

**QUALITY OF LIFE IN PARENTS OF CHILDREN WITH AUTISM SPECTRUM
DISORDERS IN THE INDIAN CONTEXT (QOLA-K)**

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18SLP017

A Dissertation Submitted in Part Fulfillment for the Degree of
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University of Mysore, Mysuru



ALL INDIA INSTITUTE OF SPEECH AND HEARING

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JULY 2020

CERTIFICATE

This is to certify that this dissertation entitled “**Quality of Life in Parents of children with Autism Spectrum Disorders in the Indian Context (QoLA-K)**” is a bonafide work submitted in part fulfillment for the degree of Master of Science (Speech-Language Pathology) of the student (Reg. No.: 18SLP017). This has been carried under the guidance of a faculty of this institute and has not been submitted earlier to any other University for the award of any other Diploma or Degree.

Mysuru

July, 2020

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DECLARATION

This is to declare that this dissertation entitled **“Quality of Life in Parents of children with Autism Spectrum Disorders in the Indian Context (QoLA-K)”** is the result of my own study, under the guidance of Dr. Jayashree C Shanbal, Associate Professor in Language Pathology, All India Institute of Speech and Hearing, Mysuru. I further declare that this work has not been submitted earlier to any other University for the award of any other Diploma or Degree.

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LIST OF ABBREVIATIONS

ASD	Autism Spectrum Disorders
QOL	Quality of Life
QOLA	Quality of Life of parents with Autism
QOLA(K)	Quality of Life of parents with Autism (Kannada)
ISAA	Indian Scales for Assessment of Autism

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Chapter 1

INTRODUCTION

The word “autism” emerges from the Greek vocabulary where “*autos*” means “self” and “*ismos*” refers to “action”. Autism Spectrum Disorder (ASD) is defined as “lifelong neuro-developmental disorder characterized by impairments in social interaction, verbal and non-verbal communication and a restricted repertoire of activities and interests” (DSM-5, American Psychiatric Association, 2013). These impairments are primarily due to the impaired developmental cascading of individual’s response to the social stimulus. Developmental cascades are the “cumulative consequences for the development of the many interactions and transactions occurring in developing systems that result in spreading effects across levels, among domains at the same level and across different systems or generations” (Masten & Ciccichetti, 2010). There are abnormalities in the development of neural circuits responsible for socio-cognition, which later on interrupts the normal development of various behavioral and functional domains (Dawson, 2008). Early deficits in joint attention and joint reference are portrayed in poor interaction with the primary caregivers.

The first systematic paper in the area of Autism research was published by Australian-American psychiatrist Leo Kanner (1943), where he introduced the term “Infantile Autism”. Leo Kanner stated that “these children have come into the world with an innate inability to form the usual, biologically provided contact with people”. From the times of Leo Kanner to 77 years later in 2020, Autism research has witnessed remarkable developments in our understanding nature of the disorder, classification, neurobiology, genetics, symptomatology, early identification and medical and behavioral management.

In spite of breakthrough advancements in Autism research, Autism is still regarded as a “mystery”. Till date, there is no consensus on the etiology of Autism and there is no definite “cure”, which makes presence of ASD a “lifelong” disability. Individuals with ASD require continuous care and support throughout the lifespan. The ASD symptoms tend to reduce with age and individuals learn to compensate over the time, still majority of them remain underemployed or unemployed and continue to be dependent on parents and other caregivers for day to day life functioning (Howlin et al., 2004; Howlin & Moss, 2012; Heijst & Geurts, 2014). Parents are the primary caregivers. Looking after a child with ASD is a lifelong responsibility, which often turns into a physical and psychological burden.

Research in the quality of life (QoL) of parents of children with Autism is a novel concept and is currently in budding stage. Literature has majorly focused on generic measures to assess the QoL and revealed poor QoL in parents of children with Autism. There is very limited research exploring the QoL of parents of children with ASD in Indian Context.

Need for the study

In the past, researchers have utilised generic health related Quality of Life measures such as World Health Organisation’s WHOQOL-BREF, Short Form Health Survey (SF-36) to study QoL among parents of children with communication disorders. These measures have reduced utility in clinical and research areas since they fail to explore specific real life difficulties faced by children and families with ASD. For example, generic measures developed for children with speech and language difficulties fail to include questions specific to ASD such as the effect of sensory issues, stereotypical behaviors, problems with understanding of non-verbal cues, figurative language or

unspoken social rules on QoL of children with ASD. These issues often continue to exist throughout the developmental period, if not provided intervention.

Parents, being the primary caregiver, suffer with high levels of stress and anxiety. They are often reluctant to report their psychological problems and seek professional help. Many parents feel guilty and blame themselves for their child's ASD diagnosis. Across the timeline, the feelings of guilt, self-doubt and dissatisfaction tend to escalate especially when the parent is under-educated or they have lack of awareness and knowledge about the disorder and also when there is a lack of affordable quality treatment services (Eapen et al., 2014; 2018; Özgür et al. 2018; Jain et al., 2019). They portray poor QoL than neurotypical children (Benjak et al., 2009; Holroyd et al., 1975) and children with other developmental disabilities such as Cerebral Palsy, Intellectual Disability and Attention Deficit Hyperactivity Disorder (Malhotra et al., 2012; Lee et al., 2007).

In a multicultural nation like India, prevalence and popularity of misconceptions and myths about "ASD as a condition and its causes" further elevates the stress levels in parent. The societal and community barriers, lack of awareness and acceptance by the community adds on to the problem. Till date there are only a handful of studies conducted in Indian scenario.

There is a dearth of tools particularly exploring ASD specific QoL in parents of children with ASD. Hence, it is necessary to identify the key factors affecting the QoL in parents in Indian Context. Development of reliable ASD specific tools to assess the QoL among parents is an essential step in this regard. Also, there is a lack of studies exploring effect of socio-communicative deficits on QoL of parents of children with Autism Spectrum Disorder in Indian context.

Hence, the present study aims to adapt a parent report based autism-specific measure of Quality of Life to the Indian context in Kannada language. The need of the hour is to understand how much the quality of life of parents of children with ASD is affected so that as professionals in the field, we could understand the clinical utility of such measures in comparison to baseline and reduction of symptoms in ASD. The tool could also be useful in counseling, documentation of treatment efficacy and improvement of QoL, thus encouraging evidence based practice in the area of ASDs.

AIM OF THE STUDY

To adapt and develop the Quality of Life questionnaire for parents of children with Autism Spectrum Disorders in Kannada language.

Objectives of the study: The study included the following objectives:

1. To develop a Quality of Life questionnaire for parents of children with ASD in Kannada (QoLA-K).
2. To investigate the quality of life of parents of children with Autism Spectrum Disorders in relation to socio-communication skills of children with ASD.
3. To compare the Quality of Life (QoL) of parents (on Part A sub-scale of QoLA-K) and Impact of ASD symptoms (on Part B sub-scale of QoLA-K) with the severity of ASD.

Hypothesis: The following null hypotheses were tested:

H₀₁ There is no significant relationship between the Quality of Life of parents and socio-communication skills of children with ASD.

H₀₂ There is no significant difference between the scores of Part A (QoL sub-scale) and Part B (Impact of ASD symptoms sub-scale) of adapted QoLA- K scale across the severity of Autism Spectrum Disorder.

Chapter 2

REVIEW OF LITERATURE

Autism Spectrum Disorder (ASD) is a “neuro-developmental disorder characterized by significant impairment in social initiations, social interactions and existence of restricted and repetitive behaviors” (DSM-5, American Psychiatric Association, 2013). Heterogeneity in manifestation is hallmark of ASD. Systematic research is documented from early 1940s, when two researchers Leo Kanner (1943) and Hans Asperger (1943) identified Autism as a unique neurological problem which is distinct from schizophrenia or mental retardation. Hopkins University published Leo’s paper “*Autistic Disturbances of Affective Contact*”, case study of 11 children, where he introduced the term “Infantile Autism”. Kanner adapted the term “Autism” from Eugen Bleuler (1908), who used it to describe patients suffering from severe schizophrenia.

From the times of Leo Kanner to 77 years later in 2020, Autism research has witnessed remarkable developments in our understanding of the nature of the disorder, classification, neurobiology, genetics, symptomatology, early identification and medical and behavioral management. Our understanding in terms of classification and severity of Autism has been drastically transformed with its inclusion and subsequent revisions in Diagnostic and Statistical Manual of Mental Disorders (DSM). Autism classification witnessed greater transformation with DSM-5 (American Psychiatric Association, 2013); where five subcategories were merged into “Autism Spectrum Disorder”. The diagnostic criteria have narrowed down from “traids” to “dyadic” symptom profile. This dyadic profile includes restricted, repetitive behaviors, interests or activities, hypo-hyper sensitivity to sensory input and impairment in social communication marked by deficits in usage of verbal and non-verbal language for social interaction which significantly affects the activities of daily living and adaptation in day to day life.

Incidence and prevalence of ASD is reported to be increasing rapidly worldwide. According to WHO, this increment in prevalence is attributed to increase in the awareness of disorder, expansion of ASD diagnostic criteria, availability of improved diagnostic tools and efficient reporting by the stakeholders. The estimates of reported prevalence vary substantially across different studies. The prevalence is reported to be greater in males than females; Male: Female ratio- 4:1 (Werling & Geschwind, 2013).

Recently WHO stated that “Worldwide 1 in 160 children has ASD”. Elsabbagh et al. (2014) reported a prevalence of 14.6 per 1000 children aged 8 years (1 in 68 children) in United States. Brugha et al. (2012) reported a weighted prevalence of 9.8 per 1000 children in United Kingdom. In Indian scenario, a recent meta-analytic study done by Chauhan et al. (2019) reported a pooled percentage prevalence of 0.11 (1-18 years) in rural setting and a pooled percentage prevalence of 0.09 (0-15 years) in urban setting. These statistics were outcome of systematic review and meta-analysis of four recent studies conducted between 2014 to 2017. There have been many methodological differences in studies pertaining to the choice of screening and diagnostic tool utilized. Such heterogeneity in the methodology could have resulted in either underestimation or overestimation of the disorder which highlights the necessity of highly controlled population based studies in India.

2.2 Clinical Manifestation of ASD: Heterogeneity and Severity

Heterogeneity in clinical manifestation is hallmark of ASD, leading to diverse ranges and level of impairment in socio-communication and behavioral features (Amaral et al., 2008; Geschwind, 2009; Masi et al., 2017). The Diagnostic and Statistical Manual of Mental Disorders (DSM, 5th ed.; American Psychiatric Association, 2013) classifies ASDs in three levels of severity from Level 1 to Level 3 (Figure 2.1).

The severity is primarily assessed on the basis of severity of core ASD features such as deficits in verbal and non-verbal socio-communication skills, poor socio-emotional reciprocity and presence of variety of stereotypical and repetitive behavior, activities and interests. Apart from the core features, other factors affecting the topography of expression of ASD and its severity are impairment at the level of sensory integration, genetic co-morbidities, intellectual and adaptive functioning, presence of behavioural issues, poor general health, sleep (Matson & Goldin, 2014). Heterogeneity and severity of the disorder has direct applications on its assessment and management (Masi et al., 2017). With increase in severity, the amount of support required by individual with ASD and their caregivers also substantially increases.

Figure 2.1

Severity Level for Autism Spectrum Disorders

Severity Level for ASD	Social Communication	Restricted interests & repetitive behaviors
Level 3 'Requiring very substantial support'	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning; very limited initiation of social interactions and minimal response to social overtures from others.	Preoccupations, fixated rituals and/or repetitive behaviors markedly interfere with functioning in all spheres. Marked distress when rituals or routines are interrupted; very difficult to redirect from fixated interest or returns to it quickly.
Level 2 'Requiring substantial support'	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions and reduced or abnormal response to social overtures from others.	RRBs and/or preoccupations or fixated interests appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress or frustration is apparent when RRB's are interrupted; difficult to redirect from fixated interest.
Level 1 'Requiring support'	Without supports in place, deficits in social communication cause noticeable impairments. Has difficulty initiating social interactions and demonstrates clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions.	Rituals and repetitive behaviors (RRB's) cause significant interference with functioning in one or more contexts. Resists attempts by others to interrupt RRB's or to be redirected from fixated interest.

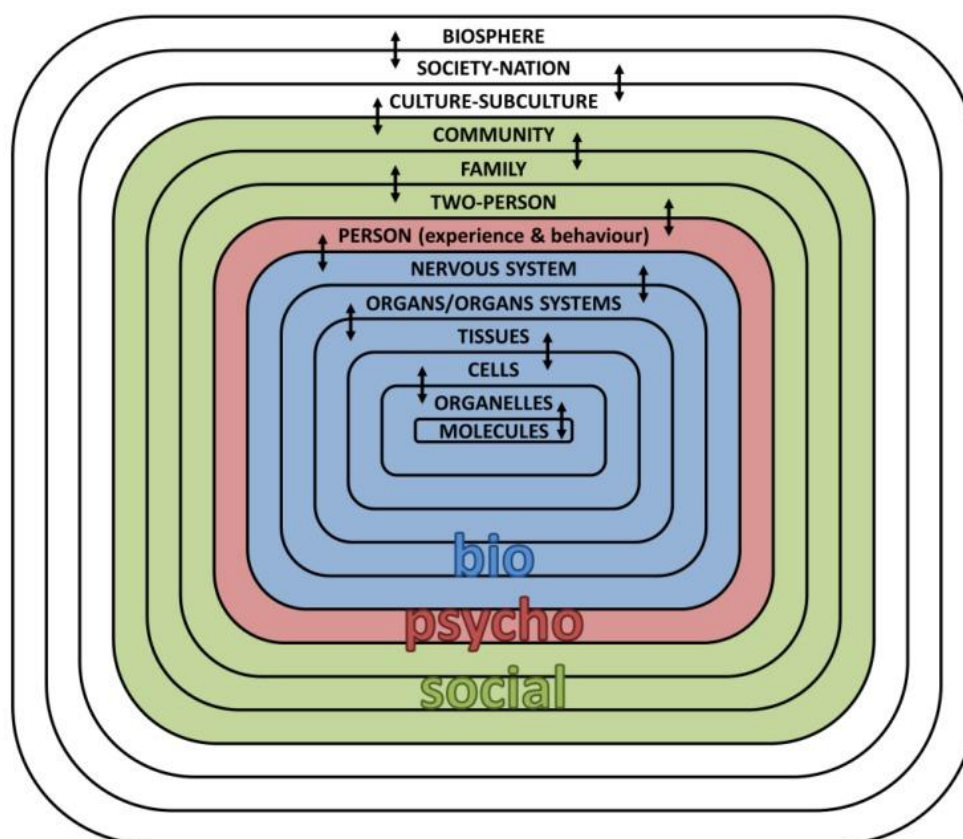
(Source Info: Diagnostic and Statistical Manual of Mental Disorders. 5thed. Washington, DC: American Psychiatric Association; 2013)

2.3 Changes in Our View of “Disability” and emphasis on Quality of life

There has been a paradigm shift in our views of disability from the “medical model of disability” to humanitarian “social model of disability”. Proponents and supporters of medical model believed that the root cause of a disability is “biomedical” in nature, which negatively affects the QoL of an individual; hence, the medical management of condition should focus on reducing or curing the medical condition (Fisher & Goodley, 2007). Considering a major emphasis on “individual limitations” and efforts to reduce or correct them, medical model fails to highlight the importance of environmental, societal and other contextual changes in improving the QoL of a person. George Engel (1960; 1977; 1978; 1980) elaborated the limitations of the medical model and proposed a “bio-psychosocial model of disability” which emphasized on efforts to enhance individual’s strengths and abilities, improving the accessibility and reduce the environmental barrier (Engel, 1980; Farre & Rapley, 2017). Figure 2.2 highlights the hierarchy and interactions of the three levels in a system namely; biological level, psychological level and social level.

Figure 2.2

Schematic Representation of Bio-psychosocial model of disability (George Engel, 1980)

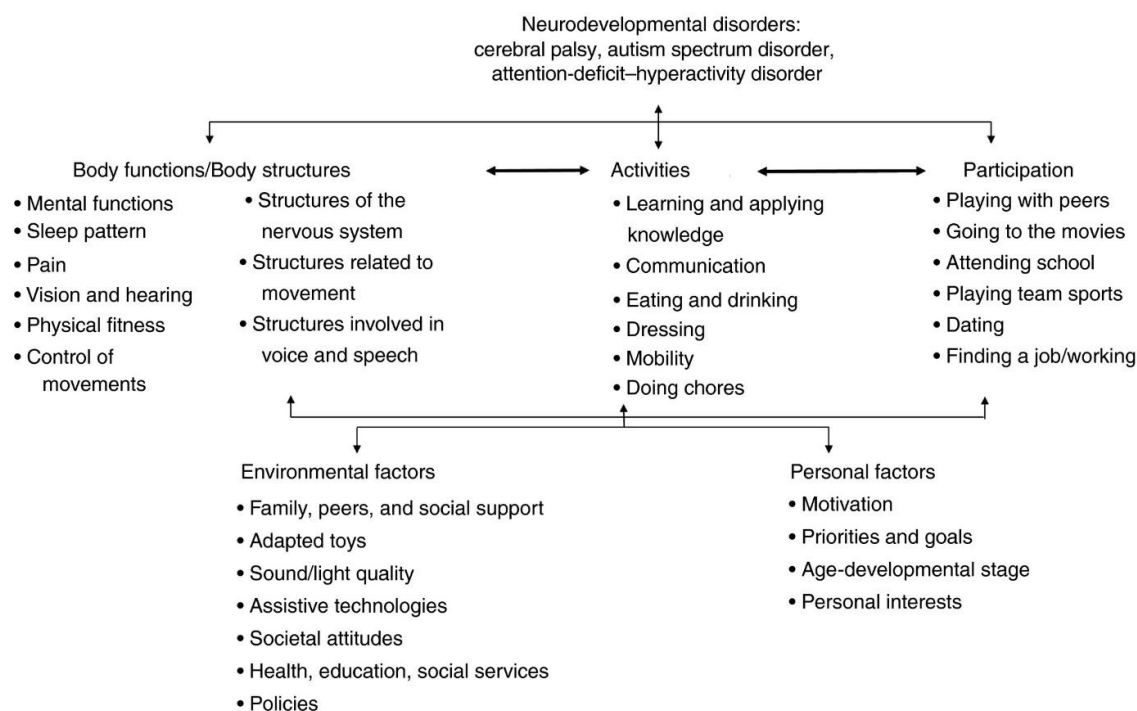


(Source Info:Farre, A., & Rapley, T. (2017). The New Old (and Old New) Medical Model: *Four Decades Navigating the Biomedical and Psychosocial Understandings of Health and Illness*. Healthcare, 5(4).<https://doi.org/10.3390/healthcare5040088>)

WHO modified the 1980's International Classification of Impairments, Disabilities and Handicaps (ICIDH) to the 2001 version- International classification of Functioning, Disability and Health (ICF). It is basically an attempt to subscribe to the notion of seeing a person "as a whole", a person is not a "disabled person" rather a "person with disability". WHO ICF classification is based on interactive Bio-Psycho-Social model of disability (WHO, 2001, 2007). Disability is not the sole "identity" of person. ICF elaborates on Environmental and Personal factors affecting the QoL along with the relationship between functioning and disability (Figure 2.3).

Figure 2.3

International Classification of Functioning, Disability and Health Core Sets for Neuro-Developmental disorders



(Source Info: Schiariti, V., Mahdi, S., & Bölte, S. (2018). International Classification of Functioning, Disability and Health Core Sets for cerebral palsy, autism spectrum disorder, and attention-deficit-hyperactivity disorder. *Developmental Medicine & Child Neurology*, 60(9), 933–941. <https://doi.org/10.1111/dmcn.13922>)

According to the WHO Quality of Life (QoL) is “An individual’s perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (Harper, 1998). The concept of QoL is multifaceted and it is both subjective and objective in nature; it is about a person perception of their well-being in several domains of functioning. WHO elaborates QoL into four domains namely- Physical, social, psychological and environmental domains.

Schalock (2000) proposed “hierarchical arrangement of the various core quality of life dimensions” of QoL describing eight domains of QoL to individuals with intellectual

disabilities; “interpersonal relations, social inclusion, personal development, physical well-being, self-determination, material well-being, emotional well-being, and human and legal rights”.

Parents are the primary caregivers. Looking after a child with ASD is a lifelong responsibility, which often turns into a physical and psychological burden. Parents of children with developmental disabilities report poor mental health (Weiss, 1991), sense of devaluation and self-blame (Holroyd et al., 1975), impaired physical functioning, tiredness or exhaustion (Emerson, 2003). Families of children with ASD are reported to have elevated stress levels than children with other disabilities such as Down Syndrome, Intellectual Disability (Holroyd & McArthur, 1976).

