

**QUALITY OF LIFE, PSYCHOLOGICAL DISTRESS AND
COPING STRATEGIES OF PARENTS OF CHILDREN WITH
NEURODEVELOPMENTAL DISORDER**

**A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE
REQUIREMENTS FOR THE DEGREE OF DOCTOR OF
PHILOSOPHY**

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STRATEGIES OF PARENTS OF CHILDREN WITH
NEURODEVELOPMENTAL DISORDER**

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**Submitted
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Philosophy in Clinical Psychology of Mizoram University, Aizawl.**



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CERTIFICATE

This is to certify that the present research work titled, **“Quality of Life, Psychological Distress and Coping Strategies of Parents of Children with Neurodevelopmental Disorder”** is an original research work carried out by Mr Lalawmpuia under my supervision. The work done is being submitted for the Award of the degree of Doctor of Philosophy in Clinical Psychology from Mizoram University.

This is to further certify that the research conducted by Mr. Lalawmpuia has not been submitted in support of an application to this or any other University or an Institute of Learning.

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DECLARATION
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I **LALAWMPUIA**, hereby declare that the subject matter of this thesis is a record of work done by me to the best of my knowledge, the contents of this thesis have not formed the basis for the award of any previous degree to me or to anyone else, and the thesis has not been submitted by me for any research degree at any other University or Institute.

This thesis is being submitted to Mizoram University for the **Degree of Doctor of Philosophy in Clinical Psychology**.

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CHAPTER-I

INTRODUCTION

INTRODUCTION

Parents of children with special needs face many physical and emotional challenges most of the time, and often exhausted and frequently become depressed. Parenting a child with a special health need poses stressors beyond those experienced in raising typically developing children (Baxter, Cummins, & Yiolitis, 2000) because of elevated medical expenses, time demands, physical care, and worry about the child's future (Brehaut, Garner, Miller, Lach, Klassen, Rosenbaum & Kohen, 2011) which may invite serious health threats and poor health outcomes (Thurston et. al., 2011). Such parents undermine parents' physical health outcomes (Allik, Larson, & Smedje, 2006). Especially, parenting to neurodevelopmental disorder child may invite psychological distress, and employ some coping strategies which may hamper the quality of life of the parents.

Quality of Life

The World Health Organization (WHO, 1994) defines "quality of life" as an individual's perception of their position in life, taking into account their culture, value systems, goals, expectations, standards, and concerns. Factors such as employment, environment, mental and physical health, education, leisure, social belonging, religious views, safety, security, and freedom are key indices of quality of life. On the other hand, psychological distress (Mirowsky & Ross, 2002) refers to emotional suffering often characterized by symptoms of depression (e.g., loss of interest, sadness, hopelessness) and anxiety (e.g., restlessness, tension).

Quality of life encompasses satisfaction in various aspects of life, including emotional, material, and physical well-being; engagement in interpersonal relationships; opportunities for personal development (such as skill-building); the ability to exercise rights and make self-determined lifestyle choices; and participation in society. Enhancing quality of life is especially important for individuals with chronic diseases, developmental disabilities, medical or psychological conditions, and older adults (APA, 2020).

The concept of Quality of Life (QOL) has evolved significantly over the past 40+ years, transitioning from a basic idea to a model and, eventually, to a theory. Although the concept itself dates back to antiquity, it gained prominence in the field of intellectual and developmental disabilities (IDD) during the 1980s. This emergence coincided with civil rights movements and deinstitutionalization efforts aimed at improving the rights, autonomy, inclusion, equity, and empowerment of individuals who had long been excluded, segregated, discriminated against, and denied basic human and civil rights. These movements called for systemic changes, with a "quality of life mentality" guiding the process of inclusion and empowerment (Salas & Robert, 2024).

In the early 1990s, concept mapping techniques were employed in the field of developmental disabilities to formulate these principles. The principles were first published in 2002 (Schalock et. al., 2002), validated in 2004 (Brown et. al., 2004), and subsequently updated through a consensus conference in 2019 (Lombardi, Claes, Bradley & Schalock, 2024). These evolving principles have played a critical role in shaping the way QOL is understood and applied, particularly in the context of individuals with intellectual and developmental disabilities (Brown et. al., 2004). The evolution of the Quality of Life (QOL) concept, among individuals with intellectual and developmental disabilities (IDD) has involved the three key principles: conceptualization, measurement, and application. Each of these components helped define and refine the framework for improving the well-being of people with IDD and guided the planning, delivery, and evaluation of services and supports (Schalock et. al., 2002).

