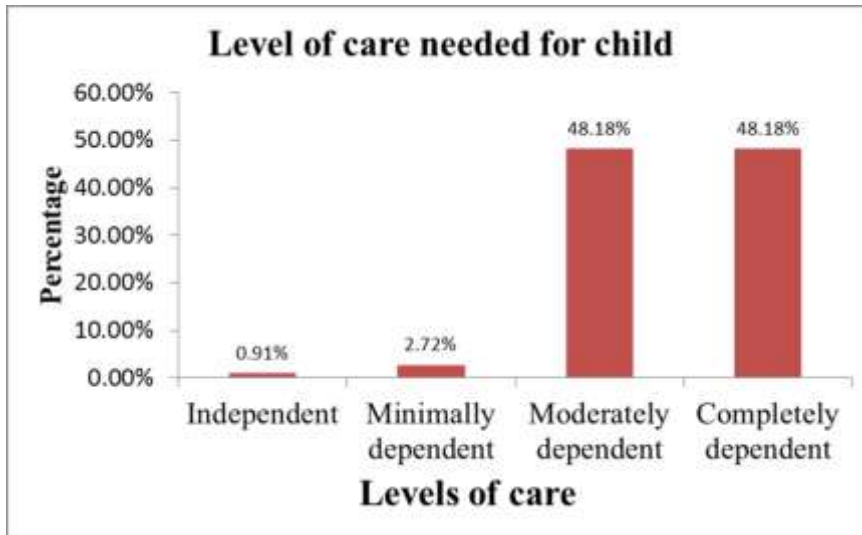
Table 4.3 Comorbidities for the child

<b>Comorbidities</b>	<b>n</b>	<b>n/29(%)</b>
Epilepsy	14	(48.2%)
Febrile seizures	5	(17.2%)
Attention Deficit Hyperactivity Syndrome(ADHD)	4	(13%)
Sleep disorders	2	(6.8%)
Skin problems	2	(6.8%)
Wheezing	2	(6.8%)
Bipolar Affective Disorder(BPAD), Sleep disorder	1	(3.44%)
Cyclomegalovirus(CMV) infection	1	(3.44%)
Clubfoot	1	(3.44%)
Hernia, cardiac issues	1	(3.44%)
Cataract	1	(3.44%)

### **4.3 Expenditure on child's treatment**

The median of monthly family expenditure for the child's treatment was reported as Rs.5000 with minimum expenditure of Rs.200 and a maximum of Rs.50, 000. Eighty per cent of families of children with ASD did not receive any financial assistance from the government. The financial assistance received, if any, were educational scholarship from panchayat, disability pension, corporation pension, Aaswasakiranam, Janmytri scholarship, or the Sarva Shiksha Abhiyan (SSA) scholarship.

Figure 4.1 Level of care needed for the child with ASD



#### 4.4 Concerns about child's future

Among fathers, anxiety about child's future was rated as higher in 36.4 percent and much higher in 36.4 percent, while in mothers, 41.4 percent rated their anxiety level as much higher level.

Table 4.4 level of anxiety about child's future

Anxiety level	N=110 n (%)
Much higher	45 (40.9%)
Higher	35 (31.8%)
Slightly lower	19 (17.3%)
Much lower	8 (7.3%)
Not at all	3 (2.7%)

Ten per cent of parents have accessed individual therapy or counselling sessions from professionals. Also, 6.4 percent of parents have attended group counselling

sessions. Two parents reported that they were on treatment for anxiety and one parent for insomnia.

#### 4.5 Family roles and responsibilities

Forty two per cent of the participants reported that they could not go for a job due to their child's condition. Among them, most of them were mothers of children with ASD (p value = 0.01).

Table 4.5: Family Responsibilities in domestic sphere across sex categories

<b>Variable</b>	<b>Fathers</b>	<b>Mothers</b>	<b>Total</b>
	N = 11 n (%)	N=99 n (%)	N=110 n(%)
<b>Care of the autistic child</b>			
Almost always myself	6(54.5%)	79(79.8%)	85(77.2%)
Myself and my spouse equally	2(18.2%)	4(4.0%)	6(5.5%)
Mainly my spouse	2(18.2%)	0(0.0%)	2(1.8%)
Me/my spouse and others	0(0.0%)	8(8.1%)	8(7.3%)
Others	1(9.1%)	8(8.1%)	9(8.2%)
<b>Care of other children</b>			
Almost always myself	1(9.1%)	42(42.4%)	43(39.1%)
Myself and my spouse equally	0(0.0%)	1(1.0%)	1(0.9%)
Mainly my spouse	1(9.1%)	0(0.0%)	1(0.9%)
Me/my spouse and others	0(0.0%)	5(5.1%)	5(4.5%)
Others	0(0.0%)	7(7.1%)	7(6.4%)
Not applicable	9(81.8%)	44(44.4%)	53(48.2%)
<b>Care of other family members or elderly</b>			
Almost always myself	0(0.0%)	13(13.1%)	13(11.8%)
Mainly my spouse	2(18.2%)	0(0.0%)	2(1.8%)
Me/my spouse and others	0(0.0%)	2(2.0%)	2(1.8%)
Others	7(63.6%)	59(59.6%)	66(60.0%)
Not applicable	2(18.2%)	25(25.3%)	27(24.6%)