Parents of children with ASD are reported to have poorer QoL than parents of neuro-typical children (Benjak et al., 2009; Holroyd et al., 1975) and children with other disabilities such as Cerebral Palsy, Intellectual Disability and Attention Deficit Hyperactivity Disorder (Malhotra et al., 2012; Lee et al., 2007). Majority of these caregivers are mothers and they opted for resigning from their occupations or staying at home for caring the child.

Families belonging from lower socio-economic status and living remote areas where accessibility of services is poor, have poorer QoL. When the parent is struggling to make the two ends meet, they experience feelings of self-doubt and inefficiency when they are not able to provide enough time to their child. Major concerns include child’s behavior in social meetings or parties, child’s indulgence in group activities and in friend circle, worries about child’s academic attendance and performance. Apart from behavioural issues, managing the issues related to inability to communicate the basic needs and complaints of incontinence (day time urine incontinence and fecal incontinence) becomes a struggle for the parent (Hanney et al., 2013; Niemczyk et al., 2017).

Children with ASD due to significant deficits in social communication and socio-emotional reciprocity are less likely to participate in shared group curriculum and activities; they are often less efficient in stress coping mechanism and become victim of bullying at schools (Lee et al., 2007). Presence of tantrums, meltdowns and self-injurious behaviors make the coping even more difficult. Parents are often worried about the future of their children, especially in situations when it is impossible for the parent to be physically present to take care of the child.

Mothers spend most of their time in caring for the child and they are not able to indulge into self-care or spare time for meeting personal needs (Kuhlthau et al., 2011). The stress levels and presence of challenging behavior in child share a positive relationship (Allik et al., 2006; Escobar et al., 2005). Hastings and Johnson (2001) concluded that higher severity of ASD symptoms is related with the higher levels of parenting stress. It all starts from ignoring physical health, which on a long run often leads to emergence of psychological issues such as anxiety, depression, sleeping disorders etc.

Parent often are reluctant to report their psychological problems and seek professional help. Many parents feel guilty and blame themselves for their child's ASD diagnosis. In a multicultural nation like India, prevalence and popularity of misconceptions and myths about "ASD as a condition and its causes" elevates the stress levels in parent. The societal and community barriers, lack of awareness and acceptance by the community also leads to poorer QoL (Alenazi et al., 2020; Davis & Carter, 2008; Jain et al., 2018). Also, issues related to misdiagnosis, lack of availability of reliable information being a cause of delay in early intervention, contribute which to increased stress levels and pessimism about child's development among parents (Sulaimani & Gut, 2019).

Lee et al. (2007) conducted a cross-sectional study to compare the QoL of parents of children with ASD with parents of children with Attention Deficit Hyperactivity Disorder (ADHD) and with parents of neuro-typical children. Authors imported the parent reported data for children from wide age group (ranging from 3 to 17 years of age) from the National Survey of Children's Health (NSCH), 2003. Data was analyzed under 3 study groups; Autism (n= 483), ADHD (n=6319) and normal children (n= 58953) across the age range. Parents in ASD group reported significantly elevated stress levels than ADHD and neuro-typical group across the age range. Parents of ASD group were seven times more likely to resign from their job and attended religious gatherings less frequently than other groups. Parents reported more concern about child's attendance at school, bullying and academic achievements such as failure or repetition of grades. Limitations of the study include its cross-sectional design where the diagnosis was based on mere parental reports and lacked validation by the professionals. Influencing factors like cognition and ASD severity were not considered. Moreover, the survey did not include condition specific questions.

Mugno et al. (2007) carried out an Italian study where they compared QoL in parents of children with three developmental disabilities; Cerebral Palsy, ASD and Intellectual disability and normal developing children using WHOQOL-BREF. Authors reported lower QoL in parents of children with ASD when compared to all other groups. Domain specific analysis revealed poor self-perceived QoL in ASD group when compared to that of Cerebral Palsy and Intellectual Disability in social relationship, psychological and physical health domain.

A Croatian study done by Benjak et al. (2010) studied the subjective QoL in parents of children with ASD (n= 177) and normal children (n= 169) by administering

Personal Well Being Index (PWI). PWI includes seven domains; health, life achievements, relationships, safety, community connectedness and future security. Results revealed that parents in ASD group had significantly poor general health and subjective QoL than control group. Limitations of the study include non random sampling and lack of ASD specific tool to further explore the specific factors leading to lower QoL in ASD group.

In a United States (US) based research study, Khanna et al. (2011) explored the factors affecting QoL in parents of children with ASD. They employed Short Form Survey (SF-16, Version 2) to assess the Generic Health related quality of life (HRQoL); Caregiver burden by using Caregiver Strain Questionnaire (CGSQ); Social Support by Multi-Dimensional Scale of Social Support (MPSS); Family functioning using General Functioning Scale (GFS); Coping by Brief Coping Orientation to Problem Experiences (B-COPE) and care recipient behavioral problem using Childhood Autism Rating Scale Parent Version (CARS-P). Results revealed significantly poor mental health in mothers of children with ASD, no significant difference between physical health was reported. Reduced social support, poor coping mechanism, poor child functioning, behavioral problems and increased family burden were identified as factors negatively affecting the QoL of mothers of children with ASD.

Eapen et al. (2014) developed “Quality of Life in Autism–Parent Version (QoLA)” and compared the QoL in 23 mothers of children with ASD with 16 parents (13 mothers and 3 fathers) of neuro-typical children living in Australia. To quantify the QoL, WHOQOL-BREF questionnaire and QoLA questionnaire were administered on both the groups. In addition, Social Communication Questionnaire (SCQ) and Vineland Adaptive Behaviour Scales Second Edition (Parent Form) (VABS-II) were administered to assess the social communication, severity of Autism and adaptive functioning in daily life; to

quantify parental wellbeing, Depression Anxiety Stress Scales (DASS-21) and The Parenting Sense of Competence Scale (PSOC) were administered on ASD group. This study was first attempt to study QoL in parents of children with ASD by utilising an Autism specific tool. QoLA consists of 48 questions divided into two sub-scales: Part A (QoL sub-scale) and Part B (impact of ASD symptoms sub-scale). Part A (QoL sub-scale) has 28 questions specifically designed to measure parents' overall perception of their quality of life. Part B (impact of ASD symptoms sub-scale) comprises of 20 questions aiming to measure the extent to which child's autism-specific difficulties are problematic for parents. The scores of these tests were also compared with population norms (Rogers & Mathews, 2004). Results revealed poorer QoL, higher depression, anxiety and stress levels in parents of ASD group. Interestingly, mothers in ASD group had higher efficacy scores than control group. No significant correlations were found between scores of Part A or WHOQOL-BREF and scores Part B or SCQ, which is indicative of lack of direct relationship between child's ASD symptoms and QoL of parents. Authors concluded that other variables such as individual's perception of social support and coping mechanisms also affect the QoL. This study had few limitations which may affect its generalizability such as small sample size and lack of representation of age groups since parents of only pre-school children were included in the study.

Eapen and Guan (2016) in their systematic review of 20 studies (published from 2006 to 2015) explored QoL in parents of Children with ASD. Poor QoL in parents of ASD group was related to the presence of four types of stresses of child bearing namely; physical, psychological, social and economic stress. Core contributors to stress were child's poor speech and language communication, poor social relationships and presence of behavioral problems which lead to reduced overall social engagement of parents. Further, reduced social support leads to elevated stress and anxiety levels. Apart from the

core features, associated developmental delay, poor cognition and lack of adaptive functioning in children elevated the parental concern. Maternal QoL was found to be poorer than paternal QoL. Moreover, fathers were found to be less likely to participate in questionnaire. Possible limitations are primarily the methodological differences of the type of sampling and most importantly, heterogeneity in choice tools to quantify the QoL. Most of the studies included in the review had cross-sectional design and none of them employed use of ASD specific measure.

2.4 Quality of Life in Parents of children with ASD in Indian Context

Research study carried out by Perumal et al. (2014) explored QoL in Indian parents in Madhya Pradesh, India. Study had parents categorized under three groups; ASD group (n= 54); Physical Disability (n=39) and control group (n=48). To assess the severity of ASD, Indian Scales of Assessment of Autism (ISAA) was utilized; Functional Ambulation Classification System was used to assess the physical disability and WHOQOL-BREF was employed to quantify the QoL. Parents in ASD group had significantly poorer scores in all domains of WHOQOL-BREF namely; Physical, Psychological, Environmental and Social domain when compared to that of parents of children with physical disability and neuro-typical children. Author stated that the elevated physical and mental stress, confusion over child's ASD diagnosis due to different statements by various professionals, lack of support from partner, poor social satisfaction, rejections by the society and lack of affordability of quality services negatively affect the QoL of parents. Limitation of study includes its cross sectional design, broad objective and lack of usage of condition specific tool.

Jain et al. (2019) studied QoL in 90 parents of young and adolescent children with ASD (3-19 years) who attended treatment services at private and government organizations in Lucknow district of Uttar Pradesh, India. Study employed purposive

sampling method and brief interview followed by administration of ISAA and WHOQOL-BREF to quantify child's Autism characteristics and QoL of parents respectively. Parents scored minimum in Physical health domain and maximum scores in environmental health domain of WHOQOL-BREF. Parents who resided in joint family and had greater awareness about the condition, scored better in environmental health domain. Most of the mothers had quit their jobs in order to take care of child. No significant differences in QoL were found with different severity of ASD, age of the child, occupation and education of the parent.

To summarize, in the western context, many researchers have studied QoL and its determinants in parents of children with Autism Spectrum Disorder. Though there is no consensus in choice of tool to assess the QoL, these studies unanimously report persistence of poor QoL in parents. There is dearth of studies utilizing ASD specific measures to explore the QoL in Indian parents and there is no Indian tool developed in Kannada Language.

Chapter 3

METHOD

The primary aim of the current study was to explore Quality of Life in Parents of children with Autism Spectrum Disorder (ASD) in the Indian Context.

The objectives of the study were as follows:

1. To develop a Quality of Life questionnaire for parents of children with ASD in Kannada.
2. To investigate the quality of life of parents of children with Autism Spectrum Disorders in relation to socio-communication skills of children with ASD.
3. To compare the Quality of Life (QoL) of parents (on Part A sub-scale of QoLA-K) and Impact of ASD symptoms (on Part B sub-scale of QoLA-K) with the severity of ASD.

Principles of the present study: The study utilized a cross-sectional study design of descriptive research method. The study was conducted in the following phases:

Phase 1: Questionnaire construction, scoring criteria and content validity of the constructed questionnaire.

Phase 2: The pilot study.

Phase 3: Administration of the questionnaire on parents of children with ASD.

Participants

Participants included thirty (30) mothers of children with Autism Spectrum Disorder (ASD). Mothers were considered for the study to maintain homogeneity in the gender of the parent. Previous research studies have reported differences in perception of

stress and lower QoL in mothers of children with ASD when compared to the fathers (Eapen et al., 2016; Özgür et al., 2018). Participants belonging to middle socio-economic status were included in the study. In order to determine the socio-economic status of participants, NIMH Socio-Economic Status Scale, Revised Version developed by Venkatesan (2011) was administered. NIMH Socio-Economic Status Scale, Revised Version assesses the socio-economic status based on monthly income, highest education, occupation and family properties. All the children were diagnosed with Spoken Language Disorder with Autism Spectrum Disorders based on DSM V guidelines by a team of qualified professionals including Speech-Language Pathologist, Clinical Psychologist and Occupational Therapist. All the participants had working knowledge of Kannada language. Children were in the age range of 2.11 to 7 years. All the participants were recruited from Mysuru, Karnataka State, India. All the participants were native speakers of Kannada Language.

The severity of ASD in children was assessed using Indian Scale for Assessment of Autism (ISAA). ISAA is a standardized Indian tool which was developed in the year 2009 by the joint efforts of the National Trust, Ministry of Health and Family Welfare and Ministry of Social Justice and Empowerment, Government of India. ISAA is based on Childhood Autism Rating Scale (CARS) and is constructed for assessing the severity of ASD symptoms and to quantify the level of disability. ISAA consists of 40 questions on following domains: Social relationship and reciprocity, Emotional responsiveness, Speech and language communication, Behavior patterns, Sensory aspects and Cognitive component. It uses a 5 point Likert rating scale ranging from 1 (never) to 5 (always) to classify the severity of Autism into Mild, Moderate and Severe.

Inclusion Criteria: The following inclusion criteria was considered

- i) Parents of children who received a diagnosis of Spoken Language Disorder with Autism Spectrum Disorder based on DSM V guidelines and ISAA (NIMH, 2009) across different severity; Mild, Moderate and Severe.
- ii) Parents of children who received a diagnosis of ASD by qualified professionals including Speech Language Pathologist, Clinical Psychologist and Occupational Therapist.
- iii) Participants were native speakers of Kannada (with Kannada as Mother tongue and native language).
- iv) All the participants had a working knowledge of Kannada.
- v) Minimal educational qualification at least tenth grade.
- vi) Families belonging to middle-socioeconomic status.

Exclusion Criteria: The following exclusionary criteria was considered

- i) Children with ASD having any other associated problem were excluded from the study.
- ii) Parents of children with ASD with any significant health issues in terms of physical and mental illness that potentially affected their QoL.

Test Material: Quality of life questionnaire for parents of children with ASD in Kannada Language (QoLA-K) was adapted from Quality of Life in Autism Questionnaire (QoLA) developed by Eapen et al., (2014). Modifications were made in the QoLA scale based on the socio-cultural considerations and its usefulness in the Indian Context.

The questionnaire was developed and studied in the following phases:

Phase 1: Questionnaire construction, scoring criteria and content validity of the constructed test material.

Phase 2: Pilot study

Phase 3: Administration of the final QoLA-K.

Phase 1: Questionnaire construction, scoring criteria and content validity of the constructed test material.

The QoLA-K was constructed as a Kannada language adaptation of the Quality of Life in Autism Questionnaire (QoLA) developed by Eapen et al., (2014). The original QoLA Scale is a self-rating scale which was developed in English Language, QoLA consists of two domains; Part A (QoL Sub-scale) and Part B (impact of ASD symptoms sub-scale). It assesses the QoL of individuals and caregivers of children with ASD.

In the present study, QoLA scale was selected since it is an Autism-specific measure of QoL for parents of children with ASD. QoLA scale is composed of clear and concise format including suitable examples providing a holistic view of QoL and it is reported to have good construct validity and internal reliability. QoLA scale is based on following QoL constructs:

- Psychological
- Environmental
- Physical
- Economical
- Social

Part A (QoL Sub-scale) includes a total of 28 items measuring caregiver's overall perception of their own Quality of Life. Part A (QoL Sub-scale) includes questions such as "I am happy and content", "I am satisfied with my social life", "I am satisfied with where I live", "I can able to get to where I need to" "I can get the support that I need from

my community and “I am satisfied with my achievements”. Individual is instructed to mark self perceived Quality of Life on a 5 point Likert Scale ranging from 1 (Not at all) to 5 (Very much). Higher values indicate better Quality of Life.

Item number 2, 4, 17 and 22 are reverse scored i.e., ranging from 5 (Not at all) to 1 (Very much). These items comprise of qualitative description of domains which are indicator of Poor QoL such as Item number 2: “I feel stressed” (Psychological domain) and item number 17: “Health problems stop me doing things that I want to” (Physical Health domain)

Part B (Impact of ASD symptoms Sub-scale) consists of questions measuring the parental perception of how problematic their child’s autism specific difficulties are for them. Example: “managing emotional responses”, “being overtly interested in certain topics” and “showing inappropriate emotional reactions”. The participants are instructed to rate the items on a 5 point Likert Scale ranging from 1 (not much of a problem” to 5 (very much of problem). Higher scores are indicative of lesser self-perceived problems specific to ASD related symptoms and behavior of their child. Part A and Part B are scored separately.

The Kannada language version of the questionnaire for assessing Quality of Life of parents of children with ASD (QoLA-K) was constructed in lines with original QoLA scale. Firstly, each item of the original QoLA scale was thoroughly reviewed for its appropriateness and relevance in Indian Context. The questions were translated in Kannada Language. The process of translation was carried out by qualified Speech Language Pathologist (SLPs) in following three steps:

- a) **Forward Translation:** Translation from English into Kannada Language was

done by three postgraduate students of Speech Language Pathology. Translators had Kannada Language as mother tongue and good proficiency in English Language. Forward translation aimed at conceptual equivalency rather than word-to-word translation of items. Questions were framed to be simple, concise and clear to be understood by common audience. Use of technical jargon, colloquial terms, idioms and vernacular terms was avoided. Finally, relevance and cultural sensitiveness in Indian context was considered.

- b) **Reverse Translation:** Reverse translation from Kannada to English Language was done by three postgraduate students of Speech Language Pathology as independent translators (Translators had no prior knowledge about the QoLA scale) to avoid any bias. SLPs had good proficiency in English Language and their mother tongue was Kannada Language. Translation was done considering the cultural and conceptual equivalence rather than literal translation.
- c) **Final Translation:** In this step, the manuscripts of forward translation and backward translation were compared. Each question was reviewed scrupulously. Discrepancy and inadequate expression of translation between forward and backward translation were identified and necessary modifications and corrections were made. Finally, the preliminary draft of QoLA-K comprised of two sub-scales; Part A (QoL sub-scale) and Part B (impact of ASD symptoms sub-scale) and a total of 48 questions. 5 point Likert scale of original scale was retained.

Content validity of the adapted test material

After the translation process, the preliminary questionnaire was provided to three

Post graduate students of Speech-Language Pathology to validate the content and provide feedback on ordering of questions, rating and appropriateness in the Indian Context. Based on Speech Language Pathologists rating and feedback, necessary modifications were made.

Phase 2: Pilot study

Pilot study was conducted by administering the questionnaire on six (6) parents of participants across different severity of ASD to check for the understandability and relevancy of the questions. SLP was present during the entire process to provide detailed instructions and assistance whenever required. The obtained responses were documented. After the Pilot Study, the ordering of 4 items- 2, 4, 17 and 22 in Part A (QoL sub-scale) was changed in order to increase the understandability and ease of rating.

Finalization of the final version of QoLA-K

Based on results of the pilot study, the questionnaire was further modified. Modification included further simplification of questions for better understanding of questions by common audience.

Part A consisted of total 28 questions. In Part A (QoL Sub-scale), for reverse scoring, the sequence of 4 questions was changed to avoid any confusion in rating the questions of QoLA-K. A percentage rating was paired with the 5 point Likert Scale to increase the ease of self-rating among the respondents. A percentage rating of 0% was paired with rating “1” indicating “Not at all” to >75% was paired with a highest score of “5” indicating “very much”. Thus, total scores on Part A ranged from 28 to 140. Higher scores on Part A indicated better QoL.

Part B of QoLA-K comprised of total 20 questions assessing the impact of child's ASD symptoms on QoL of the caregiver. Part B measures the extent of problems faced by the caregivers in day to day life due to the presence of various ASD symptoms of their child. Part B is reverse scored on a 5 point Likert rating scale where highest score of "5" indicated "not much of a problem" to least scoring of "1" indicating "very much of problem". Total score in Part B of QoLA-K can range from 20-100.

Thus, the final Kannada language version of the questionnaire for assessing Quality of Life of parents of children with ASD (QoLA-K) contained total of 48 questions; with 28 items in Part A (QoL sub-scale), 20 questions in Part B (Impact of ASD symptoms sub-scale). The QoLA-K also included a 10 point Visual analog scale ranging from 0 (Not at all satisfied) to 10 (Extremely satisfied) to self-rate the overall QoL of the respondent, where the respondent has to rate their overall Quality of Life by putting a cross line against the numerical value of visual analog scale. Finally, the last section of QoLA-K allows the respondent to provide description of other important factors which are perceived to be potentially influencing their QoL. Part A and Part B were designed to be scored separately. Higher scores indicated self-perception of better QoL in a hierarchical manner.

Phase 3: Administration of the final QoLA-K

The final version of QoLA –K was administered on Thirty (30) mothers of children with ASD. The age of participants ranged from 27 years to 41 years. The age of children with ASD ranged from 2.11 years to 7 years; 22 males and 9 females.

Procedure

The administration of the questionnaire QoLA-K was carried out in a well-lit room

with minimal background noise. All the participants were comfortably and individually seated. Prior to the administration, informed consent was taken from all the participants. Participants were explained about the purpose of the study. AIISH Ethical Guidelines for Bio-Behavioural Research involving Human Subjects (AEC, 2009) were followed.

A trained SLP extracted the demographic and clinical data during semi-structured interview and medical records were reviewed, considering the variables such as the age of child and parent, education and occupation of the parent, marital status, physical and mental health, ASD symptoms and medical history of the child, availability of rehabilitation services and duration and type of intervention taken.

Participants were provided clear and detailed instructions by the SLP and they were asked to fill the questionnaire. SLP was present during the entire process of questionnaire administration to provide any clarifications whenever necessary. Participants were told that they can take breaks in between the administration whenever required. Approximately 15-20 minutes were taken by the participants for filling the questionnaire form.