QOL Conceptualization Principles: The original conceptualization principles reflected the evolving understanding of individuals with Intellectual Development Disorder (IDD), their well-being, and the changing social-ecological model of disability. These principles emphasized the multidimensional nature of human functioning and recognized that quality of life is influenced by a combination of personal factors and broader social contexts. The conceptualization principles also framed QOL as a social construct, which encouraged a focus on enhancing personal

and family well-being through better services and support. This laid the foundation for QOL to become a guiding framework for service planning and evaluation of related outcomes (Schalock et. al., 2002).

QOL Measurement Principles: The measurement principles focused on developing and standardizing tools to assess different domains of QOL, ensuring that instruments could reliably capture various indicators of quality of life. These principles helped establish a way to measure the multiple aspects of an individual's life that contribute to overall well-being, including emotional, physical, and social factors (Schalock et. al., 2002).

QOL Application Principles: The Application principles provided guidelines for how QOL concepts and outcomes could inform policies and practices and emphasized several key points (Schalock et. al., 2002):

- 1) The importance of context and value-based preconditions in human functioning and the enhancement of valued outcomes.
- 2) The incorporation of the supports paradigm into disability-related policies and practices, recognizing the role of community-based supports in helping individuals achieve better life outcomes.
- 3) The impact of the social, political, and financial landscape on people with IDD, especially the challenges they face in accessing services in increasingly complex systems of support. These systems often involve various providers, settings, and structures.

QOL Model Development: In the second phase of the QOL concept's evolution, concept mapping was used as a tool for model development. This method, which began in the mid-to-late 1980s, helped organize and refine ideas about QOL by involving a variety of stakeholders, including people with IDD, their families, and professionals. The development process involved:

- 1) Generating ideas and listing potential domains and indicators based on input from focus groups, personal interviews, surveys, and existing literature.

- 2) Sorting these domains and indicators into meaningful categories that reflected both the values of individuals with IDD and broader community standards of QOL.
- 3) Defining each domain through measurable indicators that could be used to assess QOL.

This process led to the creation of the first QOL models, which provided a structured approach to understanding and improving QOL for people with IDD. Researchers (Brown & Faragher, 2019; Turner et. al., 2010) utilized this approach to operationalize the QOL concept into practical models used for research, service design, and evaluation. The evolution of Quality of Life (QOL) about the intellectual and developmental disabilities (IDD) has seen a progression from conceptualization to instrument construction, and finally to application. This journey has played a key role in enhancing the understanding, measurement, and improvement of the QOL for individuals with IDD and other neurodevelopmental disorders (Elena & Roxana, 2013).

QOL Instrument Construction: Once QOL models were developed and validated, efforts began to create reliable and valid QOL assessment tools. These instruments were designed around the specific domains and indicators established by the QOL models. The goal was to measure personal well-being in a structured way, helping both researchers and practitioners gather data that could guide interventions and improve services. The instruments constructed were grounded in the measurement principles, which allowed for a standardized approach to assessing the different factors contributing to QOL (Schalock et. al., 2002). After the development of models and instruments, the focus shifted to the application of the QOL concept.

This phase aimed to:

- 1) Enhance well-being within cultural contexts.
- 2) Use QOL measurements to provide formative feedback and systemic change in service delivery.
- 3) Expand understanding of the QOL construct and integrate it into broader systems.

- 4) Guide the development of policies and practices that promote well-being.

QOL Theory: The theory of QOL defines it as a multidimensional phenomenon made up of core domains that constitute personal well-being. These domains are influenced by personal characteristics and environmental/contextual factors that operate at three different levels: micro (individual), meso (family/community), and macro (societal). The theory also identifies three key components that can affect QOL outcomes (Schalock et. al., 2002):

- 1) *Quality enhancement strategies* - Approaches designed to improve life quality.
- 2) *Moderator factors* - Personal or external factors that might influence the effectiveness of interventions.
- 3) *Mediator factors* - Factors that explain how or why certain interventions or supports improve QOL.

QOL Relevance to Neurodevelopmental Disorders: QOL is also central in understanding caregivers' adjustment of children with neurodevelopmental disorders. The experiences and well-being of parents are crucial, as they directly impact the care and support of children with conditions such as autism spectrum disorder (ASD) or attention-deficit hyperactivity disorder (ADHD). Studies highlight the importance of assessing the health and daily challenges that caregivers face, as this affects both their well-being and their ability to care for their children. Research (Gislaine et. al., 2020; Laugesen et. al., 2016) underscores the importance of considering caregiver QOL as part of the larger context of managing neurodevelopmental disorders.