Table 4.6: Family Responsibilities in public sphere across sex

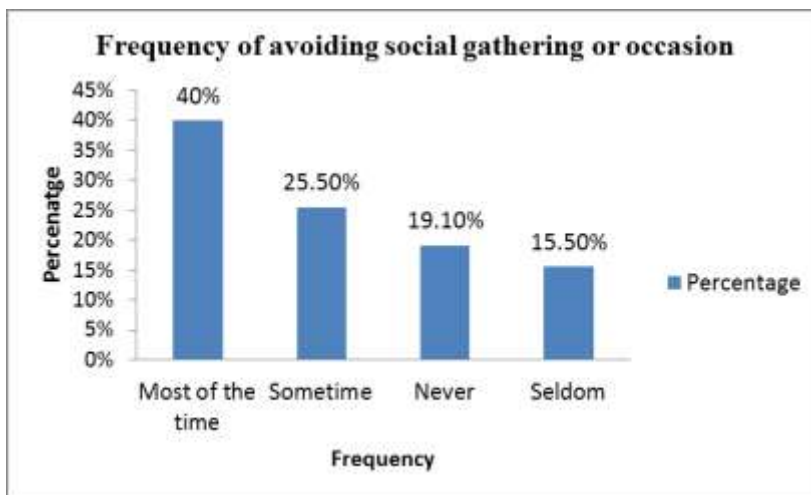
<b>Variable</b>	<b>Fathers</b>	<b>Mothers</b>	<b>Total</b>
	N = 11 n (%)	N=99 n (%)	N=110 n(%)
<b>Accompanying the child for treatment and training</b>			
Almost always myself	5(45.5%)	51(51.5%)	56(51%)
Myself and my spouse equally	5(45.5%)	27(27.3%)	32(29.1%)
Mainly my spouse	1(9%)	2(2.0%)	3(2.7%)
Me/spouse and others	0(0.0%)	15(15.2%)	15(13.6%)
Others	0(0.0%)	4(4.0%)	4(3.6%)
<b>Decision making on health care/Training</b>			
Almost always myself	3(27.3%)	29(29.2%)	32(29.1%)
Mainly myself	1(9.1%)	0(0.0%)	1(0.9%)
Myself and my spouse equally	6(54.5%)	45(45.4%)	51(46.4%)
Mainly my spouse	1(9.1%)	15(15.2%)	16(14.6%)
Me/spouse and others	0(0.0%)	5(5.1%)	5(4.5%)
Others	0(0.0%)	5(5.1%)	5(4.5%)
<b>Arranging travel or money for care seeking</b>			
Almost always myself	2(18.2%)	4(4.1%)	6(5.5%)
Mainly myself	1(9%)	0(0.0%)	1(0.9%)
Myself and my spouse equally	3(27.3%)	12(12.1%)	15(13.7%)
Mainly my spouse	5(45.5%)	76(76.8%)	81(73.6%)
Me/spouse and others	0(0.0%)	3(3.0%)	3(2.7%)
Others	0(0.0%)	4(4.0%)	4(3.6%)

#### **4.6 Social support and cohesion**

Family was reported as the major source of support for parents of children with ASD. It was reported as highest in providing emotional support (53.6 percent), and sharing happiness (70.9 percent). Parents spoke about family problems (59.1 percent), and took help making decisions (72.7 percent) mostly from family members. Among parents, 7.3 percent had no one to provide emotional support and 2.7 percent

reported that there is no one to share their concerns about their family problems. Even though fathers reported that family was an important part of their support, they verbalised their problems (36.4percent) and took help for decision making (18.2 percent) from friends. Parents and family were the main source of support for mothers. Regarding socialising by parents, forty five per cent of the participants reported that they had difficulty in interacting with people.

Figure 4.2 shows how frequent parents of children with ASD purposively avoided any social gathering or occasions



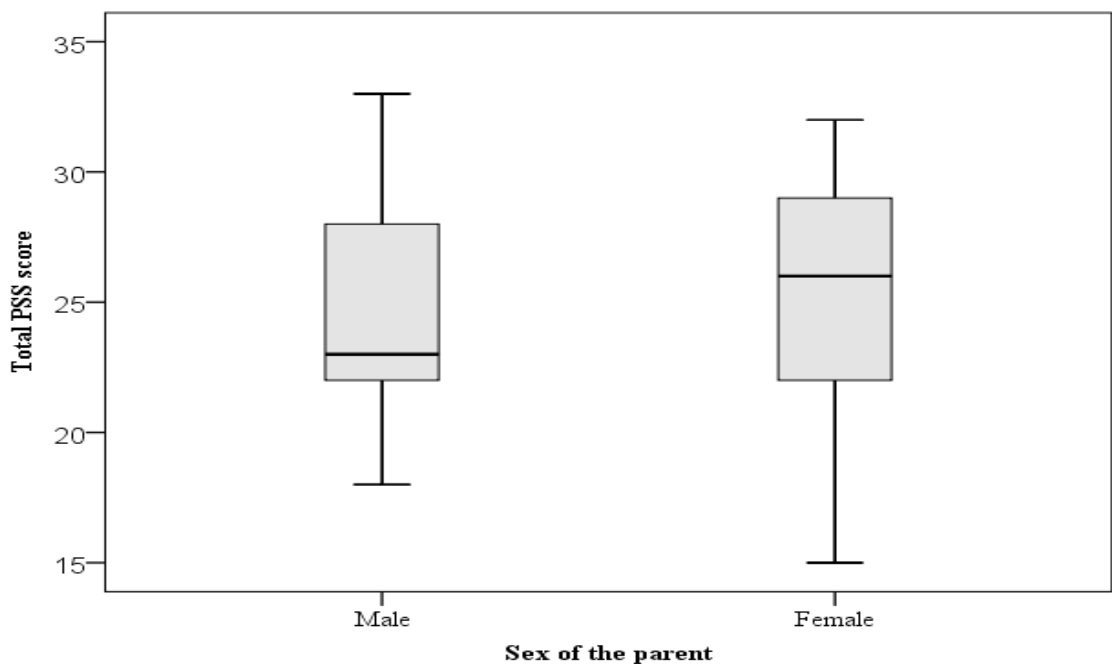
#### 4.7 Perceived stress in parents of children with ASD