Assessment of Test-retest reliability

Scoring: Part A (QoL sub-scale) and Part B (Impact of ASD symptoms sub-scale) were scored separately. The following scoring criteria were utilized:

Part A (QoL Sub-scale): Each item in QoL sub-scale was measured on a 5 point Likert scale ranging from '1' (not at all satisfied) to '5' (very much satisfied) to indicate the self-perceived satisfaction in day to day life. Higher scores indicated better QoL. The description of Likert scale is given below:

1= not at all.

2= slightly.

3= moderately.

4= quite a bit.

5= very much.

Note: The last 4 items of Part A – Item number 25, 26, 27 and 28 are reverse scored.

Part B (Impact of ASD symptoms Sub-scale): The impact of ASD symptom sub-scale used reverse scoring i.e., 5 point Likert Scale ranging from ‘5’ (not much of a problem) to ‘1’ (very much of problem). Higher scores indicated better QoL. The description of Likert scale is given below:

5= not much of a problem.

4= slight problem.

3= moderate problem.

2= quite a bit of a problem.

1= very much of a problem.

Visual Analog Scale (Overall Quality of Life): To rate the overall Quality of Life, a Visual Analog Scale ranging from 0 (Not at all satisfied) to 10 (Extremely satisfied) was included in the end of questionnaire. Participants were asked to indicate the self-perceived overall Quality of Life by striking a cross line against the numerical value of visual analog scale.

For assessing the test-retest reliability of the questionnaire, QoLA-K was re-administered on eight (8) participants after a span of one week. The responses of the

participants were analyzed using Cronbach α . The α value was 0.94 for Part A; 0.82 for Part B. These values indicated that the test-retest reliability of QoLA-K was high.

Data Analysis and Statistical Analysis

The specific scores of 48 items of QoLA-K obtained from the participants were recorded and tabulated separately for Part A (QoL sub-scale) and Part B (Impact of ASD symptoms sub-scale) the grand total of each sub-scale was calculated separately. Statistical Analysis was carried out using SPSS- Statistical Package for Social Sciences Version 21.0 (IBM Corp., Armonk, NY, USA). Descriptive and inferential statistics were done.

Chapter 4

RESULTS

The primary aim of the present research study was to explore the quality of life in parents of children with Autism Spectrum Disorder (ASD) in the Indian Context. The objectives of the study were to investigate the parental Quality of Life (QoL) in relation to the socio-communication skills of children with ASD and to compare the QoL of parents (on Part A sub-scale of QoLA-K) and impact of ASD symptoms (on Part B sub-scale of QoLA-K) with the severity of ASD. Quality of Life sub-scale (Part A) includes 28 questions related to the quality of life of parent/caregiver and Impact of ASD symptoms sub-scale (Part B) consists of 20 questions exploring the extent of problems faced by the parent/caregiver due to presence of the autistic symptoms of the child. QoLA-K was administered on thirty (30) mothers of children with ASD. Total scores for Part A (QoL sub-scale) and Part B (impact of ASD symptoms sub-scale) were calculated separately and subjected to quantitative analysis using the Statistical Package for Social Sciences (SPSS) Version 21.0 (IBM Corp., Armonk, NY, USA).

The data was subjected to Shapiro Wilk's test for normality and the results revealed that the data did not follow normal distribution ($p > 0.05$). Hence, non-parametric tests were employed. The statistical analysis of the data was done using the following statistical procedures:

- a) Descriptive statistics was carried out to obtain mean, median, standard deviation (SD) and inter-quartile range for Part A and Part B sub-scales of QoLA-K. The total scores for Part A and Part B were calculated separately.
- b) Spearman's Rho Correlation was employed to study the relationship between the QoL of the parents and the socio-communication skills of children.

- c) For between-group comparison, Mann Whitney U test was used for comparing the scores of Part A and Part B sub-scale with two severities (mild and moderate) of ASD
- d) Cronbach's Alpha was calculated to find the test-retest reliability of the QoLA-K scale

The results of the current study are elucidated under the following sections:

- 4.1 Relationship between the Quality of Life (QoL) of parents and socio-communication skills of children.
- 4.2 Comparison of Quality of Life (QoL) of parents (on Part A sub-scale of QoLA-K) and Impact of ASD symptoms (on Part B sub-scale of QoLA-K) with the severity of ASD.

4.1. Relationship between the Quality of Life (QoL) of parents and socio-communication skills of children.

In order to study if there is any significant relationship existing between the Quality of Life (QoL) of the parents/caregivers and the socio-communication skills of children with Autism Spectrum Disorder (ASD), Spearman's Rho Correlations were employed in the study. The QoL measure included the scores of Part A (QoL sub-scale) and Part B (Impact of ASD symptoms sub-scale) of QoLA-K. The socio-communication skills of children with ASD included the children's scores on "socio-emotional reciprocity" and "speech and language communication" sub-tests of the Indian Scale for Assessment of Autism (ISAA) developed by National Institute of Mental Health (2009).

Descriptive statistics is revealed in Table 4.1 which depicts the overall scores of Part A and Part B sub-scale of QoLA-K, representing the self-perceived QoL among 30

mothers and the scores of ISAA across following domains; socio-emotional reciprocity, speech & language communication and combined socio-communication skills of the children.

Table 4.1

Mean Scores and SD of Quality of Life of Parents (QoLA-K) and Socio-Communication Skills of Children (ISAA) (N=30)

Sub-Section	Mean	SD
QOLA-K		
Part A	102.41	20.25
Part B(QOLA-K)	65.48	11.43
ISAA		
Socio-Emotional Reciprocity (ISAA)	25.48	4.54
Speech and Language Communication (ISAA)	20.19	3.87
Socio-Communication Skills (ISAA)	45.64	6.05

Note. N= No. of Participants; SD= Standard Deviation.

Note. # Maximum possible score of Part A-140, Part B-100 and ISAA-70.

Analysis of QoLA-K total scores revealed that the total scores of Part A (Mean=102.41, SD=20.25) were better than the total scores of Part B (Mean=65.48, SD=11.43). Higher scores indicate better self-perceived QoL. This indicates that the presence of challenging conditions faced by the parents significantly contributed to their lower self-perceived QoL. Though differences in individual characteristics of the parents were present, they find it hard to cope up with children's ASD symptoms. Parents rated lower QoL in questions which were specifically formulated to quantify the problems secondary to child's socio-emotional deficits, speech and language deficits and behavioral problems. For example, questions such as difficulty in "socializing with people", "having

friends”, “communicating basic needs”, “showing inappropriate emotional reactions”, “needing to stick to a routine” etc. were more of a concern for the parents. Parents reported that the presence of difficulty in managing child’s symptoms often affects their daily life efficiency and QoL in a negative manner.

The overall mean scores of children with ASD assessed using the ISAA scale in the socio-communication domain were poor (Mean=45.64, SD=6.05). Analysis of the scores revealed that children performed poorer in “socio-emotional reciprocity” domain (Mean=25.48, SD=4.54) when compared to the “speech & language communication” domain of ISAA (Mean=20.19, SD=3.87). Here, higher scores indicate increase in severity of the problem. These findings suggest that children with ASD had more deficits in social domains when compared to that of speech and language communication. Further, correlation analysis was carried out to study the significance of relationship between the children’s socio-communication skills and QoL of the parents.

4.1.1 Relationship between the Quality of Life on QoLA-K and Socio-communication skills on ISAA.

To investigate the relationship between the Part A (QoL) and the socio-communication skills of children, the scores of the “socio-emotional reciprocity” and “speech and language communication” sub-test of ISAA were combined. Interestingly, the correlation analysis of these combined scores with the scores of Part A (QoL sub-scale) of QoLA-K revealed a moderate downhill (negative) relationship. Correlation analysis is revealed in table 4.2 which depicts the Spearman’s correlation values between Quality of life on Part A of QoLA-K and Socio-Communication skills on ISAA. Figure 4.1 shows scatter-plot of relationship between the Quality of Life on Part A of QoLA-K and Socio-communication skills on ISAA summarising the results of correlation analysis.

Table 4.2

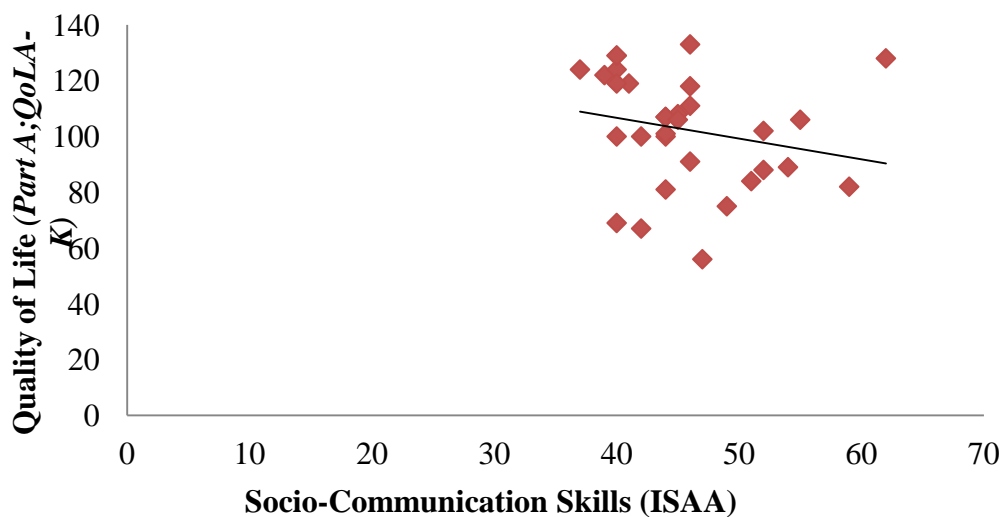
Spearman's Correlation between Quality of life (Part A;QoLA-K) and Socio-Communication skills (ISAA)

	Socio-communication Skills (ISAA)	Social & Emotional Reciprocity (ISAA)	Speech and Language (ISAA)
Part A (QoLA-K)	-0.36*	-0.27	-0.16

Note. * $p < 0.05$

Figure 4.1

Relationship Between Quality of life (Part A;QoLA-K) and Socio-Communication skills (ISAA)



In the Figure 4.1, Y-axis indicates the scores of Part A sub-scale of QoLA-K and X-axis indicates the scores of socio-communication sub-test of ISAA. Individual data points in the scatter-plot represent the scores for 30 participants. Spearman's Rho correlation revealed a significant relationship between the scores of Part A (QoL sub-scale) of QoLA-K and socio-communication sub-test of ISAA [$r_s(30) = -0.36, p=0.04$].

Results indicate that the deficits in socio-communication and QoL of the parent are inter-related. Socio-communication deficits of children with ASD negatively impact the Quality of life of their parents. With increment in the socio-communication deficit scores, there is decrease in self-perceived QoL of parents. Socio-communication deficits in children often persist for life long and have a detrimental effect on QoL of parents in a long run.

Additionally, to study the distinct relationship of the QoL on Part A of QoLA-K and Socio-communication skills on ISAA, further correlation analysis was carried out. Spearman's Rho correlation revealed a non-significant correlation between the QoL and social and emotional reciprocity skills of the children [$r_s(30) = -0.27, p > 0.05$]. There was no significant correlation observed between the QoL and speech and language skills of the children with ASD [$r_s(30) = -0.16, p > 0.05$]. These findings could be a result of small sample size considered in the current study.

4.1.2 Relationship between Impact of ASD symptoms on QoLA-K and Socio-communication skills on ISAA

To study the relationship between the the impact of problems faced by the parents and socio-communication Skills of children, the scores of the socio-emotional reciprocity and Speech and Language sub-test of ISAA were combined. Correlation analysis of these combined scores with the scores of Part B (Impact of ASD symptom sub-scale) of QoLA-K was carried out. Analysis revealed a moderate downhill (negative) relationship. Correlation analysis is revealed in table 4.3 which depicts the Spearman's correlation values between impact of ASD symptoms on Part B of QoLA-K and Socio-Communication skills on ISAA. Figure

4.2 shows scatter-plot of relationship between the impact of ASD symptoms on Part B of QoLA-K and socio-communication skills on ISAA summarising the results of correlation analysis.

Table 4.3

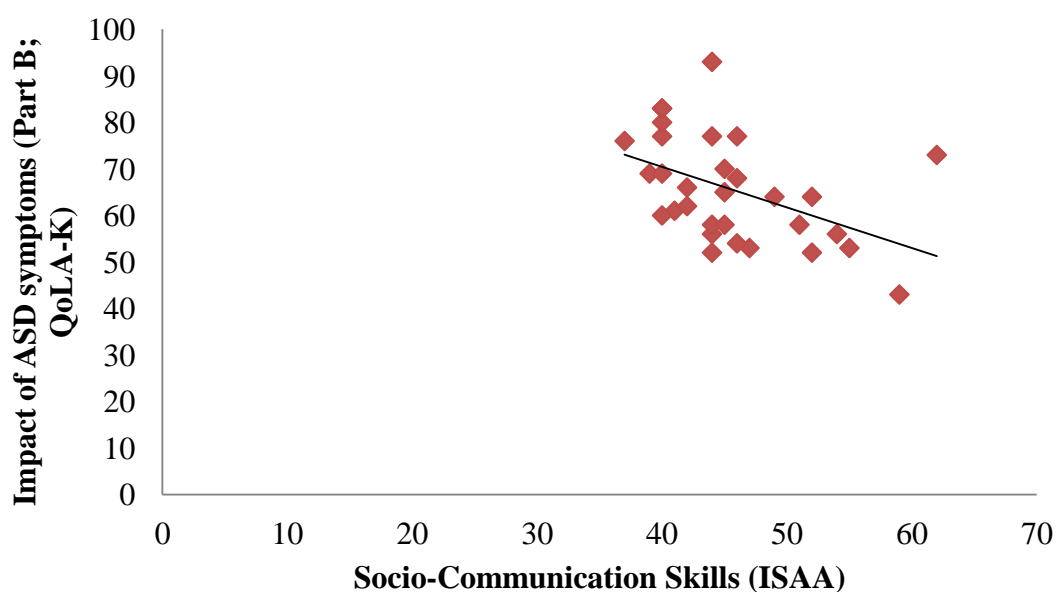
Spearman's Correlation between Impact of ASD Symptoms (Part B;QoLA-K) and Socio-Communication Skills (ISAA)

	Socio- communication Skills (ISAA)	Social & Emotional Reciprocity (ISAA)	Speech and Language (ISAA)
Part B (QoLA-K)	-0.49*	-0.45*	-0.26

Note. * $p < 0.05$

Figure 4.2

Relationship Between Impact of ASD Symptoms (Part B;QoLA-K) and Socio-Communication Skills (ISAA)



In the Figure 4.2, X-axis indicates the scores of Part B (Impact of ASD symptoms sub-scale) of QoLA-K and socio-communication sub-test of ISAA. Individual data points in the scatter-plot represent the scores for 30 participants. Spearman's Rho correlation revealed a significant relationship between scores of Part B (Impact of ASD symptom sub-scale) of QoLA-K and socio-communication sub-test of ISAA [$r_s(30) = -0.49, p=0.005$].

These results indicate that parents confront many problems in daily life due to the presence of their child's ASD symptoms. They perceive difficulty in managing the deficits in social communication skills which has a negative impact on their QoL. With increment in the socio-communication deficit, there is decrease in self-perceived QoL of parents. With increase in severity of ASD symptoms there is significant reduction in QoL of the parent.

Additionally, to explore the distinct relationship of the impact of ASD symptoms on QoLA-K with socio-emotional reciprocity and speech and language communication, further correlation analysis was carried out. Spearman's Rho correlation revealed a significant relationship between scores of Part B (Impact of ASD symptom sub-scale) of QoLA-K and social and emotional reciprocity sub-test of ISAA [$r_s(30) = -0.45, p=0.01$]. These findings indicate that the deficit in socio-emotional reciprocity impact the QoL of parent negatively. With increase in severity of these deficits, there is significant increase in problems faced by the parent.

No significant relationship was found between the scores of scores of Part B (Impact of ASD symptom sub-scale) of QoLA-K and speech and language

communication sub-test of ISAA [$r_s(30) = -0.26, p > 0.05$]. These findings could be considered as an outcome of small sample size of the current study.

4.2 Comparison of Quality of Life (QoL) of parents (on Part A sub-scale of QoLA-K) and Impact of ASD symptoms (on Part B sub-scale of QoLA-K) with the severity of ASD

To explore the differences in self perceived Quality of life (QoL) of the parent with respect to the severity of ASD of their children, the scores of the QoLA-K were bifurcated under two severities of Autism Spectrum Disorder (ASD) i.e., mild ASD and moderate ASD. The scores of Indian Scale for Assessment (ISAA) were used to assess the severity of the ASD in children. There were total Twenty-four (24) participants in the “mild” category of ASD (Group 1) and Six (6) participants in “moderate” category of ASD (Group 2). The total scores for Part A (QoL sub-scale) and Part B (Impact of ASD symptom sub-scale) were calculated separately. The results of severity wise descriptive statistics- number of participants, mean, standard deviation (SD), median and inter-quartile deviations (Q_1 and Q_3) are displayed in table 4.4.

The minimum scores obtained in Part A sub-scale were 67 and 56 in group 1 and group 2. The minimum scores for moderate category are lower than that to mild category. The maximum scores obtained for Part A were 133 and 128 for group 1 and group 2 respectively, indicating slightly higher scores in mild group than the moderate group.

Table 4.4

Measures of Central Tendency and Measures of Dispersion for the Scores of Part A and Part B of QoLA-K (N=30)

	Severity of ASD- Mild						Severity of ASD- Moderate					
	n	Mean [#]	SD	Median	Q1	Q3	n	Mean [#]	SD	Median	Q1	Q3
Part A												
Total	24	106.28	17.76	107.00	96.5	117.5	6	86.33	23.72	85.00	70.5	99.5
Part A												
Total	24	75.91	12.68	76.43	54.47	69.11	6	61.66	16.94	60.71	50.53	70.89
%												
Part B												
Total	24	67.56	10.85	66.00	56.5	75.5	6	56.83	10.42	54.50	28.5	45.5
Part B												
Total	24	67.56	10.85	66.00	56.5	75.5	6	56.83	10.42	54.50	28.5	45.5
%												

Note. Abbreviation: N= No. of Participants; SD= Standard Deviation; Q1 & Q3= First and third Quartile deviation respectively.

Note. # Maximum possible score of Part A-140 and Part B-100.

Similar trend was observed in scores of Part B subscale of QoLA-K where the minimum scores for mild group were much higher than the moderate group. Minimum scores obtained in Part B sub-scale were 52 and 43 in group 1 and group 2 respectively. The maximum scores obtained for Part A were 93 and 73 for group 1 and group 2 respectively, indicating slightly higher scores in mild group than the moderate group. Scores in mild group were nearing towards the possible grand total scores of Part B (100).

The mean scores for Part A were 106.28 and 86.33 in group 1 and group 2 respectively. The mean scores for Part B were 67.56 and 56.83 in group 1 and group 2 respectively.

It is clear from the table that the participants in “mild” category of ASD have higher scores in all the measures than “moderate” category of ASD in both Part A and Part B sub-scale of QoLA-K. These scores indicate better self-perceived QoL among the mothers of children with mild severity of ASD when compared to the mothers of children with moderate severity of ASD. There is a negative impact of the increment in severity of ASD on the parental QoL.

Mann Whitney U test was employed to study the differences between the quality of life of group 1 and group 2. The scores of QoLA-K scale were compared with the mild and moderate severity of ASD. Statistical Analysis revealed presence of significant difference in the scores of Part A (QoL sub-scale) of QoLA-K with the severity of ASD in children [$U=35$, $p=0.04$, $r=0.35$]. The effect size was 0.35. Comparison of Part B (Impact of ASD symptom sub-scale) also revealed a significant difference between the mild and moderate severity of ASD with an effect size of 0.37 [$U=33$, $p=0.03$, $r=0.37$].

Figure 4.3 and 4.4 depict the comparison of mean scores and standard deviation of Part A (QoL sub-scale) and Part B (Impact of ASD symptom sub-scale) respectively between mild and moderate severity of ASD. Significant difference in QoL of parent across the severity is highlighted. The scores for both Part A and Part B were higher in group 1 (mild severity of ASD) when compared to the group 2 (moderate severity of ASD).