QOL is increasingly being recognized in medical and psychiatric settings, where it serves as a critical standard for evaluating the effectiveness of treatments. For example, in paediatric psychiatry, QOL is used to assess clinical outcomes and inform therapy decisions. By measuring QOL, healthcare providers can better tailor interventions, medications, or psychological therapies to improve the life satisfaction of both individuals with neurodevelopmental disorders and their caregivers (Gislaine et. al., 2020; Laugesen et. al., 2016).

Key Principles of QOL: There are some prominent key principles in studying QOL which are:

- a) *Multi-dimensional*: QOL includes various components like emotional, physical, and social well-being, as well as the broader environment.
- b) *Influenced by both personal and environmental factors*: QOL is shaped by individual traits and external conditions.
- c) *Subjective and Objective*: QOL combines personal perceptions with measurable indicators.
- d) *Improved by self-determination, resources, purpose, and a sense of belonging*: These factors contribute to enhanced quality of life for individuals with IDD.

Psychological Distress

The term distress was introduced by Hans Selye (1936) as a response to stressful situations. Psychological distress is a set of painful mental and physical symptoms that are associated with normal fluctuations of mood in most people. In many cases, psychological distress may indicate the beginning of a major depressive disorder, anxiety disorder, schizophrenia, somatization disorder, or a variety of other clinical conditions. It is thought to be what is assessed by many putative self-report measures of depression and anxiety (APA, 2018). The demands of caring can contribute to an increase in the level of stress for the carers and can affect their quality of life overall, including their mental health. Approximately one-third to one-half of carers have been estimated to experience significant psychological distress, and they experience mental health problems more often than the general population (Shah et. al., 2010).

Distress is an aversive and negative state when coping and adaptation processes fail to bring an organism of physiological and/or psychological homeostasis (Carstens & Moberg 2000) due to a severe or prolonged stressor which sufficiently altered coping mechanisms overwhelmed (Moberg, 2000). The chronic distress reaction may lead to depression, and glucocorticoid feedback systems fail (Carroll et. al., 1976). Distress may not always manifest itself with recognisable “maladaptive behaviours (NRC, 2008) but the use of reserve resources to cope with

prolonged or severe stress hurts other bodily functions (including behaviour) and requires a prolonged recovery period to revert to homeostasis (Carstens & Moberg, 2000). Genetic factors together with external environmental factors (stressful events) are involved in the onset of depression (Krishnan & Nestler, 2008). Distress may cause a range of feelings, from sadness and a loss of control to depression, anxiety, panic, and isolation which can affect the quality of life of people (www.cancer.govt).

Depression or Major Depressive Disorder (MDD)

It is a mental health condition characterized by persistent feelings of sadness, hopelessness, and a profound sense of despair. It can severely affect a person's day-to-day functioning, including their ability to work, study, eat, sleep, and engage in activities they once found enjoyable. Major depression is not limited to a single episode; it can recur throughout a person's life (APA, 2013).

Symptoms of Major Depression (APA, 2013):

- 1) *Sadness*: Overwhelming and persistent sadness that affects daily functioning.
- 2) *Irritability*: Heightened frustration or anger, even over small things.
- 3) *Loss of interest in activities once enjoyed*: A marked disinterest in hobbies, social activities, or things that used to bring pleasure.
- 4) *Withdrawal from social activities*: Avoidance of family, friends, and other social interactions.
- 5) *Inability to concentrate*: Difficulty focusing or making decisions.
- 6) *Disrupted sleep*: Either sleeping too much or having trouble falling asleep.
- 7) *Fatigue or loss of energy*: A sense of constant tiredness, even after adequate rest.
- 8) *Appetite changes*: Either eating too much or not having an appetite at all.
- 9) *Thoughts of suicide*: Persistent thoughts of death or self-harm.

Psychotic depression (APA, 2013) is a more severe form of depression that includes both depressive symptoms and psychotic features such as delusions (false beliefs) and hallucinations (hearing or seeing things that aren't there). This type of depression typically reflects intense despair and negative beliefs, such as feelings of being punished or having committed a serious sin. People with psychotic depression might feel ashamed of their symptoms and often try to hide or minimize their experience, which can complicate diagnosis and treatment (APA, 2013).