Out of 110 participants, perceived stress was assessed by computing perceived stress scores. Questions in Perceived Stress Scale (PSS)-10 have score ranging from 0-4. The tool was not validated in Malayalam as such and positive and negative scoring was based on the original tool. Out of 10 questions, four questions had positive scoring. Participants who obtained a score of 0-13 was identified as low perceived stress, 14-26 as moderate perceived stress and 27-40 high perceived stress respectively. In the present study, mean stress was reported as  $25.31 \pm 4.19$  and



median stress was 26. The minimum score obtained was 15 and maximum was 33. More than half of the participants reported moderate stress and the rest (39 percent) reported high perceived stress. Thirty six percent of fathers and thirty nine percent of mothers reported high stress.

Figure 4.3: Distribution of perceived stress scores across sex of parents



#### 4.8 Coping strategies in parents of children with ASD

The coping strategies utilized by parents were assessed using a 16 item scale covering four domains. The four domains were positive reinterpretation, acceptance to child's condition, religiosity as a coping strategy and emotional support. Four questions were asked under each domain. Questions intended to assess the extent to which each parent performs each coping strategy or how frequently it was done. Each domain was given a score ranging from 1 to 4.

Table 4.7 Distribution of coping strategies in parents of children with ASD

<b>Coping strategy</b>	<b>N(%)</b>
Positive reinterpretation	
Low Positive reinterpretation	5(4.5%)
High Positive reinterpretation	105(95.5%)
Acceptance	
Low Acceptance	13(11.8%)
High Acceptance	97(88.2%)
Religiosity as a coping strategy	
Low Religiosity	40(36.4%)
High Religiosity	70(63.6%)
Emotional support	
Low emotional support	15(13.6%)
High emotional support	95(86.4%)

#### **4.9 Factors related to high perceived stress**

High perceived stress was considered as the outcome variable. Bivariate analysis was done to find out the factors associated with high perceived stress. P value less than 0.05 was considered significant

##### **4.9.1 High perceived stress and socio demographic factors**

The table 4.8 shows distribution of participants by high perceived stress by socio demographic and socioeconomic factors.

Table 4.8 : Distribution of participants by high perceived stress by socio demographic factors

Variable	Categories(N)	High Stress n(%)	P value	Crude OR	95% CI
Sex	Fathers (11)	4(36.4%)	1.00	Ref	0.312-0.414
	Mothers(99)	39(39.4%)		1.13	
Age category	19-24 years(4)	2(50%)	0.582	Ref	0.098-10.166
	25-44 years(96)	36(37.5%)		0.6	
	45-64 years(10)	5(50%)		1.0	
Marital status	Married(108)	42(38.9%)	0.753	Ref	0.096-25.807
	Others(2)	1(50%)		1.57	
Education status	Below secondary level(23)	9(39.1%)	1.00	Ref	0.389-2.559
	Diploma /degree and higher(87)	34(39.1%)		0.998	
Education status of spouse	Below secondary level(35)	15(42.9%)	0.676	Ref	0.351-1.798
	Diploma /degree and higher(75)	28(37.3%)		0.794	
Occupation	Employed(40)	16(40%)	1.00	Ref	0.425 - 2.085
	Unemployed(70)	27(38.6%)		0.942	
Occupation of spouse	Employed(102)	40(39.2%)	1.00	Ref	0.211 - 4.108
	Unemployed(8)	3(37.5%)		0.930	
Social group	APL and others(77)	27(35.1%)	0.206	Ref	0.762 - 3.988
	BPL and Antyodaya(33)	16(48.5%)		1.74	

#### 4.9.2 High perceived stress and parental morbidities

Four percent of mothers who participated in the study had a history of an abortion or still birth. Among them, high perceived stress was reported for a mother who had four miscarriages prior to the birth of her only child with ASD. Eleven per cent of parents in the study reported that they are suffering from a medical condition. The comorbidities reported by fathers were behavioural issues and hernia. Comorbidities reported by mothers were anxiety, depression, backache, hypertension, uterine fibroids, hypothyroidism, mental issues, migraine and sleep disorders.

#### 4.9.3 Child characteristics and high perceived stress

Table 4.9: Distribution of participants by high perceived stress by child characteristics

Variable	Categories (N)	High Stress n(%)	P value	Crude OR	95% CI
Age of the child	1-3 years(46)	20(43.5%)	0.810	1.026	0.306-3.434
	4-6 years(38)	13(34.2%)		0.693	0.198-2.427
	7-11 years(12)	4(33.3%)		0.667	0.135-3.303
	12-18 years(14)	6(42.9%)		Ref	
Age at diagnosis	1-3 years(93)	37(39.8%)	0.191	Ref	
	4-6 years(13)	3(23.1%)		0.454	0.117-1.761
	7-11 years(4)	3(75%)		4.54	0.455-45.331
Sex of child	Male(85)	32(37.6%)	0.643	Ref	
	Female(25)	11(44%)		1.301	0.527-3.212
Number of children	One child(52)	21(40.4%)	0.846	Ref	
	Two or more than two children(58)	22(37.9%)		0.902	0.419-1.942
Birth order of child	First born(75)	31(41.3%)	0.534	1.35	0.321-1.708
	Second or more(35)	12(34.3%)		Ref	

High perceived stress was reported greater in parents who had a completely dependent child. The odds ratio was reported as 1.93 and difference was statistically significant (p value = 0.010).