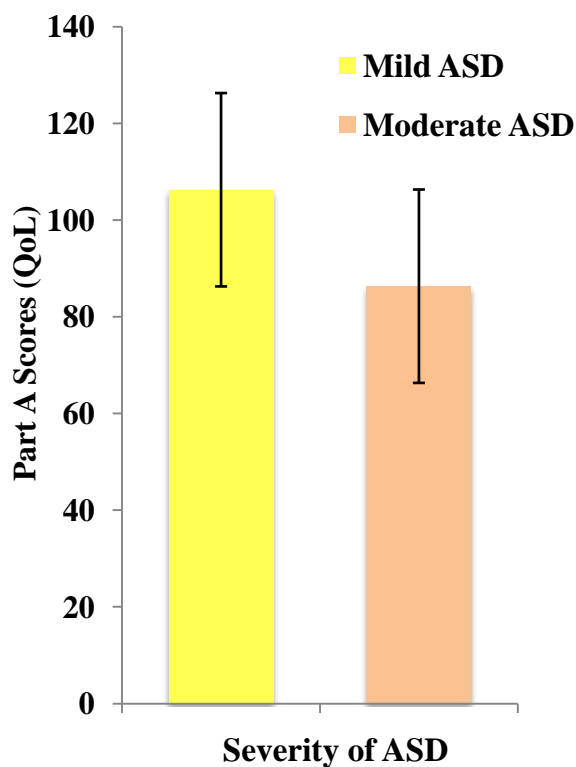


Figure 4.3

Comparison of Mean scores and SD of Part A Between Severities of ASD.

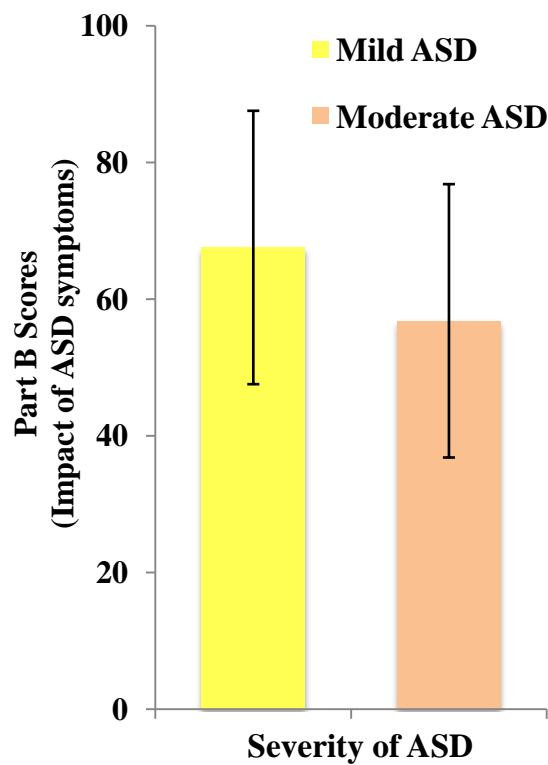


Figure 4.4

Comparison of Mean Scores and SD of Part B Between Severities of ASD.

Above mentioned findings indicate that the parents with children having milder severity of ASD displayed a better self-perceived QoL and lesser impact of ASD symptoms of the child. Parents of children having moderate ASD displayed greater negative impact of ASD symptoms of child in daily life and lesser self-perceived Quality of Life. As the severity increases, it becomes extremely challenging for the parents to have a balance between child care and personal well-being. The severity of ASD exhibits a significant effect on the QoL of the parent. With increase in severity of ASD symptoms, there is decrement in parent's QoL. These findings highlight the immediate need of developing programs for parent support and community awareness considering the severity of child's symptoms.

4.2.1 Qualitative analysis of quality of life on Part A (QoL sub-scale) across severity (mild and moderate) of ASD

The qualitative analysis of performance of participants was done for individual questions of the Part A (QoL) across severity (mild and moderate) and are explained in the following sections.

Question No. 1 “I am satisfied with my life”: Differences in participant’s choice of rating were evident. In mild severity group, 28% of participants showed perception of satisfaction in life by opting for the highest possible rating of “very much”, whereas in moderate group only 16.6% percent of participants chose rating of “very much”. 50% of mothers in moderate group chose rating their life satisfaction as “moderate” compared to 32% in milder group. Though the life satisfaction scores were found to be reduced in both the groups, mild group performed better than the moderate group.

Question No. 2 “I feel happy and content”: Marked differences in self perception were observed. In moderate group, none of the participants rated “very much”, 50% of them opted for lower rating of “slightly”. Whereas in mild group, 16% of participants chose “very much”. Overall, mothers in mild group were found to have better sense of happiness and content in their life when compared to that of mothers in moderate group.

Question No. 3 “I feel good about myself as a person”: Most of the mothers in mild group (48%) rated the highest rating of “very much”. Whereas, mothers in moderate group opted to lower ratings, 50% of them chose “quite a bit” and only 16% of them chose highest rating of “very much”. In summary, psychological well-being was found to be better in mothers in milder group than moderate group.

Question No. 4 “I am satisfied with my close relationships”: Mothers in moderate group opted for lesser rating than the mothers in mild group. 16.7% of mothers in moderate group chose the highest rating of “very much” whereas, 20% of mothers chose the same in mild group. Overall, participants in moderate group rated lesser satisfaction with their close relationships than mild group.

Question No. 5 “People are there for me when I need them”: None of the mothers in moderate group rated “very much” whereas 16% mothers in mild group opted for the same. This indicates that there is lack of awareness about ASD and caregiver support among society. Ideally with increase in the severity of ASD, the amount of support provided to the caregivers should also increase. Environmental factors such as support from the family and society play a crucial role in affecting the QoL of the parent.

Question No. 6 “I am satisfied with my social life”: Marked difference was seen across severity of ASD. 50% of the mothers in moderate group portrayed less satisfaction with social life by choosing rating of “slightly” whereas only 8% mothers in mild group chose the same. 28% mothers in mild group chose highest rating of “very much” when compared to only 16% in moderate group. Social life is an important aspect of person’s well-being. Having a child with ASD significantly reduces the “social time” among caregivers. This has a detrimental affect on their QoL.

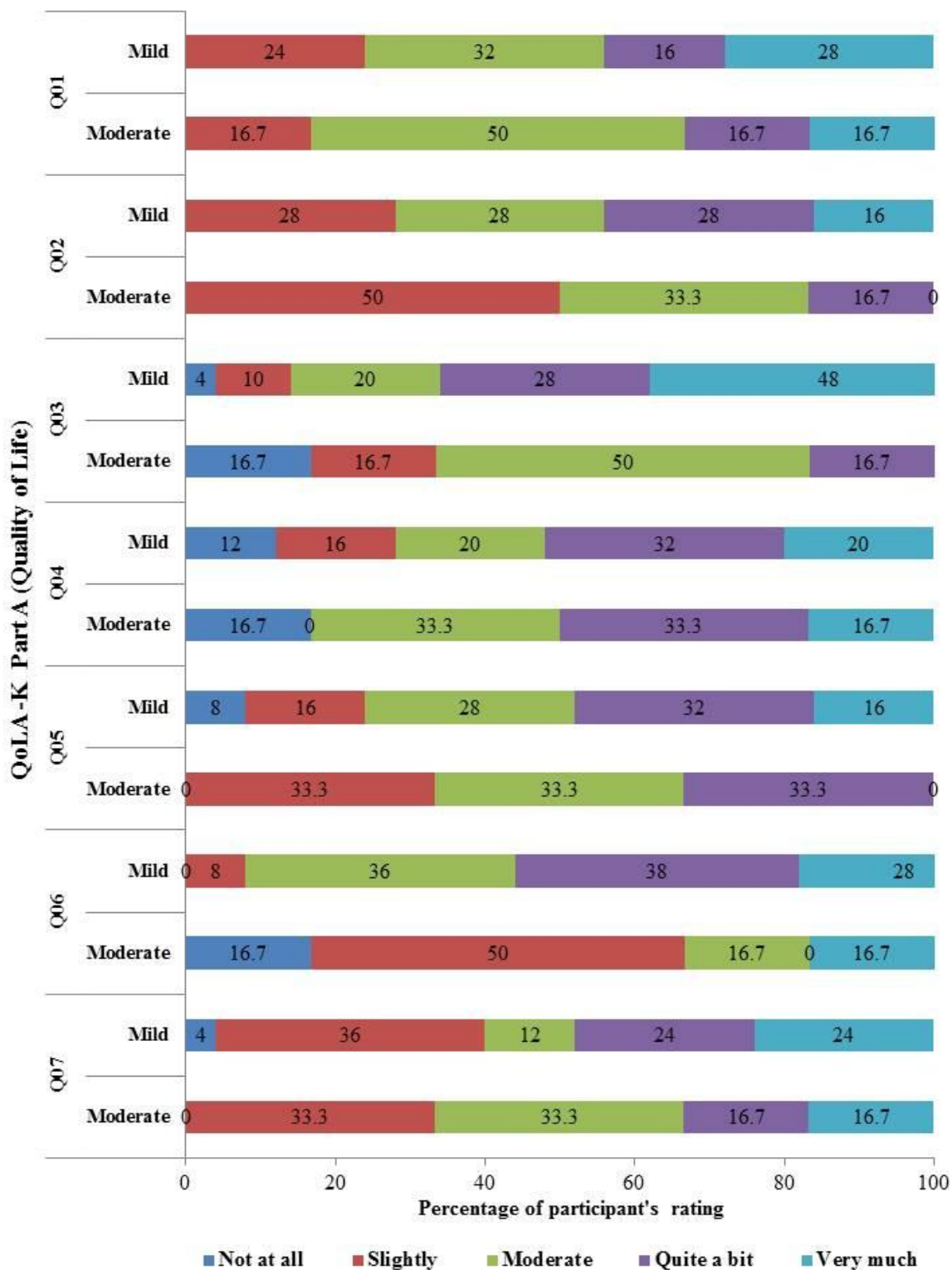
Question No. 7 “I am satisfied with my family life”: Family life is a very important aspect of an individual’s life. Mothers in both the groups portrayed reduced satisfaction. Only 24% and 16.7% of mothers in mild and moderate group respectively, opted for highest rating of “very much”. Most of them were not satisfied and chose lower rating of “slightly”. Mothers reported that they were not able to provide enough time to their other children, spouse and other family members. They somewhere felt “guilty” for

not being able to manage their time and attention, since most of their time is spent in caring and training the child with ASD.

Figure 4.5–4.8 depict the comparison of the percentage of the participant's rating between the mild and moderate severity of ASD across 5 point Likert rating scale in Part A (QoL sub-scale) of QoLA-K scale. Color coding was used to highlight the question specific response of the participants across the severity of ASD (Question No. 1-28). The 5 point Likert rating scale ranged from "1" indicating "Not at all" to the highest score of "5" indicating "very much". The distribution of the percentage of participants opting for questionnaire rating has been elucidated for different questions.

Figure 4.5

Comparison Between the Severities Across the Questions of Questionnaire Part A (Q1 to Q7)



Question No. 8 “I am satisfied with my financial situation”: 40% and 16.7% of mothers opted for rating “quite a bit” in mild and moderate group respectively. 32% and 16.7% of mothers opted for rating “very much” in mild and moderate group respectively. The task of parenting a child with ASD is challenging and most of mothers reported that they had to resign from their jobs. The cost of regular assessments and various medical and non-medical management increases the financial burden of family.

Question No. 9 “I am satisfied with where I live”: 32% of mothers in mild group opted for highest rating of “very much”, 32% of them opted for “quite a bit”. Whereas, mothers in moderate group chose lower ratings of “slightly” and “not at all”. Overall, moderate group had poorer scores than mild group. This indicated that the environmental QoL decreases with increase in severity.

Question No. 10 “I have enough money to meet my needs”: This question explores the economic factors related to QoL. Heterogenous responses were observed, 24% and 16.% of mothers opted for highest rating of “very much” in mild and moderate groups respectively. Also, 24% and 33% of mothers opted for highest rating of “slightly” in mild and moderate groups respectively. Findings indicate that economical health has a significant effect on QoL of a person. Having a child with ASD adds on to the financial expenditure.

Question No. 11 “I am satisfied with my achievements”: 50% of mothers in moderate group opted for choosing lesser rating of “slightly”. 40% of mothers in mild group opted for “moderate” levels of satisfaction. None of the mothers in moderate group chose highest rating of “very much” when compared to 20% of mothers in mild group. Findings portray differences between the severity. Mothers of children with ASD tend to sacrifice on their personal and professional goals.

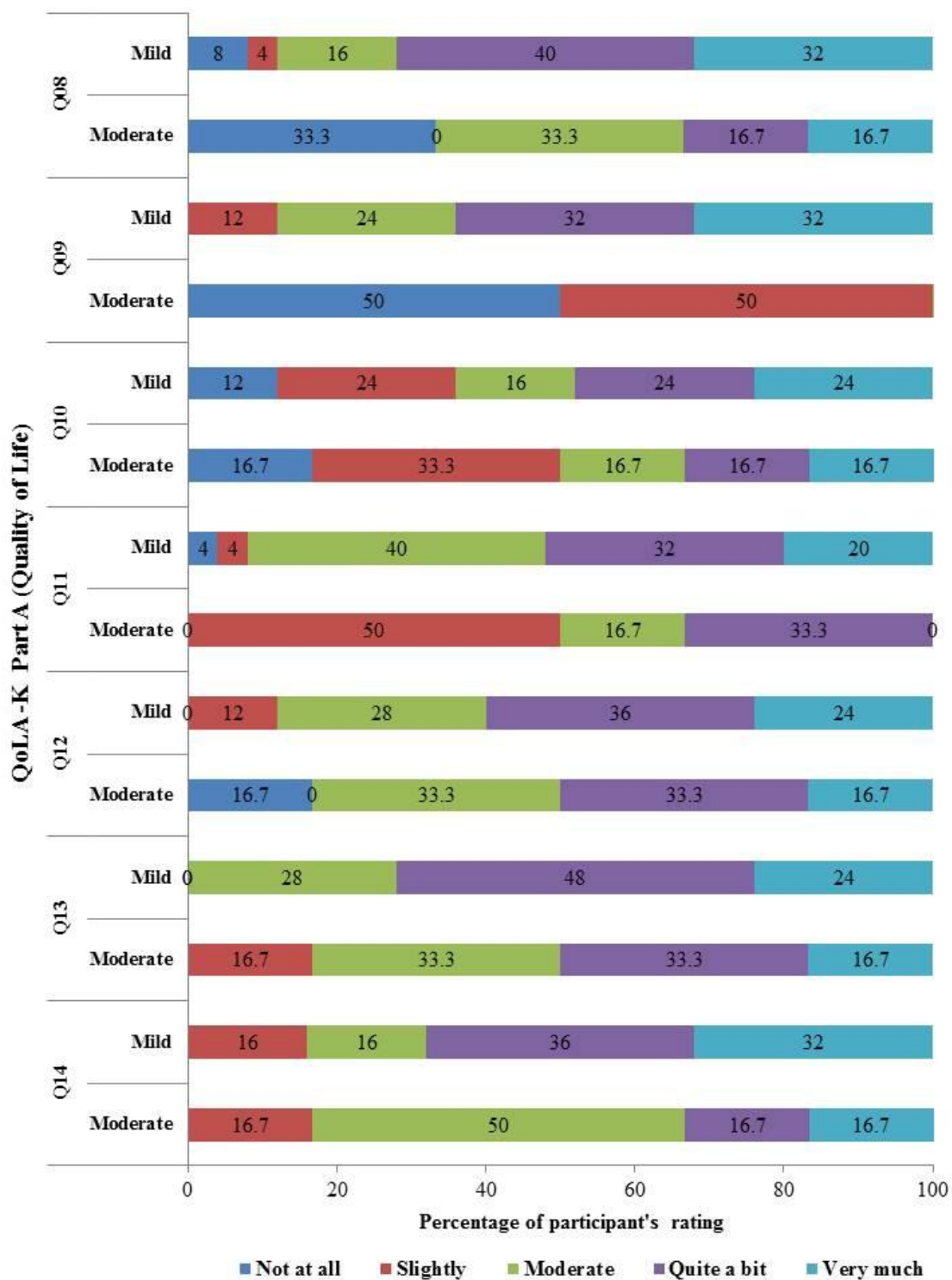
Question No. 12 “I am satisfied with my general health”: Most of the mothers (36%) in mild group and 33% in moderate group opted for rating “quite a bit”. 24% and 16.7% of mothers opted for highest rating of “very much” in mild and moderate group respectively. Overall, mothers reported that they are not able to manage to spend sufficient time personal care on a regular basis. They often had to compromise on meal time and sleeping time.

Question No. 13 “I have a healthy lifestyle”: Most of the mothers (48%) in mild group and 33.3% in moderate group opted for rating “quite a bit”. 24% and 16% of mothers opted for highest rating of “very much” in mild and moderate groups respectively. Mothers in moderate group had lesser satisfaction with their lifestyle. This has a detrimental effect on their QoL.

Question No. 14 “I am satisfied with my leisure activities”: Most of the mothers (50%) in mild group chose lesser rating of “moderate” when compared to 16% of mothers in mild group. Most of mothers in mild group (32%) opted for higher rating of “very much” when compared to only 16.7% in moderate group. Mothers express lack of satisfaction since they have scarcity of leisure time. They spend most of their daily time in child care. This affects their QoL adversely.

Figure 4.6

Comparison Between the Severities Across the Questions of Questionnaire Part A (Q8 to Q14)



Question No. 15 “I feel in control of my life”: 44% of the mothers in the mild group rated highest scoring of “very much” and none in moderate group opted for the same. Most of the mothers (50%) in moderate group chose “moderate”. Overall, mothers in moderate group portrayed lesser satisfaction when compared to mothers in mild group. Sense of having “control in life” is very subjective in nature. Every individual aims to fulfill personal, social and occupational goals in life. Mothers when bound with sense of excessive burden and stress in daily life tend to feel dissatisfied with psychological aspects of QoL.

Question No. 16 “I set and achieve goals in my life”: Most of mothers in mild group rated “quite a bit” and “very much” whereas mothers in moderate group opted for “moderate” and “quite a bit”. None of the mothers in moderate group opted for highest rating of “very much”. Findings suggest that differences in severity of ASD in children, affects maternal QoL significantly. The choice and decision of setting personal goals in life is affected. Mothers reported that they lack a sense of achievement in life since most of their time and attention is utilised in child care. These achievements include personal, familial, financial and social aspects of an individual’s life.

Question No. 17 “I can make a plan of action and follow it”: Differences in perception of mothers in mild and moderate group were found. 40% of mothers in mild group opted for highest rating of “very much” whereas only 16.7% of them opted for highest rating in moderate group. Overall, mothers in moderate group chose lesser rating when compared to that of mild group. During the long term process of care and maintenance of child with ASD, when severity of behavioral issue increases, parents often face unplanned and unexpected circumstances. This leads to perception of stress and anxiety, which has a negative impact on QoL of parents.

Question No. 18 “I make my own decisions”: Mothers in both the group reported lack of satisfaction. Only 36% and 16.7% of mothers in mild group and moderate group chose highest rating of “very much” respectively. 50% of mothers in moderate group chose to rate “slightly”. It is clear that the moderate group portrayed lesser satisfaction when compared to that of mild group.

Question No. 19 “I am a part of community”: 40% of mothers in mild group expressed highest rating of “very much”, whereas none of the mothers in moderate group opted for the same. Moreover, most of the mothers in moderate group opted for “moderate” rating (66.7%). The difference in perception of groups was observed as a function of severity of ASD. Moderate group expressed lesser satisfaction. Social well-being and participation in community activities has significant impact on QoL of parents.