The presence of psychotic symptoms like delusions and hallucinations can overlap with other mental health conditions, like schizophrenia, which may make it difficult to distinguish psychotic depression from other disorders. In psychotic depression, the delusions and hallucinations are directly tied to the depressive symptoms, whereas in schizophrenia, these symptoms are not necessarily linked to depression (Smitha, 2024). The Global Burden of Disease (GBD) study showed that depression alone accounts for 4.46% of total DALYs highlighting the burden of depression.

Diagnosis of Depression:

Medical and mental health professionals use established, research-backed guidelines, screening tools, checklists, and other criteria to help them make a diagnosis of depression (Evans et. al., 2018). Diagnosis of depression is based on a thorough understanding of symptoms, medical history and mental health history. They may be diagnosed with a specific type of depression, such as seasonal affective disorder or postpartum depression, based on the context of symptoms. To receive a diagnosis of depression, an individual must have five depression symptoms every day, nearly all day, for at least two weeks (APA, 2022). Some specific diagnostic tests of depression are:

- a) The Beck Depression Inventory (BDI)
- b) Hamilton Rating Scale for Depression (HRSD)
- c) Centre for Epidemiologic Studies Depression Scale (CES-D)
- d) Patient Health Questionnaire-9 (PHQ-9)

e) Montgomery-Åsberg Depression Rating Scale (MADRS)

Treatment of Depression:

Effective treatments are available for depression, and the first step is seeking professional care if experiencing symptoms. Depression is typically treated using a combination of psychological treatments and medications. The approach depends on the severity of depression, with milder cases primarily benefiting from psychological treatment and more severe cases requiring a combination of treatments (APA, 2022).

Psychological Treatments (First line for treatment): Psychological treatment, also known as talk therapies, focuses on helping individuals alter patterns of thinking and behaviour that contribute to depression. These treatments can be provided face-to-face or online, and can even be accessed through self-help resources, websites, or apps (WHO, 2022).

Some effective psychological treatments for depression include (WHO, 2022):

- 1) *Behavioural Activation:* Focuses on increasing engagement with positive activities to combat withdrawal and inactivity associated with depression (WHO, 2022).
- 2) *Cognitive Behavioural Therapy (CBT):* Helps individuals identify and change negative thought patterns that contribute to depression (WHO, 2022).
- 3) *Interpersonal Psychotherapy (IPT):* Focuses on improving interpersonal relationships and communication skills, addressing social issues that may contribute to depression (WHO, 2022).
- 4) *Problem-solving Therapy:* Teaches skills to better cope with daily challenges and stresses by breaking down problems into manageable steps (WHO, 2022).
- 5) *Medications:* In cases of moderate to severe depression, antidepressant medications may be prescribed to help balance chemicals in the brain that regulate mood. These medications are typically combined with

psychological treatments, especially when symptoms are more severe (WHO, 2022).

Anxiety

Anxiety disorders involve excessive fear or worry, which can manifest in response to specific situations (such as a panic attack or social interaction) or more broadly across various aspects of everyday life (as seen in generalized anxiety disorder). These feelings typically persist for a long time, often several months or more, and may interfere with the individual's ability to function in daily life (APA, 2022).

Common symptoms of anxiety disorders include (APA, 2022):

- 1) *Excessive worry or fear:* This could be about specific events (e.g., public speaking, health concerns) or more general concerns (e.g., future uncertainties).
- 2) *Trouble concentrating or making decisions:* Anxiety can cause mental fog, making it difficult to focus on tasks or decide on actions.
- 3) *Irritability, restlessness, or tension:* The emotional toll of anxiety can lead to irritability and a heightened state of tension or nervousness.
- 4) *Nausea or abdominal distress:* Anxiety can manifest in physical symptoms like stomach upset or nausea.
- 5) *Heart palpitations:* A rapid or irregular heartbeat is common during periods of heightened anxiety.
- 6) *Sweating, trembling, or shaking:* Physical signs of fear or nervousness may be seen as trembling hands or excessive sweating.

7) *Sleep disturbances*: Difficulty falling asleep or staying asleep is common due to anxiety-induced mental unrest.

8) *Sense of impending doom or danger*: People may feel like something terrible is about to happen, even when there is no immediate threat.

Major Comorbidity of Anxiety Disorders:

It can have a profound impact on mental and physical health. They increase the risk for other conditions (APA, 2022), including:

- 1) *Depression*: Chronic anxiety may lead to feelings of hopelessness or helplessness, potentially contributing to depression.
- 2) *Substance Use Disorders*: In an attempt to self-medicate, individuals with anxiety may turn to alcohol, drugs, or other substances.
- 3) *Suicidal thoughts and behaviours*: The distress caused by anxiety can lead to thoughts of self-harm or suicide.