#### **4.9.4 Expenditure on child's treatment and high perceived stress**

Due to issues related measurement of family expenditure, this variable was excluded from further analysis. There was no observed difference in high perceived stress between parents who received financial assistance from government and parents who did not.

#### **4.9.5 Familial roles and responsibilities and high perceived stress**

High perceived stress was reported greater in parents who could not go for a job due to child's ASD diagnosis (P value=0.058). Forty three percent of participants who cared for their autistic child by themselves had high stress. More than half of parents who cared for other children with the help of spouse or other family members reported high stress. Stress was reported highest in participants who reported that decision making is mainly from spouse. Thirty eight percent of parents who took care of elderly or other family members by themselves experienced high stress. Stress was reported highest in parents who had to arrange travel or money for child's care seeking. Forty one percent of parents who had to do household activities and 44 percent of parents who accompanied their child for treatment had high stress.

Kruskal Wallis test was performed for examining relationship between total PSS score and parental anxiety about child's future. There was an observed difference and the association was statistically significant (p value=0.034). High perceived stress

was greater when parents avoided social gatherings most of the time. The association was found to be statistically significant (p value=0.002). Parents who had difficulty in interacting with people had greater levels of high perceived stress and this difference was statistically significant (p value=0.037).

#### **4.9.5.1 Changed gender role for parents of children with ASD**

The familial roles and responsibilities of parents of children with ASD are predominantly gendered, but some changes from gendered pattern were also observed. While analysing this domain, a group of parents were identified as parents in changed gender role. This implies that for managing their child with ASD, some fathers are taking up traditional care giver role and certain mothers are taking what could be considered masculine role or role in a public sphere of being the provider or decision maker in the family. The analysis is based on the premise that men are expected to be breadwinners of family and women are caregivers for other family members in a gendered society.

A comparison of parents in changed gender role with perceived stress was done. Seven variables on familial responsibilities namely: responsibility of caring autistic child, care of other children, care of other family members, doing household chores, arrangement of travel or money for care seeking, decision making for treatment of child and accompanying child for treatment were selected. In each variable, responses on role of subjects for each responsibility were examined using a gender lens. Three caring roles and responsibility for doing household chores were categorised under domestic domain. Arrangement of money, decision making and accompanying child was considered under public domain. Responsibilities in

domestic domain and public domain were added separately followed by addition of both of domains. To convert this added into standard normal distribution, Z transformation was done.

Table 4.10 comparison of responsibilities in domestic and public domain with sex of parent

Variable	Sex	
	Male	Female
<b><i>Domestic domain</i></b>		
Caring for autistic child		
Not responsible	3(27.3%)	<b>8(72.7%)</b>
Shared responsibility	2(14.3%)	12(85.7%)
Solely responsible	<b>6(7.1%)</b>	79(92.9%)
<b><i>Domestic domain</i></b>		
Care of other children		
Not responsible	10(16.4%)	<b>51(83.6%)</b>
Shared responsibility	0(0%)	6(100%)
Solely responsible	<b>1(2.3%)</b>	42(97.7%)
<b><i>Domestic domain</i></b>		
Household chores		
Not responsible	4(14.8%)	<b>23(85%)</b>
Shared responsibility	2(9.5%)	19(90.5%)
Solely responsible	<b>5(8.1%)</b>	57(91.9%)
<b><i>Domestic domain</i></b>		
Care of other family members		
Not responsible	11(11.6%)	<b>84(88.4%)</b>
Shared responsibility	0(0%)	2(100%)
Solely responsible	<b>0(0%)</b>	13(100%)
<b><i>Public domain</i></b>		
Accompanying child for care seeking		
Not responsible	<b>1(14.3%)</b>	6(85.7%)
Shared responsibility	5(10.6%)	42(89.4%)
Solely responsible	5(8.9%)	<b>51(91.1%)</b>
<b><i>Public domain</i></b>		
Arranging travel/money for child's treatment		
Not responsible	<b>5(5.9%)</b>	80(94.1%)
Shared responsibility	3(16.7%)	15(83.3%)
Solely responsible	3(42.9%)	<b>4(57.1%)</b>

<b>Public domain</b>		
Decision making for the child	<b>1(4.8%)</b>	20(95.2%)
Not responsible	6(10.7%)	50(89.3%)
Shared responsibility	4(12.1%)	<b>29(87.9%)</b>
Solely responsible		

❖ *Highlighted numbers identifies parents with gender role change*

Pearson's correlation was performed to find correlation between perceived stress score and gender role change in fulfilling parental responsibilities. Pearson's correlation coefficient was reported as 0.195 and relationship was statistically significant (p value =0.041). Due to issues related to gender role categorisation of 'accompanying child for treatment' variable, it was removed and analysed again. At this stage, the correlation was not statistically significant. Among mothers, a positive relationship between PSS score and gender role change in performing responsibilities was reported. The result was statistically significant. This implies that responsibilities secondary to a role different from prevailing gendered roles may elevate the stress levels in mothers.

#### **4.9.6 Social support/cohesion and high perceived stress**

Table 4.11: Distribution of participants by high perceived stress by social support/cohesion related factors

<b>Variable</b>	<b>Categories(N)</b>	<b>High Stress n (%)</b>
Emotional support	Present(102)	41(40.2%)
	Absent(8)	2(25%)
Share happiness	Present (108)	43(39.8%)
	Absent (2)	0(0%)
Speak on family problems	Present (107)	43(40.2%)
	Absent (3)	0(0%)



<b>Variable</b>	<b>Categories(N)</b>	<b>High Stress n (%)</b>
Help in taking decision	Present (105)	40(38.1%)
	Absent (5)	3(60%)

#### **4.10 Coping strategy and high perceived stress**

Eighty percent of parents who had low positive reinterpretation had high perceived stress (p value= 0.075). Compared to parents who had low positive reinterpretation, parents with high positive reinterpretation reported 85 percent less odds of being highly stressed. Thirty percent of parents who reported low acceptance on child's condition reported high perceived stress. High perceived stress was greater in parents who reported low religiosity. Forty eight percent of parents who had low emotional support experienced high perceived stress.