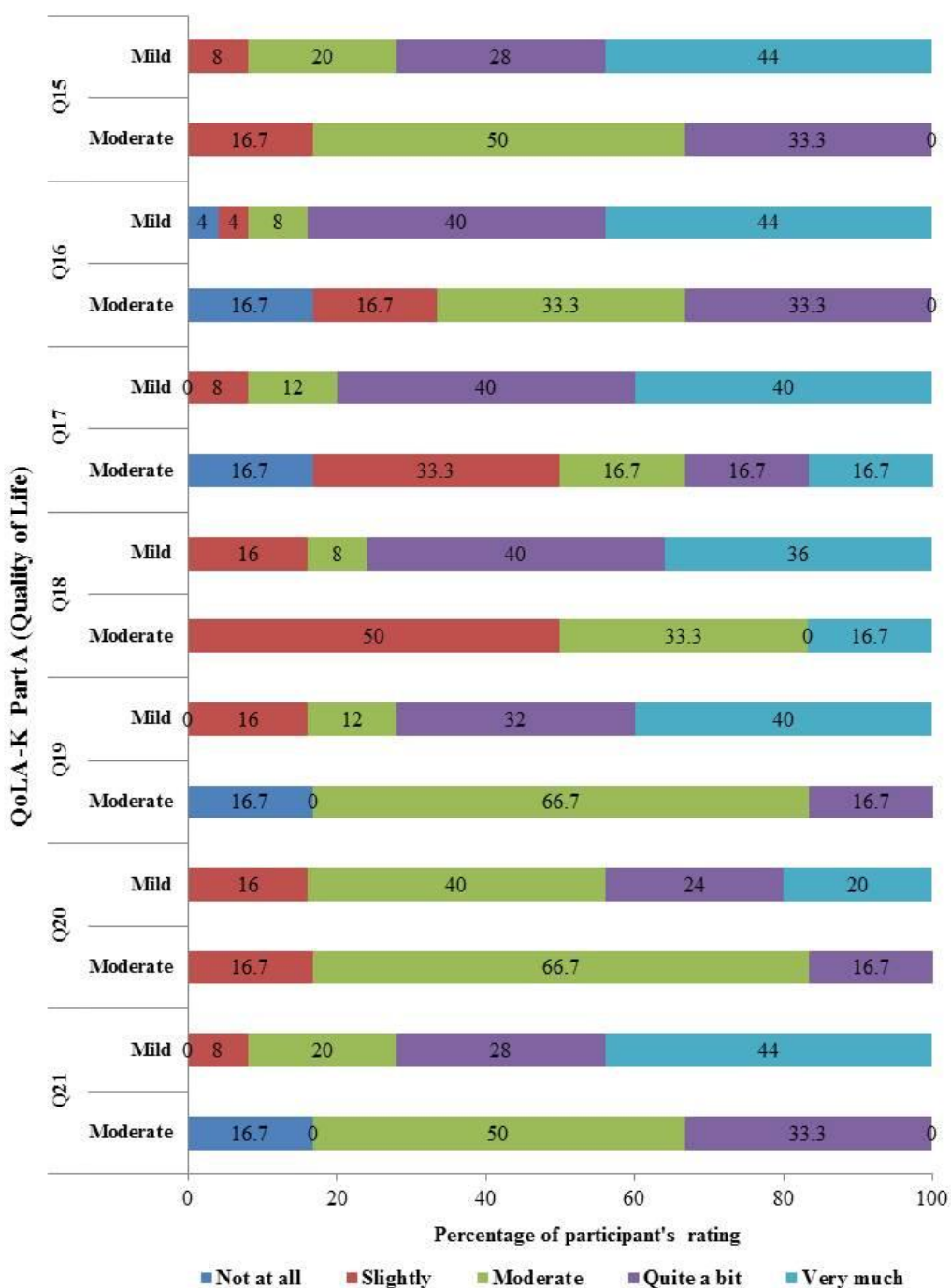
Question No. 20 “I can get the support that I need from the community”: None of the mothers in moderate group opted for highest rating of “very much” when compared to the mothers in mild group (20%). Majority of them chose lesser ratings of “slightly” and “moderately”. Both the groups expressed that they get lesser support from the community. There is lack of awareness and acceptance. With increase in child’s symptoms and ASD severity, feelings of shame and embarrassment also arise. This has a negative effect on QoL of the parents. Findings highlight immediate need of systematic programs and research studies to enhance the societal awareness and support for problems faced by caregivers of children with ASD.

Question No. 21 “I am able to get to where I need to”: 44% of mothers in mild group rated highest rating of “very much”; 28% rated “quite a bit”; 20% rated “moderate” whereas none of the mothers in moderate group rated “very much; 33.3% rated “quite a bit”, 50% rated as “moderate”. The differences in accessibility facilities also play a crucial

role in mobility. Also, the presence of sensory and behavioral issues play a significant role. Hence, it was observed that moderate group has lesser levels of satisfaction when compared to that of mild group.

Figure 4.7

Comparison Between the Severities Across the Questions of Questionnaire Part A (Q15 to Q21)



Question No. 22 “I feel safe in my everyday life”: The differences in feeling of “being safe” among both the groups were not pronounced. Mothers in both the groups opted for higher levels of satisfaction; “very much” 48% and 33.3% in mild and moderate group respectively. None of the mothers in both the groups chose lower rating of “not at all” or “slightly”.

Question No. 23 “I feel respected in my everyday life”: 40% of mothers in mild group opted for highest rating of “very much” when compared to 16.7% in moderate group. Most of mothers in moderate group (66.7%) chose rating of “moderate” . The sense of being “respected by others” is governed by many factors. Personal characteristics, acceptance of ASD as a condition, amount of respect and empathy provided by the spouse, family and society members are few of them. Some of the mothers reported that their spouse lack acceptance and dedication for caring their child. They don’t feel respected by their own family members and society as well.

Question No. 24 “I am satisfied with the availability of health services”: Mothers in both the groups felt the need of improving the health facilities. Only 48% and 16.7% of mothers in mild group and moderate group chose highest rating of “very much” respectively. Mothers in moderate opted for lesser ratings when compared to that of mild group. The availableness, ease of access and consumer-driven nature of medical and non-medical services are very essential factors. Lack of efficiency and availability of quality services has a detrimental effect on QoL of parent.

Question No. 25 “I feel Stressed”:36% of the mothers in mild group rated “slightly” whereas, 66.7% of mothers in moderate group rated “moderately”. 16.7% mothers rated “ quite a bit”. Most Psychological well-being is an important aspect of persons quality of life. Mothers of children with ASD suffer with elevated stress levels.

With increase in severity of the condition, it worsens. Mothers in moderate group portrayed higher levels of stress than compared to mild group.

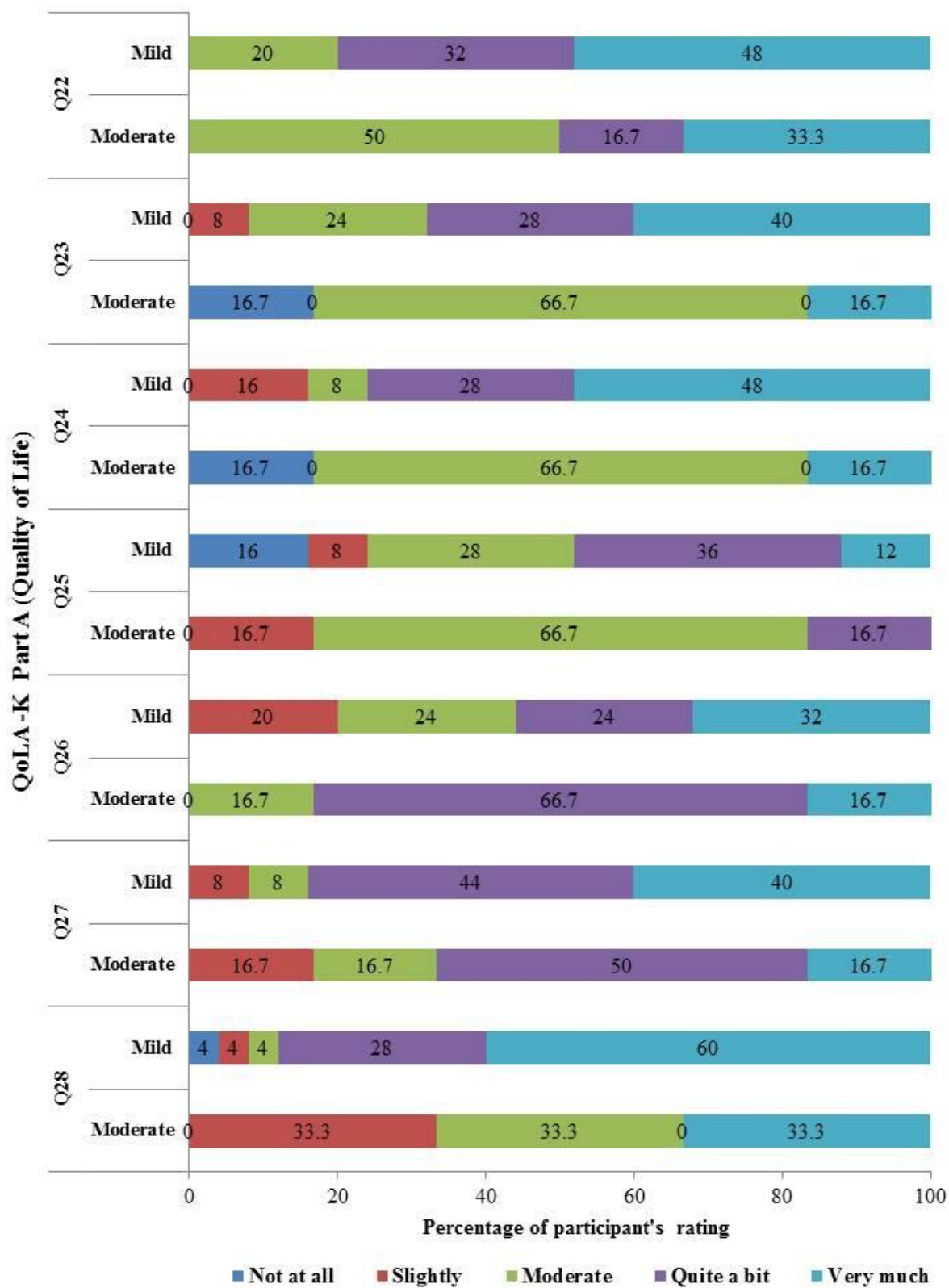
Question No. 26 “I feel depressed or anxious”: Most of the mothers in mild group (32%) portrayed no feelings of depression when compared to only 16.7% mothers in moderate group. Overall, mothers in moderate group expressed about the presence of frequent bouts of despression and anxiety when compared to that of mild group. The tidious task of caring for their child when accompanied with lack of support from the family and society and lack of availability of quality health services results in psychological disadvantages, depression, anxiety etc. to name a few.

Question No. 27 “Health problems stop me doing things that I want to”: 16.7% and 8% mothers in moderate group and mild group respectively reported presence of “quite a bit” health problems that hinder their activities. Physical well-being is certainly one of the most importanat factor affecting person’s QoL. Mothers spend most of their time in child care and often ignore dedicating time for personal health care. This has a detrimental effect on their QoL.

Question No. 28 “I feel guilty”: Mothers in moderate group expressed more feelings of guilt when compared to that of mild group. 60% of mothers in mothers in mild group potrayed no feeling of guilty when compared to only 33.3% in mild group. Feelings of guilt arise due to variours reasons. People who subscribe to orthodox ideologies of myths and misconceptions often blame parent for their child condition. Infact early research in ASD, during the times of Leo Kanner also blamed “unsensitive” mother being the cause of condition. Such myths are baseless and have no scientific basis. Thats why awareness about the causes of ASD is the need of the hour.

Figure 4.8

Comparison Between the Severities Across the Questions of Questionnaire Part A (Q22 to Q28)



4.2.2 Qualitative analysis of quality of life on Part B (Impact of ASD symptoms sub-scale) across severity (mild and moderate) of ASD

The qualitative analysis of performance of participants was done for individual questions of the Part B (Impact of ASD symptoms) across severity (mild and moderate) and are explained in the following sections.

Question No. 1 “Socialising with people”: Differences in problem perception of participant across the severity of ASD were evident. In mild severity group, 52% of the mothers indicated perception of “moderate problem” whereas only 33.3% of the mothers in moderate group opted for the the same. 16.7 % of mothers in moderate group indicated “quite a bit of a problem” and 16.7% of mothers indicated “very much of a problem”. Whereas in mild group only 4% of mothers opted for rating “very much of a problem”. Mothers in both the groups expressed variety of problems, however, mild group performed better than the moderate group. Mothers complained that due to the presence of socio-communication deficits in the child, they faced difficulties in attending public gatherings. They identified presence of social-communication deficits as a major hinderence in their child’s overall development.

Question No. 2 “Having friends”:Marked differences in problem perception were observed. In moderate group, none of the particants rated “not much of problem” and only 12% in mild group rated the same. 33% of mothers in moderate group opted for lowest rating of “very much of a problem” when compared to that 8% in mild group. Overall, mothers in mild group were found to have lesser problems when compared to that of mothers in moderate group. Mothers in both the group expressed feelings of stress and anxiety. They are often worried about the well-being of child especially when they are not

around. Children with ASD face significant challenges in making friends and maintaining kinship which significantly affects the QoL of their parents.

Question No. 3 “Understanding others feelings”: Most of the mothers in mild group (44%) rated having “slight problem” whereas 50% of mothers in moderate group opted for rating “moderate problem”. Whereas, mothers in moderate group opted for lower ratings, 16.7% of them chose “very much of a problem” when compared to that of 4% in mild group. Children with ASD have significant deficits in Theory of Mind (TOM) which exposes them to the disadvantage of not being able to understand other’s feelings and emotions and misunderstanding of feelings. This leads to frequent communication breakdown. ASD Children often are characterised as being “under-sensitive” to emotions. Mothers also reported that their children tend to become victim of bullying at school or playground and they fear about the future of their child.

Question No. 4 “Holding a conversation”: Mothers in moderate group portrayed greater extent of problems with their child’s conversation level deficits than compared to mothers in mild group. Most of the mothers in moderate group opted for lesser rating than mild group, they rated “very much of problem”, “quite a bit of a problem” and “moderate problem”, 33.3% for each of the rating. Whereas mothers in mild group preferred to chose slightly higher rating scale of “slight problem” and “not much of a problem”. Most of the children in our study, were non-verbal in mild group and all the children in moderate were non-verbal. Overall, participants in moderate group expressed more problems with their child’s communication deficits when compared to the mild group.

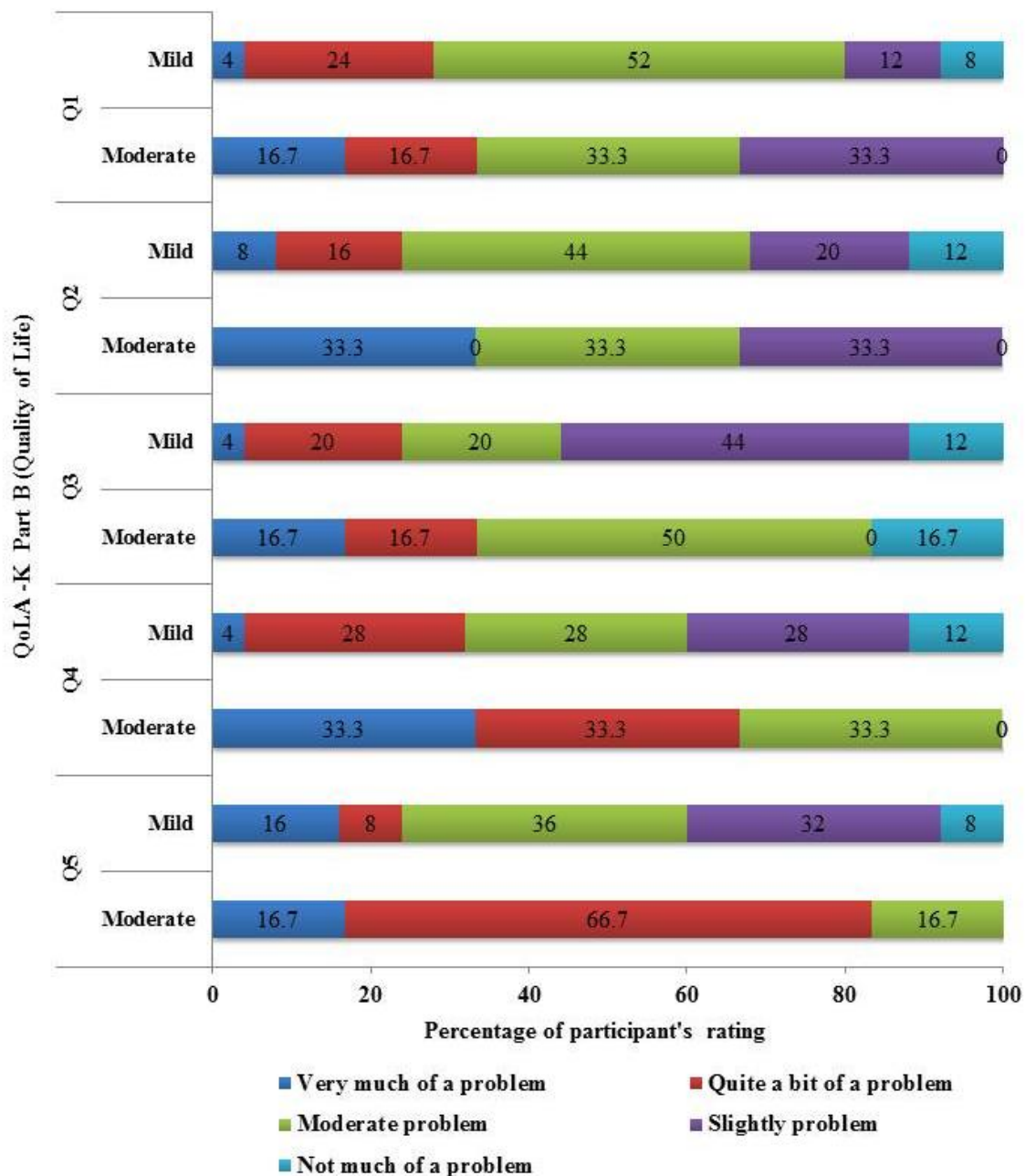
Question No. 5 “Communicating needs”: None of the mothers in moderate group opted for rating “slight problem” and “not much of a problem”. Most of them (66.6%) rated “quite a bit of problem” whereas 8% mothers in mild group opted for the same.

Mothers were quite concerned and often face stress and anxiety. Children portray full time dependency on the caregiver due to such deficits. Inability to express one's needs leads to significant dependency and long term burden on the mothers. With increase in severity, these deficits affect the QoL of parents to a much greater extent.

Figure 4.9–4.12 depict the comparison of the percentage of the participants between the mild and moderate severity of ASD across 5 point Likert rating scale in Part B sub-scale (Impact of ASD symptom sub-scale). Color coding was used to highlight the questions specific response of the participants across the severity of ASD (Question No. 1-20). Part B is reverse scored on a 5 point Likert rating scale where highest score of “5” indicated “not much of a problem” to least scoring of “1” indicating “very much of problem”. The distribution of the percentage of participants opting for questionnaire rating varies for different questions.

Figure 4.9

Comparison Between the Severities Across the Questions of Questionnaire Part B(Q1 to Q5)



Question No. 6 “Taking a literal meaning of comments”: Marked difference was seen across severity of ASD. 66.7% of the mothers in moderate group portrayed more problems choosing rating of “quite a bit of a problem” whereas only 8% mothers in mild group chose the same. 36% of the mothers in mild group chose rating of “moderate

problem” when compared to only 16.7% in moderate group. Figurative language comprehension is a very important domain of successful social interaction and social life is very crucial aspect of person’s well-being. This results in miscommunication and awkward communication situations. Most of the time, parents tend to act as a “communication partner” between the child and their friends. Parents perceive persistence of socio-communication deficits in children as a major problem and it has a detrimental affect on their QoL.

Question No. 7 “Saying things that are socially embarrassing”: 28% and 16.7% of mothers in mild and moderate group respectively, opted for highest rating of “not much of a problem”. Most of them were not satisfied and chose lower rating of “quite a bit of a problem” and “very much of a problem”. Mothers reported that they face specific problems in managing child’s verbal behavior in situations where the child expresses embarrassing things in a social gathering. Mothers said that they tend to avoid the frequency of social meetings due to the same reason. This has a negative impact on their social QoL.