Types of Anxiety:

According to APA (2022), there are several kinds of anxiety disorders, including:

- 1) *Generalized anxiety disorder* (persistent and excessive worry about daily activities or events)
- 2) *Panic disorder* (panic attacks and fear of continued panic attacks)
- 3) *Social anxiety disorder* (high levels of fear and worry about social situations that might make the person feel humiliated, embarrassed or rejected)
- 4) *Agoraphobia* (excessive fear, worry and avoidance of situations that might cause a person to panic or feel trapped, helpless or embarrassed)
- 5) *Separation anxiety disorder* (excessive fear or worry about being separated from people with whom the person has a deep emotional bond)
- 6) *Specific phobias* (intense, irrational fears of specific objects or situations that lead to avoidance behaviour and significant distress)

- 7) *Selective mutism* (consistent inability to speak in certain social situations, despite the ability to speak comfortably in other settings, primarily affecting children)

It is common for individuals to experience multiple anxiety disorders simultaneously. Symptoms typically emerge during childhood or adolescence and persist into adulthood. Girls and women are more likely to develop an anxiety disorder compared to boys and men (WHO, 2022).

Anxiety disorders, like other mental health conditions, arise from a complex interplay of social, psychological, and biological factors. While anyone can develop an anxiety disorder, individuals who have experienced abuse, significant losses, or other adverse events are at a higher risk. Anxiety disorders are closely linked to physical health, with many effects of anxiety—such as physical tension, overactive nervous system responses, or the harmful use of alcohol—serving as risk factors for conditions like cardiovascular disease. Conversely, individuals managing such diseases may develop anxiety disorders due to the challenges associated with their health conditions (Alonso et. al., 2018).

Diagnosis of Anxiety:

Diagnosis of anxiety requires validated, structured, or semi-structured clinical interviews, such as the DSM-5-based or ICD-11-based composite international diagnostic interview (Robins et. al., 1988) or structured clinical interview for DSM disorders, which can assist in correct diagnostics (Spitzer et. al., 1992). To diagnose an anxiety disorder, a mental health provider may:

- a) Give a psychological evaluation to discuss thoughts, feelings, and behaviour.
- b) Compare symptoms to the criteria in the DSM-5.
- c) Do a physical exam to rule out other conditions.
- d) Ask detailed questions about symptoms and medical history.
- e) Use psychological questionnaires to help determine a diagnosis.

Some specific diagnostic tests of anxiety are:

- a) Zung Self-Rating Anxiety Scale
- b) Hamilton Anxiety Scale (HAM-A)
- c) Beck Anxiety Inventory (BAI)
- d) Social Phobia Inventory (SPIN)
- e) Penn State Worry Questionnaire
- f) Generalized Anxiety Disorder Scale
- g) Yale-Brown Obsessive-Compulsive Scale (YBOCS)

Caregiver Burden

Caregiving burden refers to the stress experienced by individuals who care for others, while caregiver burden is the emotional or physical strain felt by caregivers themselves (Mosley et. al., 2017). The concept was first introduced by Treudley in 1946, who suggested that caregiving negatively affects the caregiver's mental health and quality of life (Chadda, 2014). In fulfilling caregiving responsibilities, caregivers often exhaust their physical, mental, social, and financial resources. The caregiver burden is a common issue globally, with about 80% of caregivers reporting it as a significant challenge in their duties (Chadda, 2014). Various factors can influence the severity of caregiver burden, including the characteristics of the patient (e.g., gender, lower education level), the caregiver's attributes, the caregiver-patient relationship (e.g., cohabitation), the amount of time spent caregiving, and the nature and severity of the illness (Adelman et. al., 2014).

Currently, approximately 25% of the global population is affected by mental health conditions, making it a significant contributor to the overall disease burden. Around 450 million people worldwide are experiencing mental or behavioural disorders (Walke et. al., 2018). Depression accounts for the largest share, contributing to 4.3% of the global disease burden and is one of the leading causes of mental illness globally (Walke et. al., 2018). However, many informal caregivers, who often take on these responsibilities, may not have received adequate training or education in caregiving. As a result, mental illness affects not only the individuals diagnosed but also those who provide care. Research has shown that caregivers of

individuals with mental illness often face higher rates of mental health challenges compared to the general population (Azman et. al., 2019). While the benefits and drawbacks of caregiving are not always clear, caregiving frequently leads to high level of stress (Alves et. al., 2019).