#### **4.11 Multiple Logistic Regression model**

All predictor variables which exhibited alpha value less than 0.05 on bivariate analysis was taken for building a model. Dependent variable was high perceived stress. In the final model Backward LR method was used with alpha less than 0.05.

On bivariate analysis, level of care needed for child, anxiety about child's future, avoiding social gatherings, and difficulty in interacting with people came out to be statistically significant. Effect of ASD diagnosis in employment status (p value= 0.058) was retained in the model because it could be a relevant predictor variable for stress. On binary logistic regression two variables were found to be significant after adjusting with other predictor variables. Purposely avoiding social gatherings was found as a significant predictor for high perceived stress in parents of children with

ASD. High anxiety about child’s future was found to be significantly associated with high perceived stress. Parents with high anxiety were 4.3 times more likely to have high perceived stress.

Table 4.12 Factors associated with High perceived stress: Results of multiple logistic regression analysis

<b>Variable</b>	<b>Adjusted OR</b>	<b>P value</b>	<b>95% CI</b>
<b>Anxiety</b>			
Low anxiety	Ref		
High anxiety	4.38	0.012	1.38-13.93
<b>Purposively avoid social gathering</b>			
Most of the time	Ref		
Sometime	0.87	0.790	0.32-2.34
Seldom	1.88	0.344	0.50-6.95
Never	0.12	0.012	0.026-0.63

#### **4.12 RESULTS OF OPEN ENDED QUESTIONS**

Questions on different aspects were included in present study for exploring opinions about child’s condition. Questions were on understanding about child’s condition, cause of ASD in their child, symptom which worries them as a parent and effects of child’s condition in parent. Responses reflecting parental stress and related factors were extracted from the narratives. Certain modifications on grammar and punctuation were made for ease of reporting.

Parents of children with ASD reported considerable amount of stress in their day to day lives. They were living amidst of constellation of difficulties and stressors. On

the other hand, certain factors in the individual, family and society levels are succouring them to handle stressors and cope with it.

#### ***4.12.1 Accepting child condition***

The normal parental expectations from a child get conflicted when parents identify that their child has a disorder. In the initial phase, they might deny their child's issue. Some parents blame themselves for their child's condition. They try to find reasons for the cause of ASD in their child and criticize themselves for not caring for the child appropriately. Mothers are stressed than fathers of children with ASD. Even fathers who participated in the study reported that their spouse is more distressed about their child's condition than him. Quantitative part has thrown light on this.

*“..I am mentally distressed. But I think my wife is more tensed than me.His (child's) problem is affecting her very much..”*

*- A 40 year old man's response when asked on effect of child's condition in their life*

#### **4.12.2 Self-blame in parents**

Some mothers of children with ASD perceived that they are the ultimate cause of child's condition. They believed that child's diagnosis is due to their carelessness and inattention. Mother's criticized themselves for working or studying during child's early years of life. They felt that child's condition is the result of understimulation from their side. But this was not the scenario for fathers of children with ASD. None of the fathers participated in the study reported that it was due to his inattention.

Fathers verbalised that as parents both of them were responsible for child's diagnosis. Father's generally used "we" while mothers used "I" for blaming.

*"We were in Saudi Arabia. My wife was also working..We didn't have time to interact with him..."*

*- Reply by a father when asked about cause of autism in their child. He was the sole caregiver for the child. The couple was settled abroad but currently for child's treatment, father resigned his job and relocated to Thiruvananthapuram.*

#### **4.12.3 Child characteristics and stress**

Parents verbalized that as child's age progresses; they understood strategies to manage their child during different life situations. This reduced stress and aided them for better coping. On the other hand, some parents had the opinion that increasing parental age was stressful for them, as they were not able to control their child due to their own medical morbidities. Parents were more stressed if child was completely dependent for an activity of daily living. This was also reflected in quantitative part. They were concerned about the future of the child after their death. Parents never wanted their child to be burden to anyone after their life.

#### **4.12.4 Effect of sociodemographic factors**

Mothers who were divorced and separated had issues related to bringing up their child alone. They were depending on either their parents or siblings for care of autistic child. Parents from lower socioeconomic status were in dearth of money for child's treatment. They couldn't even go for a daily wage work as there was no one to take care of the child.

*“I do not have money even for his treatment. I am in extreme poverty..I cannot go for job leaving him alone..All my children left us...”*

*-Reply given by a 57 year old widow. She was depending solely on government pension for daily living*

Employment status of parents of children with ASD was predominantly affected. Some parents had to resign from their existing job, take a part time job or choose not to do a job. Mostly they were mothers of children with ASD. Working parents had issues related to frequent absenteeism from workplace and inability to go back to workplace especially to an abroad country due to their child’s condition. The pre-existing gendered role for fathers and mothers were manifest in many accounts. As mothers, piling up of familial responsibilities as a mothers and homemakers had impacts on their stress levels.

#### **4.12.5 Adolescent child and parental role**

Parents of girl children verbalized different perspectives on their concerns about the child. A few parents mentioned about their issues during their child’s menstruation. During menstruation, child will be disturbed in addition to the hygiene related issues. There will be an exaggeration of existing stress for parents. Societal perspective on roles and responsibilities about a female child is not fulfilled when a child with disability is born in the family. Disappointments on disruption of prospects about future life and marriage of their girl child create considerable distress in them. A father as the sole caregiver of an adolescent girl with ASD had to take up a role that

is conventionally in the feminine domain. As a father, he has limitations to involve in the self-care activities of his child. This role conflict results in stress for these parents.