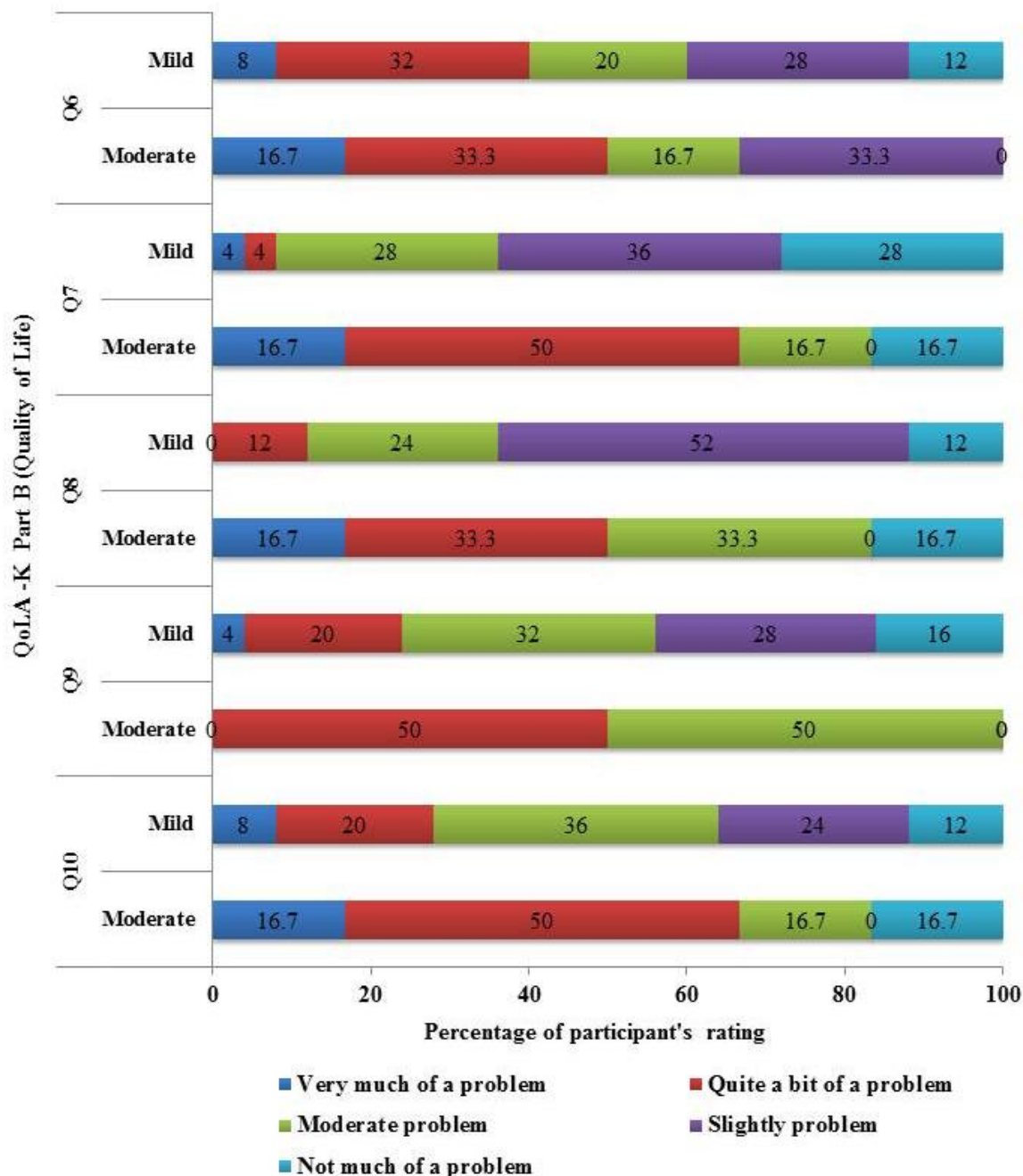
Question No. 8 “Needing to stick to a routine”: 12% and 33.3% of mothers opted for rating “quite a bit of a problem” in mild and moderate group respectively. 52% mothers in mild group opted “slight problem” and 32% of mothers in moderate group opted “moderate problem”. The task of parenting a child with ASD becomes even more challenging when severity of symptoms such as lack of flexibility, inherent need to stick to a routine etc.increases. Mothers reported that they have very less or negligible time remaining for self care since most of them are always indulgent in managing child’s symptom. This dependency on mother has a negative impact on QoL.

Question No. 9 “Being overly interested in a particular topic”: This question explores the stereotypical choices and behavior of children with ASD. Heterogenous responses were observed, 28% and 16% of mothers opted for highest rating of “slight problem” and “not much of a problem” in mild group respectively. Whereas none of the mothers in moderate group opted for the same, they rather chose lower ratings of “quite a bit of a problem” and 50% -“moderate problem”. Children with ASD have specific interests with inanimate or undesirable objects or a particular topic during the conversation. It becomes very difficult for the mother to distract the child from unwanted object or topic and focus their attention on important things. Findings indicate that mothers were very concerned about their child’s lack of flexibility and stereotypical nature of behavior.

Question No. 10 “Getting anxious in a specific situation or during changes”: 50% of mothers in moderate group opted for lesser rating of “quite a bit of problem” when compared to that of 20% in mild group. 8% and 16.7% of mothers opted for rating “very much of a problem” in mild and moderate group respectively. Findings portray differences in problem perception across severity. Children with ASD lack sensory integration which becomes apparent to others in the form of unexplained anxiety or problem behavior in a particular scenario. Children with ASD lack adaptive functioning skills and generally don’t adapt well to the environmental changes. This elevates stress levels among the mother and reduces their QoL.

Figure 4.10

Comparison Between the Severities Across the Questions of Questionnaire Part B(Q6 to Q10)



Question No. 11 “Sensitivity to certain sensations”:Most of the mothers (32%) in mild group and 33% in moderate group opted for rating “moderate problem”. 33% of mothers in moderate group opted for lower rating of “quite a bit of problem” whereas

only 16% mothers in mild moderate group opted for the same. Overall, with increase in severity of ASD, mothers reported that their difficulty in managing child's sensory issues also increases. Children portray "hypo-sensitivity" or "hyper-sensitivity" to certain stimulus on a daily basis. This makes simple chores like brushing, eating and bathing very difficult for the mothers very challenging. Mothers express a lot of concern and portray elevated stress levels. Persistence of such issues has a detrimental effect on their QoL.

Question No. 12 "Understanding the rules of social interaction": Most of the mothers (66.7%) in moderate group expressed concern by rating "quite a bit of a problem". Only 16.7% of mothers in moderate group rated "moderate problem" when compared to 32% in mild group. 28% of mothers in mild group opted for highest rating of "not much of a problem" whereas none of the mothers in moderate group chose the same. Children with ASD have significant impairments at the level of socio-communication. They are often unaware of "unspoken" rules of verbal and non-verbal communication behavior. Attending a social gathering which is usually refreshing and joyful for a person, becomes tedious and awkward for mothers of children with ASD. Even in 2020s, people of community lack acceptance of ASD as a condition and often make fun of child and caregiver. Mothers tend to avoid or reduce the number of social gatherings.

Question No. 13 "Managing emotional responses": Most of the mothers (32%) in mild group chose rating of "moderate problem" and 20% of them opted for highest rating of "not much of a problem". None of the mothers in moderate group chose highest rating, 33% and 50% of them opted for "quite a bit of problem" and "moderate problem" respectively. Emotional regulation skills in children increase with severity, children often display inappropriate emotional reactions like excessive crying, self harm behavior, injuring

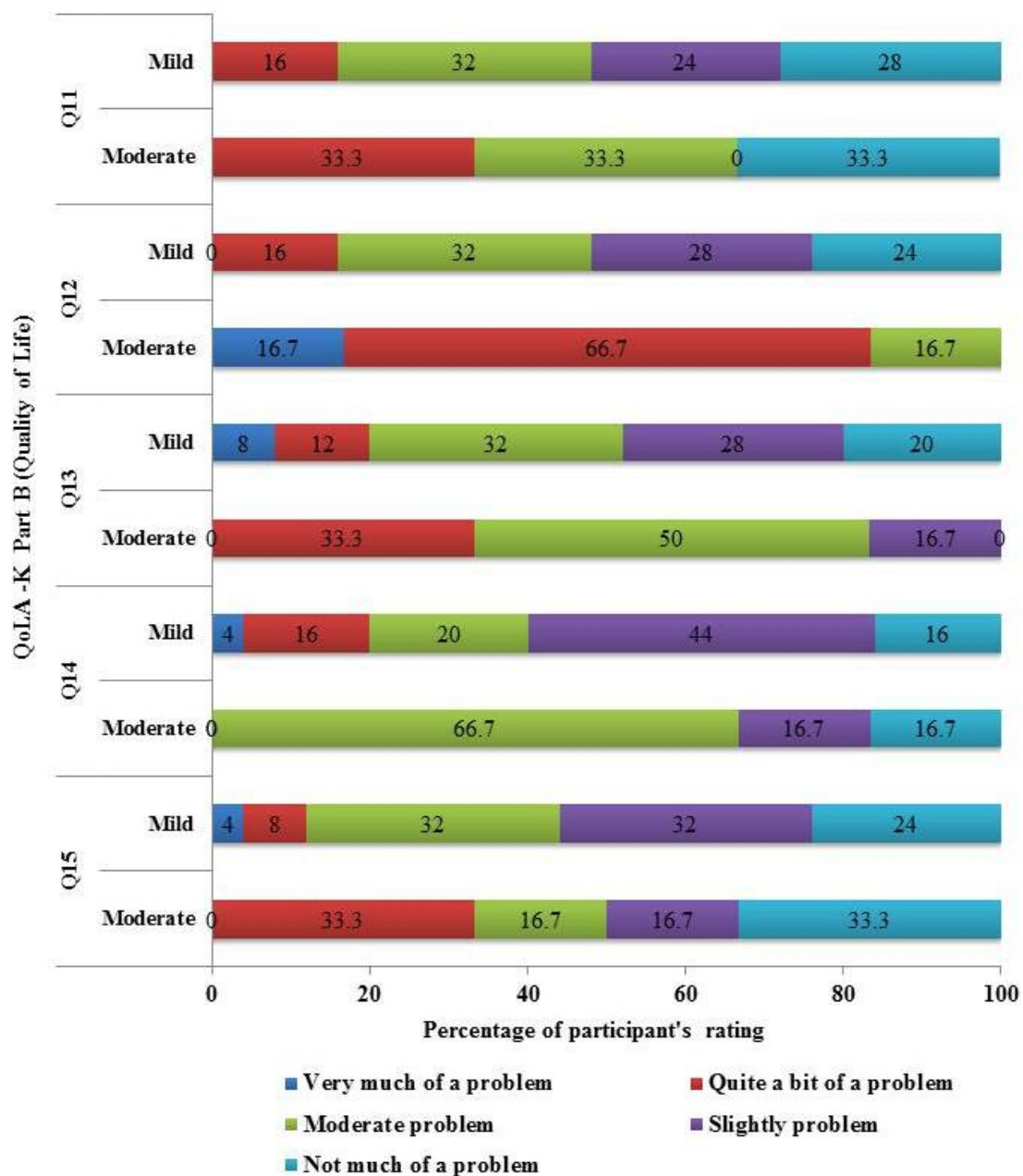
others, excessive laughing etc. Persistence of these deficits increase the stress levels in parent and affects their QoL in a negative manner.

Question No. 14 “Needing to do things a certain way”: 44% of the mothers in the mild group rated higher scoring of “slight problem” and only 16.7% in moderate group opted for the same”. Children with ASD show adherence to regimens and stereotypy. This lack of flexibility leads to occurrence of unwanted and awkward situations. Mothers are very reluctant to leave their child with others even for small duration of time. Mothers tend to sacrifice on personal and professional goals. With increase in severity of symptoms, mothers when bound with sense of excessive burden and stress in daily life tend to feel dissatisfied with psychological aspects of QoL.

Question No. 15 “Destructive behavior including anger and aggression”: Most of mothers (32%) in mild group rated “moderate problem” and “slight problem”. 33.3% mothers in moderate group chose lower ranking of “quite a bit of a problem” when compared to 8% mothers in mild group opted for the same. Children with ASD indulge in aggressive behaviors such as self harm, hitting, head banging, throwing objects etc. This aggression is often considered a part of ritualistic and stereotypical behavior (Reese et al., 2005); Presence of socio-communication deficits also leads to aggression secondary to frustration of not being able to communicate the needs in an efficient manner. This aggression has negative impact on treatment outcome, school attendance and academic profile of the child. This leads to distress among the parent and has negative impact on their QoL.

Figure 4.11

Comparison Between the Severities Across the Questions of Questionnaire Part B(Q11 to Q15)



Question No. 16 “Showing inappropriate emotional reactions”: Differences in problem perception of mothers in mild and moderate group were found. 24% of mothers in milder group opted for highest rating of “not much of problem” whereas only 16.7% opted for the same in moderate group. Overall, mothers in moderate group, portrayed

more problems with child's emotional deregulation. Children with ASD suffer with various sensory issues, social anxiety and meltdowns. They lack TOM and have deficits in controlling the emotional expression. Attending a social gathering where the child and mother often becomes victim of "being judged" by people. This leads to perception of stress and anxiety on the part of parent as well, and has a negative impact on QoL of parent.

Question No. 17 "Unusual repetitive behavior and body movements": Only 20% and 16.7% of mothers in mild group and moderate group chose highest rating of "not much of a problem" respectively. 66.7% of mothers in moderate group chose to rate "moderate problem". It is clear that moderate group expressed more concern when compared to that of mild group. Children with ASD tend to indulge in repetitive and stereotypical verbal behavior such as echolalia and bodily movements such as rocking, swinging, jumping, digital movements, eye movements etc. Persistence of such issues leads to embarrassment and awkwardness among the family members especially in a social setting such as school or at a party. Children suffer bullying at school. Mothers express consistent worry and stress about child's behavior and their safety.

Question No. 18 "Engaging in reckless or tactless behavior": 83.3% of mothers in moderate group expressed rating of "moderate problems" when compared to that of mild group. Mothers in milder group expressed lesser concern and 36% of them opted for a rating of "slight problem" and 20% of them expressed "not much of a problem". The differences in perception of groups was observed as a function of severity. With increase in severity of ASD, frequency and occurrence of tactless behaviors increase which could be self pleasing or self stimulatory in nature. Controlling such problem behavior is important for successful learning of skill behavior. Mothers reported that presence of such behavior

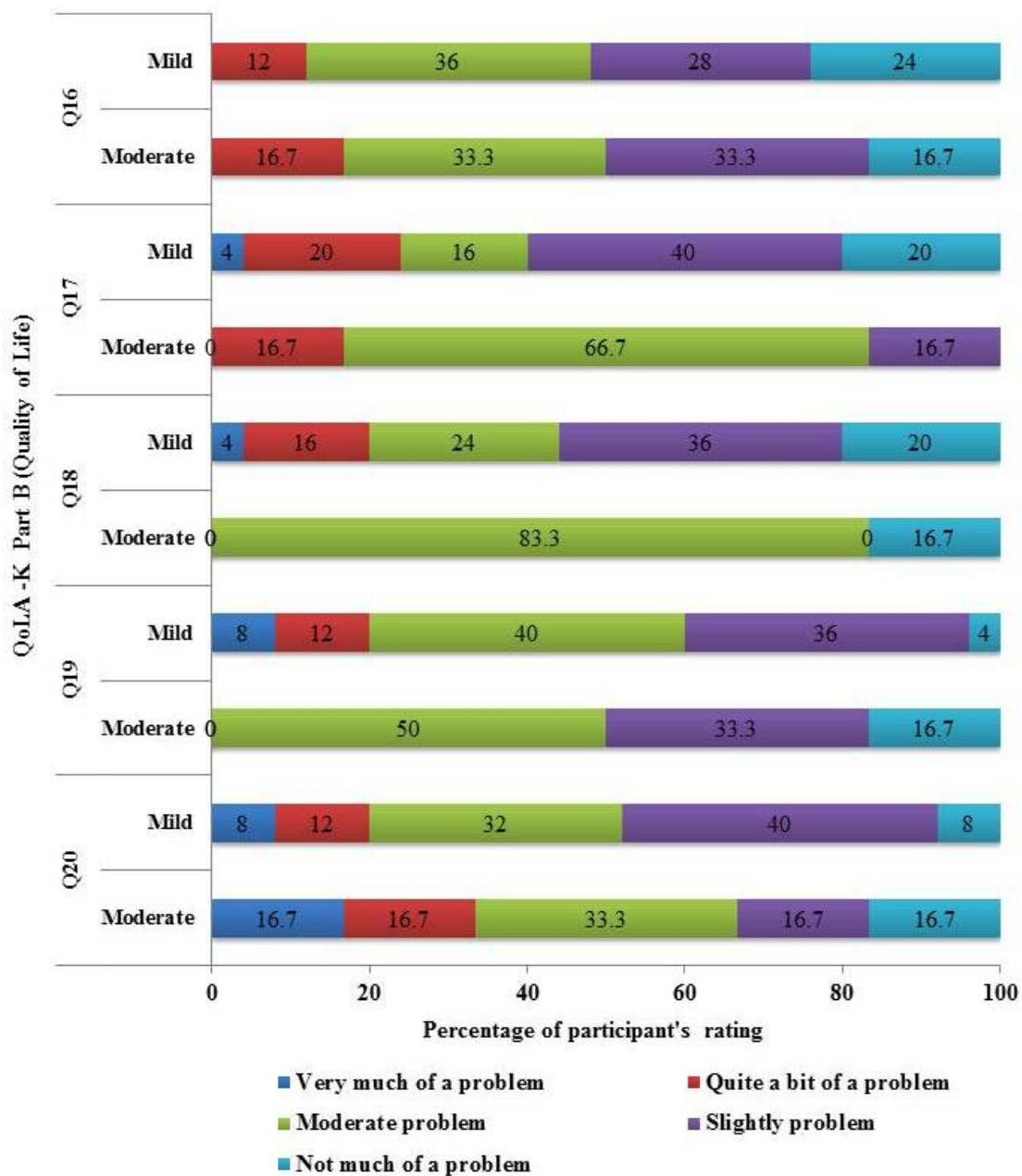
inhibits or shuffles the child attention from the desired behavior. Mothers report frequent bouts of anxiety and elevated stress levels which has a negative impact on psychological well-being.

Question No. 19 “Doing daily tasks independently”:None of the mothers in moderate group opted for rating of “moderate problem” when compared to the mothers in mild group (40%). Majority of them chose lesser ratings of “slight problem”. Both the groups expressed that the constant need of being present with child all the time, leaves them with very less time for self care. This has a negative effect on QoL of the parent.

Question No. 20 “Responding when approached socially”: Mothers in moderate group expressed more concern when compared to the mothers in mild group. 16.7% mothers identified social deficits as being “very much of a problem” when compared to 8% in the mild group. Children with ASD lack socio-emotional reciprocity due to which they appear to be reluctant to engage in a social dialogue. Non-verbal social interaction such as waving hand for indicating greeting, social smile and eye contact are also affected to a varying degree. Mothers feel worried about the development and maintenance of child’s friend circle which is often very much restricted. Mothers often choose to avoid social meetings which has a negative impact of their QoL.

Figure 4.12

Comparison Between the Severities Across the Questions of Questionnaire Part B(Q16 to Q20)



Cronbach α was employed to analyze the test-retest reliability of the questionnaire QoLA-K on 8 participants. Results revealed high reliability for both the sub-scales of QoLA-K; Part A (Cronbach's $\alpha=0.94$) and Part B (Cronbach $\alpha=0.82$).

Chapter 5

DISCUSSION

The findings of the present study are explained under the following headings:

- 5.1 Relationship between the Quality of Life (QoL) of parents and socio-communication skills of children.
- 5.2 Comparison of Quality of Life (QoL) of parents (on Part A sub-scale of QoLA-K) and Impact of ASD symptoms (on Part B sub-scale of QoLA-K) with the severity of ASD.

5.1 Relationship between the Quality of Life (QoL) of parents and socio-communication skills of children

The QoL measure for assessing the self-perceived QoL among the parents included the scores of Part A (QoL sub-scale) and Part B (Impact of ASD symptoms sub-scale) of the QoLA-K. The socio-communication skills of children with ASD were represented by the children's scores on "socio-emotional reciprocity" and "speech and language communication" sub-tests of the Indian Scale for Assessment of Autism (ISAA) developed by National Institute of Mental Health (2009). The findings for both the sub-tests are explained below:

5.1.1 Relationship between the Quality of Life on QoLA-K and Socio-communication skills on ISAA

The findings of the present study indicated that there is a significant relationship between the QoL of parents and socio-communication skills of the children. Hence, the deficits of socio-communication skills of the children and QoL of the parent are inter-related. Socio-communication deficits of children with

ASD negatively impact the Quality of life of their parents. With increment in the socio-communication deficit scores, there is a decrease in self-perceived QoL of parents. These findings are in consensus with the previous research (Allik et al., 2006; Eapen et al., 2014; Eapen & Guan, 2016; Khanna et al., 2011; Özgür et al., 2017).

Children with ASD often are unable to react appropriately in a social setting and face significant difficulties in using verbal and non-verbal language as a tool to communicate their basic needs. Across the timeline, deficits in emotional regulation, maintaining friendships, conversation maintenance and decoding figurative language tend to amplify parental problems and significantly affect the child's ability to function independently as an "individual" (Alenazi et al., 2020; Allik et al., 2006; Escobar et al., 2005; Lee et al., 2007). Hence, it increases their dependency on the parents for daily life functioning. Thus, socio-communication deficits of children affect the QoL of mothers negatively.

The lower scores of the mothers in Part A (QoL sub-test) of QoLA-K scores are suggestive of problems faced by the mothers in managing their physical and mental health, personal and social life. The mothers rated lower QoL in questions such as "I feel satisfied with my social life", "I am satisfied with my achievements", "I am satisfied with my leisure activities", "I feel stressed", "I can get the support that I need from the community", "I feel happy and content", "I am satisfied with my family life" "I have a healthy lifestyle" etc.

There is lack of awareness and empathy among the society about ASD and problems faced by the parent. Mothers recognize the "lack of support from their community" as an important factor affecting their QoL (Davis & Carter, 2008; Jain

et al., 2019; Perumal et al., 2014). Socio-communication deficits in children often persist for life long and have a detrimental effect on QoL of parents in a long run.

5.2.2 Relationship between Impact of ASD symptoms on QoLA-K and Socio-communication skills on ISAA

Parents confront many problems in daily life due to the presence of their child's ASD symptoms. Children with ASD due to significant deficits in social communication and socio-emotional reciprocity are less likely to participate in shared group curriculum and activities; they are often less efficient in stress coping mechanism and become victim of bullying at schools (Lee et al., 2008).

The findings of current study indicated that the socio-communication deficits in children have direct impact on the QoL of the parent. Parents reported increment in the amount of problems faced in day to day life secondary to the severity of the socio-communicative deficits seen in their child. With increase in the socio-communication deficit, there is decrease in self-perceived QoL of parents. These findings are in consensus with studies done by Eapen et al. (2014) and Lee et al. (2009). With increase in severity of ASD symptoms there is significant reduction in QoL of the parent.

Part B of QoLA-K scale included ASD specific questions and was formulated to assess the magnitude of problems faced by the parent in managing these problems. It encompasses deficits related to the sensory, behavioral, speech and language and social-emotional domains and dependency in daily life.

In our study, mothers reported more problems, hence, rated lower self-perceived QoL in questions such as difficulty in “socializing with people”; “having

friends”; “communicating basic needs”; “showing inappropriate emotional reactions”; “needing to stick to a routine” etc. As the severity of symptoms increased, they find it even more difficult to manage.

Mothers being the primary caregivers, sacrifice on self-care and personal achievements in order to provide full time attention to their child’s needs (Eapen & Guan, 2016; Khanna et al., 2011). Lack of pro-social behavior in children increases the stress and anxiety levels in mothers, since it leads to delay in attainment of other essential developmental skills and increases the dependency on the caregiver (Hastings & Johnson, 2001). To sum up, children’s deficits in socio-communication impact the QoL of the mother negatively. These findings highlight the importance of parental well-being.

With the above mentioned findings, the null hypothesis stating that there is no significant relationship between the Quality of Life of parents of children and socio-communication skills of children with ASD is rejected. In the current study, Quality of Life of parent and socio-communication skills of children shared a significant negative relationship. With increase in the socio-communication deficits, it was found that the quality of life as reported by parents of children with ASD was poorer.

5.2 Comparison of Quality of Life (QoL) of parents (on Part A sub-scale of QoLA-K) and Impact of ASD symptoms (on Part B sub-scale of QoLA-K) with the severity of ASD

Children are dependent on their parents for activities of daily living. In Indian scenario, mothers are considered as the conventional primary caregivers. Practicing the

challenging task of parenting, mothers of children with ASD sacrifice a significant amount of personal well-being, which ultimately reduces their QoL. The severity of ASD is primarily assessed on the basis of severity of core ASD features such as deficits in verbal and non-verbal socio-communication skills, poor socio-emotional reciprocity and presence of variety of stereotypical and repetitive behavior, activities and interests. With increase in severity, the amount of support required by individual with ASD and their caregivers also substantially increases. Hence, in our study, in order to understand the factors affecting the QoL of the parent, severity of ASD was studied.

To order to explore the differences in self perceived Quality of life (QoL) of the parent with respect to the severity of ASD of their children, the scores of the QoLA-K were bifurcated under two severities of Autism Spectrum Disorder (ASD) i.e., mild ASD and moderate ASD. The scores of Indian Scale for Assessment of Autism (ISAA) were used to assess the severity of the ASD in children.

The findings of the present study indicated that there was a significant difference between the QoL scores of the both the sub-scales of the QoLA-K, Part A (QoL sub-scale) and Part B (Impact of ASD symptom sub-scale) across the severity of ASD. The participants in the mild group of ASD had better QoL scores than the moderate group. Findings suggest that the severity of ASD plays a significant role in the QoL of the parent. With the increase in severity of ASD, QoL in parents decreases.

Mothers in moderate group reported that since they spend most of their time in managing child's daily schedule and training them, they are left with very less time for personal care. As the severity of behavioral problem increases, they often are "scared of leaving their child alone" even for a small duration time. Mothers experience feeling of prolonged physical fatigue and mental stress. Hastings and Johnson (2001) concluded that

higher severity of ASD symptoms is related with the higher levels of parenting stress. Contrarily, in an Indian study, Perumal et al. (2014) reported no significant differences between QoL of the parents across the severity of ASD, but the differences between the scores of QoL were also noted.

Mothers in moderate group, choose to avoid social meetings and gatherings. This could relate to the fact that with increase in severity of ASD, the dependency factor also increases. Children face significant problems in expressing their basic needs and they lack necessary skills such as socio-emotional regulation and adaptive functioning skills. Children with ASD face problems in adapting to any change in routines and they insist on sameness. Apart from the child's dependency on the mother, the attitude of the society and family members also plays a role (Eapen & Guan, 2016; Khanna et al., 2011).

A qualitative analysis of individual data was also done and the salient features have been reported in the section below.

a) ASD¹ versus ASD⁵: Participant ASD¹ was a 29 year old lady. She was wife to a 32 year old man and mother to a 3 year old male child who received a recent diagnosis of Mild ASD. She had studied diploma course. Both husband and wife were serving as a forest guard in government facility. (QoLA-K- Part A score: 100 and Part B score 93). She had two abortions before the birth of this child. She reported that she was concerned about the child's behavior since past 2 years. She started noticing unusual signs in child's behavior since he was 6 months of age. She reported that she was competing with consistent stress and anxiety; she expressed feelings of dissatisfaction and lack of support from her close relationships (spouse and family members). She was blamed by the family members and the society for lack of parenting skills. The process of

getting a diagnosis of ASD had been time consuming and stressful for her. She was solely responsible for bringing the child for assessment and therapy. She was not provided with a comfortable environment from the employer. She was also being forced by the family members for another child. Her child care leave application was not being processed. Moreover, she reported that she was being threatened for termination from her duties. She felt that she was not being respected by people. Their reaction and lack of acceptance made her feel guilty and less efficient as a mother and she wanted to resign from her job and provide full time care for the child.

Participant ASD⁵ was a 33 year old homemaker. She was married to a 34 year old man, who was working as a health instructor in a private firm. She was mother to a 5.6 year old male child, who received the diagnosis of ASD at the age of 3 years. (QoLA-K- Part A score: 122 and Part B score 69). She reported noticing the signs of ASD in her child, since he was 1.5 years of age. Her husband accompanied her throughout the process of assessment. The couple decided to be single parents, in order to provide undivided attention for their child. She expressed very much satisfaction from her close relationships (Spouse and friends). She has been accompanying the child for therapy since past 18 months. She reported presence of physical fatigue, strain and bodily pain. Her daily schedule included child care and household work. She reported lack of time from self-care. She reported having problems due to child's ASD symptoms like lack of socialization, poor speech and language behavior and presence of behavioral issues.

The differences in QoL of both the participants are clear. Even though, the severity of same, mother's QoL was affected in different aspects. ASD¹ struggled with lack of support from family and surroundings. Her Part A scores were poorer than ASD⁵ and Part B (Impact of child's ASD symptoms) scores were much better than ASD⁵. ASD¹'s QoL was more affected in psychological, social, economic and environmental domain whereas ASD⁵ was mostly affected in economic and physical health domain. ASD¹ reported more stress, anxiety and bouts of depression. ASD¹ struggled with more psychological issues than ASD⁵. Contrarily, ASD⁵ had more problems with child's ASD symptoms than ASD¹, which was reflected in much lower Part B scores. Overall, Part A (QoL sub-scale) was better in ASD⁵ whereas Part B (Impact of ASD related symptoms) was better in ASD¹.

- b) ASD³ versus ASD⁷:* Participant ASD³ was a 27 year old homemaker, parenting a 6.6 year old child with moderate ASD. She was married to a 38 year old man since past 7 years. She studied till Pre University College (12th standard). (QoLA-K- Part A score: 56 and Part B score 53). She had responsibility to take care of two kids, 6.6 year old male child (diagnosed at the age of 4 years) and a neuro-typical new born girl child of 7 months. She reported that she was having consistent feelings of guilt and dissatisfaction and she does not feel good about herself "as a person". She expressed unhappiness and dissatisfaction from her social life as well. She was not satisfied with her life goals and achievements. She was not provided with the much necessary choice of making decisions of her own life by the close relationships (spouse and family members). She wanted to pay attention to child with ASD but she was being forced to conceive a "normal child". She reported feelings of extreme

psychological stress as she was not being able to balance her time between both of her children. Moreover, most of the time she stayed at home doing home chores and was not able to accompany the child for therapy. In fact, child's uncle accompanied him for therapy. Mother was not satisfied with the progress in child's speech and language and social skills. She was not able to provide sufficient home training to the child. She felt guilty about herself as a mother.

Participant ASD⁷ was a 37 year old homemaker, mother to a 6.6 year old male child (diagnosed with Moderate ASD) and a neuro-typical male child of 4.6 year old. (QoLA-K- Part A score: 89 and Part B score 56). She was married to a 37 old businessman. She had studied post-graduation. She reported that she is not satisfied with her professional and social life. Earlier, she was working as a school teacher, but she had to quit her job for child care. She expressed feelings of lack of achievements in her life "as an individual". Her life decisions were mostly bound by child care. She was not able to provide enough time for self-care and growth. She reported that she suffers from physical pain, fatigue and tiredness and psychological stress since she finds it hard to balance her time and energy between two children. She expressed more problem with child's behavioral problems, lack of social skills, speech and language issues. Child was non-verbal and totally dependent on mother for his basic needs. Other neuro-typical child's care also demanded for her time and attention. She also expressed lack of social support.

Above mentioned participant description highlights similarities and differences in QoL of mothers of children with ASD. Though the severity of ASD was same, there were considerable differences. ASD^{3's} life decisions were

extremely defined by the opinions and thought process of significant others. Her QoL was affected in all aspects i.e., physical, psychological, social, environmental and economical domain. Whereas, participant ASD^{7's} QoL was affected majorly in psychological, social and environmental domain. ASD^{3's} Part A (QoL sub-scale) scores were poorer than that of ASD⁷. ASD⁷ reported the lack of social support and awareness as a major factor influencing her QoL. ASD³ also suffered with stress, guilt and anxiety but she remained to be relatively less vocal about her problems.

- c) *ASD¹⁹ versus ASD²³*: ASD¹⁹ was a 30 year old homemaker, who had to leave her job for child care. She studied post-graduation and felt dissatisfaction about her career goals and social life. (QoLA-K- Part A score: 133 and Part B score 77). She was a mother to a 5 year old male child with mild ASD. Her husband was a 33 year old businessman. She chose to restrict her family planning in order to provide full time support for the child. She reported she felt dissatisfied due to the lack of acceptance and awareness in community. She reported that she was happy with the support provided by close relationships (spouse and family) and availability of health services. She reported problems with child's ASD symptoms such as poor socialization skills and stereotypical and repetitive behavior. She felt stressed when others compared her child's lack of socio-emotional reciprocity with so called "normal behavior".

Participant ASD²³ was a 33 year old homemaker, parenting a 4.6 year old child (who was diagnosed as having moderate ASD at the age of 4 years) and a 6 year old neuro-typical female child. (QoLA-K- Part A score: 82 and Part B score 43). She studied till pre-university college. Her spouse was a 40

year old farmer. She reported that she was unaware about early signs and symptoms of ASD. She was unable to notice child's lack of social skills in early childhood therefore, she had feelings of guilt and self-blame. She expressed dissatisfaction with her social life and economic life. She reported that quality treatment facility was not available in her town so, she had to leave the girl child at hometown and shift to a new city (Mysuru) for taking care of child with ASD. She was solely responsible for child care and often had to travel to travel to and fro between cities on weekly basis. She felt extremely tired and fatigued in the process. She reported feelings of confusion, stress, anxiety and depression. Amount of support provided by the spouse was less. She felt consistently worried about the girl child. Moreover, she reported facing a lot of problems due to presence of behavioral issues, stereotypical and repetitive behavior of child. The child had significant deficits in social and speech-language skills; he was completely dependent on mother for basic needs.

The difference between the self-perceptions and QoL of both the participants is appreciable in their QoLA-K scores as well. ASD¹⁹ scored much higher in Part A (QoL) than ASD²³. ASD¹⁹ expressed reduced QoL in social and psychological domain whereas ASD²³ had reduced QoL in all the domains namely, psychological, social, economic, physical health and environmental domain. ASD²³ reported the severity of child's symptoms and lack of quality treatment facilities and financial assistance as major factor affecting her QoL negatively. ASD²³ had much poorer scores in Part B (Impact of ASD symptoms) than ASD¹⁹.

Above mentioned findings indicate that the mothers with children having milder severity of ASD displayed a better self-perceived QoL and lesser impact of ASD symptoms of the child. Mothers of children having moderate ASD displayed greater negative impact of ASD symptoms of child in daily life and lesser self-perceived Quality of Life. Moreover, QoL is reported to be poorer in mothers when compared to the fathers (Alenazi et al., 2020; Özgür et al., 2018; Mugno et al., 2007). Present research findings are in consensus with literature. As the severity increases, it becomes extremely challenging for the parents to have a balance between child care and personal well-being (Allik et al., 2006; Mugno et al., 2007).

Mothers reported lack of acceptance by the close relationships (family and friends) and their own community. With increase in child's behavioral symptoms, it becomes hard to mask them in a social setting. In a country like India, social acceptance and conformity very much defines an individual's QoL. Specially, when the societal awareness and acceptance is less, Parents become victim of public shaming and stigmatization by the community. This often leads to conflict between personal and family life, occupational roles and social life (Eapen & Guan, 2016; Perumal et al., 2014).

Mothers tend to resign from their jobs and indulge in full time care of the child. Being responsible for care and maintenance of the child, they often experience feelings of stress and anxiety. They dedicate most of their time in child care and ignore or fail to accommodate time for self-care (Khulthau et al., 2011).

Children with ASD have long term complaints of incontinence (day time urine incontinence and fecal incontinence), therefore, toilet training and "communication training" becomes a struggle for the parent (Hanney et al., 2013; Niemczyk et al., 2017).

Caring a child with ASD also affects family planning. In our study, most of the parents chose to have a single child, in order to provide full attention and time to the child. Mothers who had more than one child had inconvenience and poor physical and psychological health. Mothers reported difficulties in balancing between two children and self-care, when one of them is diagnosed as having ASD. They often report feeling that they are neglecting other child while caring for child with ASD.

Medical, non-medical and miscellaneous expenses required for child caring affect the economic health of the family (Eapen et al., 2014; 2016; Lee et al., 2009; Jain et al., 2019). The frequency of appointments and visits to the hospitals, cost of medical treatment, behavioral training, pre-school training, speech-language therapy, sensory training adds on to the financial burden. Presence of co-morbid condition such as ADHD, Congenital heart disease, Hearing loss, Intellectual disability, Cerebral palsy etc. adds on to the existing economic expenses. Hence, availability of affordable quality medical facilities is very important.

Mothers also reported that the process of assessment and obtaining the appropriate diagnosis for their child was very confusing, time consuming and effortful. The lack of consensus among various diagnostic facilities they visited, added to the confusion and uncertainty (Eapen et al., 2016; Mugno et al., 2007; Perumal et al., 2014). Parents reported the lack of early referral by medical professional to the speech-language pathologist, occupational therapist and psychologist. Sulaimani and Gut (2019) reported misdiagnosis, lack of availability of reliable information being a cause of delay in early intervention, which leads to stress and pessimism about child's development among parents.

In our developing nation India, many attempts have been made to provide quality services to the persons with disabilities, still parents are often counseled by the medical

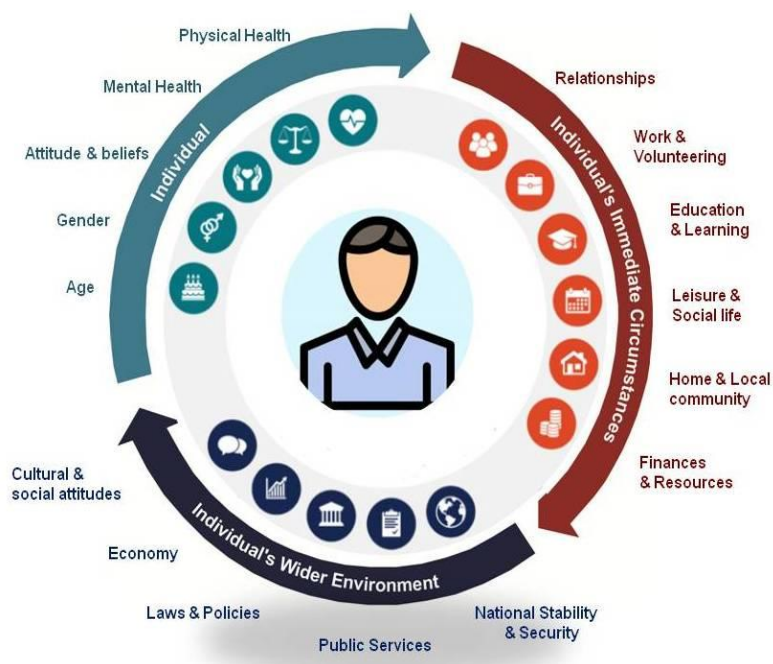
professional to “wait and watch” and prescribed medications as a “cure of autism”. Early intervention is the foremost crucial step in ASD management and has a positive effect on parental QoL of life (Allik et al., 2006, Jain et al., 2019). Health care worker require training and assessment to enhance their level of knowledge.

Most of the mothers chose to resign from their respective jobs. Mothers, who were working, reported that they face lot of problems balancing personal and professional life. Employers lack of awareness about ASD and portray lack of support. They were not provided enough child care leave and targeted in their workplace for applying for child care leave. Mothers also reported fear of reduction in salaries and losing their job. On the other hand, working mothers expressed occasional feeling of guilt because of not being able to provide enough time for child care. Lack of support from the family and society adds on to the burden. They face high levels of stress and anxiety (Khanna et al., 2011; Lee et al., 2008).

The World Health Organization (WHO) defines Quality of Life (QoL) as ‘[an] individual’s perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns’ (Harper, 1998). Figure 4.15 depicts various aspects of individual’s QOL.

Figure 5.1

Factors affecting QoL of an individual.



WHO summarizes QoL into four domains: physical (including pain, energy), psychological (including positive and negative feelings, concentration), social (personal relationships, friendships, and sex life), and environment (including monetary resources, safety, partaking in leisure activities) (Harper, 1998). This concept of QoL is essentially multifaceted in nature; It includes variables related to individual's Personal life, the circumstances and the surrounding environment. QoL is a broad subjective appraisal of how an individual relates to the world in the context they currently experience.

In our study, among all the domains of QoL, namely Physical, Psychological, Social, Economic and Environmental domains, mothers had maximum problems in psychological, social and economic domain. Performance was relatively better in physical and environmental health.

These results highlight the importance of maternal well-being as an "Individual". Also, there is a need of efficient and affordable parent counseling, self-help group and

training programs in Indian context. We as a society are approaching the ending of decade in 2020, in spite of breakthrough research developments in the field of ASD; have overlooked the concept of parental well-being. The Persons with Disability Act (PWD) was revised in December, 2016 where ASD was included among the 21 disabilities (RPWD, 2016). However, no provisions or schemes for parental/caregiver assistance have been framed. These findings highlight the immediate need of awareness programs and suitable government policies to enhance the QoL among the parents of children with ASD considering various domains of individual QoL.

On the basis of above mentioned findings, the null hypothesis stating that there is no significant difference between the scores of Part A (QoL sub-scale) and Part B (Impact of ASD symptoms sub-scale) of adapted QoLA- K scale across the severity of ASD, is rejected. We found a significant difference in QoL scores of parents across the severity of ASD. With increase in the severity of ASD, it was found that the quality of life as reported by parents of children with ASD was poorer.

Chapter 6

SUMMARY AND CONCLUSION

The present study aimed to explore the Quality of Life (QoL) among parents of children with Autism Spectrum Disorder (ASD) in Indian context. The objective of the study was to adapt Quality of Life in Autism questionnaire for parents and caregivers of children with ASD (QoLA) originally developed by Eapen et al. (2014) to Indian population in Kannada language. The other objectives of the study were to investigate the parental Quality of Life (QoL) in relation to the socio-communication skills of children with ASD and to compare the QoL of parents (on Part A sub-scale of QoLA-K) and impact of ASD symptoms (on Part B sub-scale of QoLA-K) with the severity of ASD.

A total of thirty (30) mothers of children with ASD were considered as the participants for the current study. The adapted Quality of Life questionnaire for parents of children with ASD (QoLA-K) was administered on the participants. Participants self-rated the two sub-scales of QoLA-K, Part A (QoL sub-scale) and Part B (Impact of ASD symptoms sub-scale) using a 5 point Likert rating scale. The total scores of both sub-scales were calculated separately. Higher scores indicated better self-perceived QoL.

The findings of the current study revealed the significant relationship between the parental Quality of Life (QoL) and socio-communication skills of children with ASD. It has been found that children with ASD often are unable to react appropriately in a social setting and face significant difficulties in using verbal and non-verbal language as a tool to communicate their basic needs. Children with ASD due to significant deficits in social communication and socio-emotional reciprocity are less likely to participate in shared group curriculum and activities; they are often less efficient in stress coping mechanism and become victim of bullying at schools. This lack of pro-social behavior in children

increases the stress and anxiety levels in mothers, since it leads to delay in attainment of other essential developmental skills (Hastings & Johnson, 2001). Mothers reported feelings of consistent worry and pessimism about their child's future. Across the timeline, deficits in emotional regulation, maintaining friendships, conversation maintenance and decoding figurative language tend to amplify parental problems and significantly affect the child's ability to function independently as an "individual". Hence, it increases their dependency on the parents for daily life functioning. Thus, socio-communication deficits of children affect the QoL of mothers negatively. Hence, with increase in the socio-communication deficits of the children, the self-perceived QoL among the parents becomes poorer.