*“I do not have any support from her mother. I tried to teach her certain self-care activities. But I do not have any support from her mother. I cannot involve in all her activities...She is a girl,you know..”*

- *Reply by a 60 year old father on his helplessness to involve in daughter’s day to day activities. His wife had mental health issues and she did not help him for the care of their child*

Parents of adolescent boys with ASD verbalised that they were in considerable psychological distress due to sexuality related needs of their child. If mother is the sole caregiver, she has to face a lot of unpleasant situations which will have huge impact on parental stress.

*“As he is getting old, it is very difficult to control his feelings (sexual)..Do you have any medicine to reduce his feelings? I can't sleep near him..”*

- *A mother shared her difficulty to take care of 18 year old son. She approached many doctors to control sexual feelings of her son as at times he tries to be physically violent*

#### **4.12.6 Attracting public attention and stress**

Parents shared their experiences of taking their child to a public domain. Due to disease condition, the child might act inappropriately which in turn attract unsolicited

attention from public. Parents were fearful anticipating criticism from other people that they were not able to control their child. They had the feeling that people around them might think that as parents they are not bringing up their child appropriately. Many parents did not tell others about their child's diagnosis to others as they were apprehensive that people might mock or criticize them.

*“Whenever I take her outside, people will stare at her.. As she is very active, they might think that we did not raise her properly.. I am anxious thinking whether they will criticize us.”*

*- Reply of a mother who avoids social gatherings most of the time due to child's hyperactivity*

#### **4.12.7 Coping strategies and stress**

Parents verbalised on different strategies they utilized for coping with stress. In case of religiosity, one parent reported that she was distressed with the concept of religion. She stopped praying as she thought that God was unfair to her. This was reflected in the quantitative part as well. Sixty per cent of the parents who reported high stress had high religiosity.

*“No God had has given me any blessing. I used to go to temple before marriage. God didn't give me a caring husband..and son is like this. I stopped praying to God..”*

*- A 38 year old mother's response on religiosity as a coping strategy*

On the other hand, one parent had the opinion that they were surviving only because of God's help. Doing yoga was another coping strategy to manage day to day stress. Parents of older children accepted their child's condition and verbalised that were acclimated to child's routines and diagnosis. A supporting family especially spouse was an important factor which helped them in managing stress. Sharing problems with family was also one of the strategies. Mostly parents spoke about their worries to their spouse.

#### **4.13 PSYCHOMETRIC PROPERTIES OF PSS-10 MALAYALAM VERSION**

The assessment of psychometric properties of PSS-10 was performed by calculating cronbach's alpha and content validity index. Ten experts who work closely with parents and children with ASD were selected and tool for face validity was administered. Cronbach's alpha was done for internal consistency. Face validity from each expert was used for describing the content validity index of the tool. For internal consistency, alpha model was selected for analysing. The cronbach's alpha for the scale was reported as 0.334 and internal consistency is considered very low.

Content validity index was done for finding the content validity of PSS-10 Malayalam version. Item level content validity index (I-CVI) and Scale level content validity index(S-CVI) was performed. In S-CVI, there are two methods for finding content validity namely: scale level content validity index-averages method(S-CVI/Ave),scale level content validity index-universal agreement(S-CVI-UA).For content validity, there were 10 experts and 10 questions in the present study. As per



Lynn's(1986) criteria, a minimum I-CVI of 0.78 for 6 to 10 experts .The S-CVI/UA(Scale level content validity-Universal agreement) should be 0.90 or higher is judged as excellent content validity. In the present study, 8 items have excellent content validity. The S-CVI/Ave was reported as 0.83 ranging from 0.7- 1.The S-CVI/UA was 0.1 and question.9 was universally agreed by all the experts.

Question(Q) 9 : In the last month, how often have you been angered because of things that were outside of your control?

Q9: കാര്യങ്ങൾ കൈവിട്ടു പോകുമ്പോൾ പ്രകോപിതനാകാറുണ്ടോ?

Two questions which had least item level content validity index in the perceived stress scale was:

Q3.In the last month, how often have you felt nervous and “stressed”?

Q3.എപ്പോഴെങ്കിലും മാനസികസംഘർഷവും പിരിമുറുക്കവും അനുഭവപ്പെട്ടിട്ടുണ്ടോ?

Q7. In the last month, how often have you been able to control irritations in your life?

Q7. കാര്യങ്ങളെക്കുറിച്ച് വ്യക്തമായ ധാരണ/ അറിവ് നിങ്ങൾക്കുണ്ടെന്ന് എപ്പോഴെല്ലാം തോന്നിയിട്ടുണ്ട്?

Implications of these results and import for state response in parents of children with ASD are discussed in the next chapter.

## **CHAPTER 5**

### **DISCUSSION AND CONCLUSION**

#### **5.1 Brief summary**

The present study on stress and coping strategies provides insights on the level of stress, factors associated with stress and coping strategies utilized by parents of children with ASD. High perceived stress was the dependent variable for the study. In a wider perspective, this study recognizes gaps in the needs of parents of autistic children.

#### **5.2 Study design**

The study design was an institution based cross sectional study. Institutions included governmental and non-governmental organisations rendering primary, secondary and tertiary level services for children with disabilities. As it is an institutional based study, sample might not be representative of the population. Children from interior regions like tribal areas and children from high income families might be excluded from the study. But the study will be largely unaffected as expected numbers of such children are considerable low. Selecting Kudumbashree buds schools rather, expanded the scope of the study, including groups (for example: poor social groups) that may not reach tertiary level services.