The findings also revealed the effect of severity of ASD on the QoL of the parents. Among the two severities of ASD considered (mild and moderate), mothers of children with mild severity portrayed significantly better QoL scores than the mothers of children with moderate ASD. With increase in the severity of ASD, mothers reported increment in caregiver burden. With increase in child's behavioral issues, mothers reported feelings of self-blame and insufficiency as a primary caregiver. Lack of acceptance and empathy by close relationships and community aggravates the stress levels in mothers. Mothers tend to sacrifice on personal and professional goals and reported lack of time for self-care. While caring for the child with ASD, they find it hard to manage their physical and mental health. This also has a detrimental effect on their personal, social and economic QoL. Hence, with increase in the severity of ASD, parent's self-perceived QoL became poorer.

To sum up, in Indian scenario, mothers being the primary caregivers of the child ASD, tend to sacrifice on personal well-being, occupational and societal roles. This affects their QoL negatively and lack of much required support from close relationships and community exaggerates the problem. The current study adapted an ASD specific

questionnaire in Kannada language and reflected on essential aspects of maternal well-being and effect of socio-communication deficits and severity of ASD on QoL of the mothers from Speech-Language Pathologist's perspective.

Implications of the current study

- The results of the study highlighted the importance of maternal well-being as an “Individual”. Parental QoL measures should be part of evidence based practice in ASD management. There is a need of efficient and affordable parent counseling, self-help groups and training programs to enhance self-efficacy among the parents. This tool could also help in building better clinician-caregiver relationships.
- The current research utilized a condition specific tool rather than generic health measure to study the QoL. Future directions could involve development and utilization of condition-specific and language specific tools in other Indian language in order to bring uniformity in treatment efficacy measures.
- Results provide insights into the role of family, social and workplace support in enhancing the parental QoL. It is the need of the hour to organize effective awareness programs in order to eradicate the prevailing myths and misconceptions about ASD and promote acceptance and support for the parents. Also, family therapy could be provided in order to facilitate better understanding of the issues and encourage shared responsibility among the family members.
- Future directions could involve nation-wide large scale cohort studies and longitudinal studies in order to explore the determinants of parental QoL so that suitable governmental schemes can be framed.

- The results of the study provide insights to the differences in QoL of parents across the severity of ASD. Professionals working in the area of ASD, should frame the treatment goals and counseling in such a way that it improves parental QoL with respect to the with respect to the severity of ASD and individual characteristics of the parent.
- It is noteworthy that the current study is one of its kind, the first attempt utilizing an Autism-specific questionnaire to study the QoL among Indian parents of children with ASD. Till date, only few research studies have explored this topic. Moreover, these studies have utilized generic QoL questionnaires, which fail to study Autism-Specific QoL among parents in depth. Hence, it is suggested to withdraw cautious conclusions while comparing the findings of generic and condition- specific questionnaire based studies.

Limitations and Future directions of the current study

The present study employed a cross-sectional design and a limited number of participants. Therefore, further research is required to generalize the findings to the population. The sample size across the groups (mild ASD and moderate ASD) was not equal. The study included only the mothers of children to maintain the homogeneity of gender among the participant.

Future directions could involve inclusion of independent variables such as gender of the parent, educational and socio-economic status of the family, urban and rural background, cultural background, gender and age of the child, type and duration of treatment for in-depth exploration of determinants affecting the QoL among the parents.

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QUALITY OF LIFE IN AUTISM QUESTIONNAIRE IN KANNADA (QoLA- K)

This survey assesses quality life in people who have Autism Spectrum Disorder (ASD)

Name of child:

Name of parent:

Age/Gender of child:

Age/Gender of parent:

Provisional Diagnosis:

Case No:

PART A

ನೀವು ಕೆಳಗಿನ ಪ್ರಶ್ನೆಗಳಿಗೆ ಉತ್ತರಿಸುವಾಗ, ಕಳೆದ ನಾಲ್ಕು ವಾರಗಳಿಂದ ನಿಮ್ಮಲ್ಲಿ ಮೂಡಿರುವ ಅನಿಸಿಕೆಗಳನ್ನು / ಭಾವನೆಗಳನ್ನು ಸೂಕ್ತವಾಗಿ ಬಿಂಬಿಸಿರುವ ಬಾಕ್ಸ್‌ನಲ್ಲಿ ದಯವಿಟ್ಟು (✓) ಟಿಕ್ ಮಾಡಿ.

ಉದಾಹರಣೆಗೆ ನೀವು ಮೊದಲಿನ ಪ್ರಶ್ನೆಗೆ 'ಸುಮಾರು' ಎನ್ನುವುದನ್ನು ಆಯ್ಕೆ ಮಾಡಿದಲ್ಲಿ 'ಈ ನಾಲ್ಕು ವಾರಗಳಲ್ಲಿ ನನ್ನ ಜೀವನವು ಸುಮಾರಾಗಿ ತೃಪ್ತಿಕರವಾಗಿದೆ ಎಂದು ಅರ್ಥೈಸುತ್ತದೆ'.

		ಖಂಡಿತ	ಸ್ವಲ್ಪ	ಸುಮಾರು	ಸ್ವಲ್ಪ	ಬಹಳ	ಅನ್ವಯಿ- ಸುವುದಿಲ್ಲ	ಅನಿಸಿಕೆ
		ಇಲ್ಲ	ಮಟ್ಟಿಗೆ		ಚಾಸ್ತಿ			
		0 %	<25%	25-50 %	50-75%	>75%		
1	ನಾನು ನನ್ನ ಜೀವನದಲ್ಲಿ ಸಂತೃಪ್ತನಾಗಿದ್ದೇನೆ							
2	ನಾನು ಖುಷಿಯಾಗಿದ್ದೇನೆ ಹಾಗೂ ತೃಪ್ತಿಕರನಾಗಿದ್ದೇನೆ							
3	ವೈಯಕ್ತಿಕವಾಗಿ ನನಗೆ ನನ್ನ ಬಗ್ಗೆ ಖುಷಿಯಿದೆ							
4	ನನ್ನ ಹತ್ತಿರದ ಸಂಬಂಧದಿಂದ ತೃಪ್ತಿಯಾಗಿದ್ದೇನೆ							
5	ನನಗೆ ಅವಶ್ಯಕತೆಯಿದ್ದಾಗ ಜನರು ನನ್ನ ಜೊತೆಗಿದ್ದಾರೆ							
6	ನನ್ನ ಸಾಮಾಜಿಕ ಜೀವನದಲ್ಲಿ ನಾನು ಸಂತೃಪ್ತಿಯಾಗಿದ್ದೇನೆ							
7	ನನ್ನ ಕೌಟುಂಬಿಕ ಜೀವನದಲ್ಲಿ ನಾನು ಸಂತುಷ್ಟನಾಗಿದ್ದೇನೆ							
8	ನನ್ನ ಆರ್ಥಿಕ ಪರಿಸ್ಥಿತಿಯ ಬಗ್ಗೆ ನನಗೆ ಸಂತೃಪ್ತಿ ಇದೆ							
9	ನಾನು ವಾಸವಿರುವ ಸ್ಥಳದಲ್ಲಿ ನಾನು ಸಂತುಷ್ಟನಾಗಿದ್ದೇನೆ							
10	ನನ್ನ ಅವಶ್ಯಕತೆಗಳನ್ನು ಪೂರೈಸಲು ನನ್ನ ಬಳಿ ಸಾಕಷ್ಟು ಹಣವಿದೆ							

		ಖಂಡಿತ ಇಲ್ಲ	ಸ್ವಲ್ಪ ಮಟ್ಟಿಗೆ	ಸುಮಾರು	ಸ್ವಲ್ಪ ಜಾಸ್ತಿ	ಬಹಳ	ಅನ್ವಯಿ-ಸುವುದಿಲ್ಲ	ಅನಿಸಿಕೆ
		0 %	<25%	25-50 %	50-75%	>75%		
11	ನನ್ನ ಸಾಧನೆಗಳ ಬಗ್ಗೆ ನನಗೆ ತೃಪ್ತಿಯಿದೆ							
12	ನನ್ನ ಆರೋಗ್ಯದ ಬಗ್ಗೆ ನನಗೆ ಸಂತೃಪ್ತಿಯಿದೆ							
13	ನನ್ನ ಜೀವನಶೈಲಿ ಆರೋಗ್ಯಕರವಾಗಿದೆ							
14	ನನ್ನ ಪುರುಸತ್ತಿನ ಚಟುವಟಿಕೆಗಳ ಬಗ್ಗೆ ನನಗೆ ತೃಪ್ತಿ ಇದೆ							
15	ನನಗೆ ನನ್ನ ಜೀವನದಲ್ಲಿ ಹಿಡಿತವಿದೆ							
16	ನಾನು ಜೀವನದಲ್ಲಿ ಗುರಿ ಹೊಂದಿರುತ್ತೇನೆ ಮತ್ತು ಗುರಿ ತಲುಪುತ್ತೇನೆ							
17	ನಾನು ಕ್ರಿಯಾಯೋಜನೆಗಳನ್ನು ರೂಪಿಸಿಕೊಂಡು ಅದನ್ನು ಪಾಲಿಸುತ್ತೇನೆ							
18	ನಾನು ನನ್ನ ನಿರ್ಧಾರಗಳನ್ನು ಸ್ವತಃ ತೆಗೆದುಕೊಳ್ಳುತ್ತೇನೆ							
19	ನಾನು ಒಂದು ಸಮುದಾಯದ ಭಾಗವಾಗಿದ್ದೇನೆ							
20	ನನಗೆ ಬೇಕಿರುವ ಬೆಂಬಲವನ್ನು, ನನ್ನ ಸಮುದಾಯದಿಂದ ಪಡೆಯಬಹುದು							
21	ನಾನು ತಲುಪಬೇಕಿರುವ ಸ್ಥಳಕ್ಕೆ ತಲುಪಲು ನನಗೆ ಸಾಧ್ಯವಾಗುತ್ತದೆ							
22	ನಾನು ನನ್ನ ದಿನನಿತ್ಯದ ಜೀವನದಲ್ಲಿ ಸುರಕ್ಷಿತವಾಗಿರುವಂತೆ ಭಾಸವಾಗುತ್ತದೆ							
23	ನನ್ನ ದಿನನಿತ್ಯದ ಜೀವನದಲ್ಲಿ ನನ್ನನು ಗೌರವಿಸಲ್ಪಡುವಂತೆ ಭಾಸವಾಗುತ್ತದೆ							
24	ಲಭ್ಯವಿರುವ ಆರೋಗ್ಯ ಸೇವೆಗಳ ಬಗ್ಗೆ ನನಗೆ ತೃಪ್ತಿಯಿದೆ							
		ಬಹಳ	ಸ್ವಲ್ಪ ಜಾಸ್ತಿ	ಸುಮಾರು	ಸ್ವಲ್ಪ ಮಟ್ಟಿಗೆ	ಖಂಡಿತ ಇಲ್ಲ	ಅನ್ವಯಿ-ಸುವುದಿಲ್ಲ	ಅನಿಸಿಕೆ
		>75%	50-75%	25-50 %	<25%	0 %		
25	ನಾನು ಒತ್ತಡದಲ್ಲಿ ಇದ್ದೇನೆ							
26	ನಾನು ಖಿನ್ನತೆ ಅಥವಾ ಆತಂಕಗೊಳಗಾಗಿದ್ದೇನೆ							
27	ಅನಾರೋಗ್ಯವು ನನ್ನ ಚಟುವಟಿಕೆಗಳಲ್ಲಿ ಅಡೆತಡೆಗಳನ್ನುಂಟು ಮಾಡುತ್ತದೆ							
28	ನನಗೆ ಅಪರಾಧಿಪ್ರಜ್ಞೆ ಕಾಡುತ್ತದೆ							

PART B

ಆಟಿಸಂ ಹೊಂದಿರುವ ಮಕ್ಕಳು ಹಲವಾರು ಬಗೆಗಳ ಸಮಸ್ಯೆಗಳನ್ನು ಅನುಭವಿಸುತ್ತಾರೆ. ಈ ನಾಲ್ಕು ತಿಂಗಳಲ್ಲಿ, ಇಲ್ಲಿ ಹೇಳಿರುವ ಸಮಸ್ಯೆಗಳಿಂದ, ನಿಮಗೆ ಎಷ್ಟು ತೊಂದರೆಯಾಗುತ್ತಿದೆ.

ಉದಾಹರಣೆ: ಮೊದಲನೇ ಪ್ರಶ್ನೆಗೆ ನೀವು 'ಸ್ವಲ್ಪ ಮಟ್ಟಿಗೆ ತೊಂದರೆ' ಎಂಬುದನ್ನು ಟಿಕ್ ಮಾಡಿದಲ್ಲಿ, ಅದು 'ನನ್ನ ಮಗು ಜನರೊಡನೆ ಬೆರೆಯುವಲ್ಲಿ ಹೊಂದಿರುವ ಸಮಸ್ಯೆಯು ನನಗೆ ಕಳೆದ ನಾಲ್ಕು ವಾರಗಳಿಂದ ಸ್ವಲ್ಪ ಮಟ್ಟಿನಲ್ಲಿ ತೊಂದರೆಯುಂಟುಮಾಡಿದೆ' ಎಂದು ಅರ್ಥೈಸುತ್ತದೆ.

ಆಟಿಸಂ ಹೊಂದಿರುವ ಮಕ್ಕಳು ಅನುಭವಿಸುವ ಸಮಸ್ಯೆಗಳು		ಈ ನಾಲ್ಕು ತಿಂಗಳಲ್ಲಿ, ಇಲ್ಲಿ ಹೇಳಿರುವ ಸಮಸ್ಯೆಗಳಿಂದ, ನಾನು ಎಷ್ಟು ತೊಂದರೆಗೊಳಗಾಗಿದ್ದೇನೆ?					ಅನ್ವಯಿ-ಸುವುದಿಲ್ಲ	ಅನಿಸಿಕೆ
		ಹೆಚ್ಚಾಗಿ ಇಲ್ಲ	ಸ್ವಲ್ಪ ಮಟ್ಟಿಗೆ	ಸುಮಾರು	ಸ್ವಲ್ಪ ಜಾಸ್ತಿ	ಬಹಳ		
		0 %	<25%	25-50 %	50-75%	>75%		
1	ಜನರ ಜೊತೆ ಬೆರೆಯುವುದು							
2	ಸ್ನೇಹಿತರನ್ನು ಹೊಂದಿರುವುದು							
3	ಬೆರೆಯುವ ಭಾವನೆಗಳನ್ನು ಅರ್ಥಮಾಡಿಕೊಳ್ಳುವುದು							
4	ಸಂಭಾಷಣೆಯನ್ನು ಹೊಂದುವುದು							
5	ಆಗತ್ಯಗಳನ್ನು ಸಂವಹನ ಮಾಡುವುದು							
6	ಸಲಹೆಗಳನ್ನು ಅಕ್ಷರಶಃವಾಗಿ ಅರ್ಥೈಸಿಕೊಳ್ಳುವುದು							
7	ಸಮಾಜದಲ್ಲಿ ಸೂಕ್ತವಲ್ಲದ, ಮುಜುಗರ ಉಂಟಾಗುವಂತೆ ಮಾತನಾಡುವುದು							
8	ನಿತ್ಯಕ್ರಮವನ್ನು ತಪ್ಪದೆ ಪಾಲಿಸುವ ಆಗತ್ಯವಿರುವುದು							
9	ನಿರ್ದಿಷ್ಟ ಕೆಲಸದ ಮೇಲೆ ಅತಿಯಾದ ಆಸಕ್ತಿ							
10	ನಿರ್ದಿಷ್ಟ ಸಂದರ್ಭದಲ್ಲಿ ಅಥವಾ ಬದಲಾವಣೆಗಳು ಆದಲ್ಲಿ ಉದ್ದೇಶಗಳಿಗಾಗುವುದು							
11	ನಿರ್ದಿಷ್ಟ ಸಂದರ್ಭದಲ್ಲಿ ಬಹಳ ಸೂಕ್ಷ್ಮವಾಗಿ ಪ್ರತಿಕ್ರಿಯಿಸುವುದು							
12	ಸಾಮಾಜಿಕ ಸಂವಹನೆಯ ಕಟ್ಟುಪಾಡುಗಳನ್ನು ಅರ್ಥಮಾಡಿಕೊಳ್ಳುವುದು							
13	ಭಾವನಾತ್ಮಕ ಪ್ರತಿಕ್ರಿಯೆಯನ್ನು ನಿರ್ವಹಿಸುವುದು							

ಆಟಿಸಂ ಹೊಂದಿರುವ ಮಕ್ಕಳು ಅನುಭವಿಸುವ ಸಮಸ್ಯೆಗಳು		ಈ ನಾಲ್ಕು ತಿಂಗಳಲ್ಲಿ, ಇಲ್ಲಿ ಹೇಳಿರುವ ಸಮಸ್ಯೆಗಳಿಂದ, ನಾನು ಎಷ್ಟು ತೊಂದರೆಗೊಳಗಾಗಿದ್ದೇನೆ?					ಅನವಯಿ-ಸುವುದಿಲ್ಲ	ಅನಿಸಿಕೆ
		ಹೆಚ್ಚಾಗಿ ಇಲ್ಲ	ಸ್ವಲ್ಪ ಮಟ್ಟಿಗೆ	ಸುಮಾರು	ಸ್ವಲ್ಪ ಜಾಸ್ತಿ	ಬಹಳ		
		0 %	<25%	25-50 %	50-75%	>75%		
14	ಕೆಲಸಗಳನ್ನು ನಿರ್ದಿಷ್ಟ ರೀತಿಯಲ್ಲೇ ಮಾಡುವ ಅಗತ್ಯ							
15	ಕೋಪ ಮತ್ತು ಅಕ್ರಮಣಕಾರಿ ವರ್ತನೆ/ ಉದ್ದೇಗದಂತಹ ವಿನಾಶಕಾರಿ ವರ್ತನೆಗಳು							
16	ಅನುಚಿತವಾದ ಭಾವನಾತ್ಮಕ ಪ್ರತಿಕ್ರಿಯೆಗಳನ್ನು ತೋರುವುದು							
17	ಅಸಹಜವಾದ, ಪುನರಾವರ್ತಿತ ವರ್ತನೆ ಹಾಗೂ ದೈಹಿಕ ಚಲನೆಗಳು							
18	ಎಚ್ಚರಿಕೆ ಇಲ್ಲದೆ ಹಾಗೂ ಚಾಕಚಕ್ಯತೆಯಿಂದ ವರ್ತನೆಗಳಲ್ಲಿ ತೊಡಗಿಕೊಳ್ಳುವುದು							
19	ದೈನಂದಿನ ಚಟುವಟಿಕೆಗಳನ್ನು ಸ್ವತಂತ್ರವಾಗಿ ಮಾಡುವುದು							
20	ಸಾಮಾಜಿಕವಾಗಿ ಸಂಪರ್ಕಿಸಿದಾಗ ಪ್ರತಿಕ್ರಿಯಿಸುವುದು							

ಒಟ್ಟಾರೆಯಾಗಿ, ನಿಮ್ಮ ಜೀವನದ ಗುಣಮಟ್ಟವನ್ನು ನೀವು ಹೇಗೆ ರೇಟ್ ಮಾಡುತ್ತೀರಿ? (ಕೊಟ್ಟಿರುವ ಗೆರೆಯ ಕೆಳಗೆ ಕ್ರಾಸ್ ಮಾರ್ಕ್ ಹಾಕಿ)

ತ್ಯಷ್ಟಿ ಇಲ್ಲ

ಹೆಚ್ಚಾಗಿ ಸಂತ್ಯಷ್ಟಿ

0 1 2 3 4 5 6 7 8 9 10

ನಿಮ್ಮ ಜೀವನದ ಗುಣಮಟ್ಟದ ಮೇಲೆ ಪ್ರಮುಖ ಪ್ರಭಾವ ಬೀರುತ್ತದೆ ಎಂದು ನೀವು ನಂಬುವ ಬೇರೆ ಯಾವುದಾದರೂ ವಿಷಯಗಳಿವೆ ದಯವಿಟ್ಟು ವಿವರಿಸಿ:

****ಈ ಸಮೀಕ್ಷೆಯನ್ನು ಪೂರ್ಣಗೊಳಿಸಿದ್ದಕ್ಕಾಗಿ ಧನ್ಯವಾದಗಳು****