#### **5.3 Measurements and methods**

Interview schedule which captured different domains of stress and coping strategies was administered to the participants. Perceived Stress Scale-10 item was used for

assessing stress. Parental perspective on child's condition was explored from open ended questions. Narratives describing stress, factors associated with stress and strategies of coping were extracted for analysis. The cronbach's alpha for Perceived Stress Scale-10 (PSS-10) was reported as 0.334 which is considered as very low. Two possible reasons for this could be the lack of heterogeneity in the outcome variable and the design of the tool itself. Parents of children with ASD cannot be identified as a typical group for assessing internal consistency. Absence of heterogeneity in stress levels can affect the internal consistency, as all parents were stressed about their child's diagnosis. Previous literatures suggest that there will be variability in internal consistency according to design of test (Bollen& Lennox 1991). Hence a measure which reflects the causes of the variable (in this context, using a life event for measuring stress), internal consistency may be low (McDowell 2006). On the other hand, reduced cronbach's alpha is possibly related to high sensitivity, as a very high alpha implies high specificity. This implies that all parents who are stressed will be captured by the tool. (MacDowell I& Newell C 1978). In this scenario, there is possibility of overestimation of stress levels for parents. But this measurement error might be comparatively harmless as the overestimation can be expected to be uniform and same direction for all parents. Due to the existing features of tool, the overestimation bias is also not of a harmful nature as parents labelled as high stress would be advised counselling services. Therefore, the study is not rejecting the validity of PSS-10. But researchers should be cautious while utilizing PSS-10 in specific contexts with limited heterogeneity.

## **5.4 Study findings**

In the current study, all subjects had moderate to high levels of stress, with more than half of the participants reporting moderate stress and thirty nine percent reporting high perceived stress. Impact on employment status, anxiety about child's future and purposively avoiding social gatherings were significant predictors of stress in parents of autistic children. High perceived stress was reported to a greater extent in parents who had a completely dependent child and parents who faced difficulty in interacting with people. The discussion is based on conceptual framework developed on the basis of literature review on stress and coping in parents of children with ASD.

## **5.5 Stress in parents of children with ASD**

Findings of this study reveal that all parents of children with ASD had considerable levels of perceived stress. This is consistent with other studies which revealed that parents of children with ASD undergo high levels of stress due to frustrations they face in day to day life (Blacher 2001). A meta-analysis on parenting stress compares stress levels in parents of autistic children and non-autistic children reports that parents of autistic children underwent more stress than parents of typically developing children and children with other disabilities (Hayes & Watson 2013).

### **5.5.1 Socioeconomic status**

In the current study, parents in BPL (Below Poverty Line) and antyodaya category reported greater percent of high stress than parents in APL (Above Poverty Line) category. This is in concordance with the study done to investigate relationship between the level of depression and stress among mothers. The study reported that

family income is negatively correlated with stress and depression in mothers of children with autism (Athari et al. 2013). This implies that at lower levels of family income, stress levels of parents especially mothers tend to be higher.

### **5.5.2 Familial Characteristics**

Parents who had only one child reported more stress than parents with two or more children. Also, thirty one out of seventy five subjects who reported high stress had a first born child with ASD. Expectations about a couple's first born might be a possible reason for this. A couple with one child is experiencing parenthood for first time. Each milestone of the child might be a new experience for them. In this context, child inability to accomplish milestones might be a cause of distress for them. One of the parents in this study verbalised her frustration on inability to appreciate her first born's milestones which were expected in his current age.

### **5.5.3 Familial Responsibilities and its gendered component**

Most of the mothers who participated in the study cared for their autistic child by themselves and were not part of formal employment. When social practices mould gender norms and expectations, it is likely that these expectations might further create gender inequalities. In case of mothers of children with ASD, the gender norm of being the principal caregiver for the child and family might affect her employment status and prospects (Rosenfield & Mouzon 2013). In this study, mothers of children with ASD reported higher levels of stress than fathers. This is similar to studies which reports that mothers are more stressed than fathers (Davis & Carter 2008); (Dabrowska & Pisula 2010). Due to gendered upbringing, women may appraise

stressors differently than men, and may cope in different ways. Therefore, in an overall view we can claim that the gender norms and expectations can have an impact on the way an individual experience, appraise and express stress (Thoits 2009).

As such having more responsibilities in parents of children with ASD did not influence stress levels, but roles reflected a gendered pattern, with several exceptions. On examining role change from expected gendered pattern, a positive correlation between perceived stress score and changed role was reported. Among mothers with role change, the relationship between responsibilities and PSS scores were statistically significant. For mothers, increase in responsibilities with role change can result in high stress. A possible cause of stress can be inability to adequately care for other children and family members. This was also reflected in the qualitatively component. Mothers were anxious about their inability to care for other children. Also, sole responsibility for arranging money and other logistics for child can be factor causing distress in mothers

#### **5.5.4 Child characteristics**

Parents of children in the age group of 1-3 years reported higher stress. This is consistent with a study performed among 54 families of toddlers with ASD reported higher prevalence of stress in parents of younger children with ASD. Increase in stress levels can be due to frustration associated with child's diagnosis and initiation of treatment (Davis & Carter 2008). On the other hand, a study done on children and adolescents with autism found that there was no association between general stress in parents and child's age (McStay et al. 2014). Parents of male children were found to

have more stress. But this can also be due to higher prevalence of autism in male children. High perceived stress was reported greater in parents who had a completely dependent child. This is in contrast with studies which reports that impaired daily living skills and parenting stress is not associated (Estes et al. 2009). High perceived stress was reported greater in parents of children who got diagnosed in between seven to eleven years. Early identification of ASD and early initiation of intervention can yield better outcomes for the child (Myers & Johnson 2007). Initiation of treatment in late years might have resulted in increased severity of symptoms. This can be a possible cause of parental stress.

#### **5.5.5 Concerns about the child**

In the present study, relationship between total PSS score and parental anxiety about child's future was statistically significant. In a study which compared stress in parents of children with and without ASD utilizing physiological indicators, reported significantly higher levels of parental distress, anxiety, and depression in parents of children with ASD (Padden & James 2017).

#### **5.6 Coping strategies utilized by parents of children with ASD**

Majority of parents (eighty percent) who had low positive reinterpretation had high perceived stress. Among parents of children with ASD evidences suggesting utilization of positive reappraisal as their coping strategy already exists (Dardas 2014).Forty eight percent of parents who had low emotional support experienced high perceived stress. Previous literatures suggest that seeking social support' was one of the most used coping strategies in parents of children with Autistic Disorder.

(Gray 2006) (McCubbin& Patterson 1983).High perceived stress was greater in parents who reported low religiosity. There can be potential of distress in relating stress with religiosity. Certain literature suggests that high religiosity is related to low stress. Religiosity was considered as an important coping strategy especially for mothers and many of them found support in faith (Gray 2003).

### **5.7 Physical and medical comorbidities for parents**

Eleven per cent of parents in the study reported that they are suffering from a medical condition. Thirty three percent of parents who were suffering from medical morbidities reported high stress. A study which compared the psychological wellbeing of parents of children with ASD and typically developing children found that autistic children's parents reported more depressive symptoms than the other group (Lai et al. 2015).

### **5.8 Societal and State response**

Eighty per cent of families who participated in this study did not receive any financial assistance from government for the treatment of their child with ASD. A systematic review by Ilias et al. 2018 reports that one of the causes of stress in parents of children with ASD in Southeast Asia was financial constraints secondary to child's treatment cost. Thirty nine percent of parents who did not receive any financial assistance from government reported high stress. But this relationship was not statistically significant. In the present study, thirty eight percent of mothers who did not receive any financial assistance from government reported high perceived stress. The association was not statistically significant. Persons with better social support may leverage such resources and social support may help prevent or alleviate



stress as well. However previous literature have suggested that woman are less likely to receive pensions or health insurance (Rosenfield & Mouzon 2013). This chronic stress can reflect in the overall stress levels of mothers of children with ASD (Watkins & Whaley 2000).

### **5.8.1 Inclusiveness**

High perceived stress was greater when parents avoided social gatherings most of the time. The association was statistically significant. The externalizing behaviour of the child might be the probable cause of this. Parents' fear that a non-acquaintance who is unaware of child's condition may misinterpret their child has been reported earlier (McStay et al. 2014). Parents who face difficulty in interacting with people had greater levels of high perceived stress and this difference was statistically significant. Interacting with significant others can have an impact on stress levels of parents. Previous researches have shown that supportive family members and interacting with other parents of children with autism can decrease parenting stress (Boyd 2002). Also peer support groups can aid in alleviating physiological and emotional distress of parents to a considerable level (Bray et al. 2017).

### **5.9 Conclusion of the study**

The present study examines the stress and coping strategies of parents of children with ASD. The findings suggest that all subjects had moderate to high levels of stress, with more than half of the participants reporting moderate stress and thirty nine percent reporting high perceived stress. The main factors associated with stress were anxiety about child's future, purposely avoiding social gathering, difficulty in

interacting with others, level of dependency of child and effect on employment status. Unfavourable coping strategies like low positive reinterpretation and low emotional social support tend to be related with high stress.

Gaps in needs of parents of children with ASD have to be fulfilled by constitutional provisions and society. Society should be more open to children with disabilities. Rather than providing only relief measures, social structures should be inclusive for families of children with ASD. Building a constructive environment for autistic children in society can strengthen and encourage their families

#### **5.10 Future perspectives**

The constitutional provisions of the country assure every citizen right to lead a life with dignity and personal liberty. Rather than a human rights perspective where all individuals and families are able to maintain their dignity and contribute to society what they can, interventions for families of children with disabilities merely seem to focus ameliorating the problem. Thus the current philosophy for management of children with ASD concentrates on a disabled approach rather than an abled approach. A disabled approach might produce inferior outcomes for children with ASD or their parents, when better solutions are possible.

Each child is unique and they have innate strengths which need to be identified and developed. Treatment strategies for a child with ASD should be focused on what the child can do. For this, parents should act as ‘torchbearers’ for their children. They should assist the treatment team in identification of their child’s strengths and

treatment. This might be an additional stressor with their everyday frustrations. Still considering long term implications, parents should take up this responsibility.

### **5.11 Immediate policy implications**

- Incorporation of programs on stress management for families with existing treatment strategies for Children with ASD
- Refinement of PSS-10 Malayalam version can be considered
- Counselling services for parents at the time of diagnosis of child
- Sensitizing the community on significance of supporting families of people with disabilities

### **5.12 Strengths of the study**

- This study analyses stress and coping strategies of parents of children with ASD. Such studies among parents are rare in Kerala
- Most of the institutions catering for children with disabilities in Trivandrum were covered
- Chances of inter observer bias is minimized as data collection was done by a single investigator
- Validation of the tool used for outcome measurement (PSS-10 Malayalam version) was also done to know implications of using it for the current project as well as future research.

### **5.13 Limitations of study**

- Cross-sectional institution based study with a small time frame for data collection
- Only the accompanying parent was studied. Including the other parents would have enriched the findings of the study
- All forms of coping were not explored. Only emotion focused alone were explored

## **LIST OF ANNEXURES**

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Annexure II.....	Information sheet and consent for subjects
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