Individuals with major mental illnesses often become highly dependent on their caregivers due to the significant disability associated with their condition. Those affected by severe mental illness experience substantial functional and role impairments, as well as difficulties in maintaining employment. Around 90% of people with serious mental health conditions receive daily practical and emotional support from family caregivers (Gharavi et. al., 2018). The psychological distress and caregiving burdens experienced by those supporting a mentally ill family member not only negatively impact the caregivers' quality of life and health but also reduce their productivity and ability to provide effective care. This, in turn, can worsen the patient's condition and decrease the chances of recovery or improvement in their health (Udoh et. al., 2021).

Stress

The word “stress” is borrowed from physics. Stress is also defined as “a pattern of physiological and/or psychological reactions exhibited by a person who is under pressure from a disturbing or dysfunctional environment” (Cushway, 1995).

Patients often exhibit identical signs of distress called “general adaptation syndrome,” which describes the body’s short-term and long-term reactions to stress (Selye, 1951). When the demand of the organism exceeds the organism’s reasonable capacities, stress occurs. The Transactional Model postulates that stress is a result of a transaction between an individual and their environment which mentions the connection between stressors, the individual’s appraisal of stressors, and the subsequent coping responses (Lazarus & Folkman, 1984). The coping process is a response to a cognitive appraisal of a situation that may be stressful as it may significantly exceed the person’s resources for coping (Folkman, 2011).

The role of positive emotions in the coping process even in the context of stress influences coping strategies (Folkman & Moskowitz, 2000). Contemporary Research expands the areas of stress including its relation to resilience, well-being, and managing stress (Biggs, Brough, & Drummond, 2017) which is useful for understanding how individuals perceive and manage stress and this has paved the way for therapeutic approaches and interventions.

Stressors: Stressor refers to the external events or situations that place demands on an individual and potentially trigger a stress response; it can be a physical, emotional, environmental, or psychological response, and vary in intensity and duration from minor everyday hassles to major life events.

Types of stressors: There are two main types of stressors - Acute and chronic stressors: Acute Stressors are sudden and short-term stress such as getting into an argument with someone or experiencing a near-miss accident. Chronic Stressors are ongoing stress-inducing situations that persist over a longer period such as work-related pressures, financial difficulties, or chronic health issues.

The stress response model, first introduced by Hans Selye in 1956, describes stress as a physiological reaction and is outlined in his general adaptation syndrome (GAS). Selye suggested that the outcomes of stress could be positive or negative, depending on how individuals cognitively interpret the physical symptoms or physiological experiences associated with stress.

In the 1960s, the theory of stress as a stimulus emerged, framing stress as a significant life event or change that requires adjustment or adaptation. Holmes and Rahe (1967) developed the Social Readjustment Rating Scale (SRRS), which includes 42 life events ranked based on the amount of adjustment they would demand from a person (e.g., marriage, divorce, job changes, or the loss of a loved one). They proposed that stress acts as an independent variable in the health-stress-coping model, suggesting it is the cause of an experience, not the experience itself. While some studies found correlations between SRRS scores and illness (Rahe,

Mahan, & Arthur, 1970; Johnson & Sarason, 1979), the stress-as-stimulus theory faced challenges and limitations.

To better understand stress as a dynamic process, Richard Lazarus developed the transactional theory of stress and coping (TTSC), which views stress as the result of an interaction between an individual (encompassing cognitive, physiological, emotional, psychological, and neurological systems) and their complex environment (Lazarus, 1966; Lazarus & Folkman, 1984). This transactional perspective gained prominence when Dr. Susan Kobasa introduced the concept of hardiness (Kobasa, 1979). Hardiness is a set of personality traits that help individuals maintain good health despite life stress, distinguishing them from those who may develop health problems under similar conditions (Kobasa et. al., 1982; Kobasa & Maddi, 1981). Hardiness shares common features with other psychological constructs, such as locus of control (Rotter, 1966), sense of coherence (Antonovsky, 1987), self-efficacy (Bandura, 1997), and dispositional optimism, all of which are related and will be discussed in the following section. To account for the complexity of stress experiences, researchers introduced multiple variables into the stress-as-transaction model, expanding and categorizing factors that shape how individuals encounter or react to stressors (Werner, 1993), and coping with the situation.

Coping to Stress

Lazarus and Folkman (1984) defined coping as a dynamic process involving changing cognitive and behavioural efforts to manage specific external and internal demands which are perceived as overwhelming or beyond a person's available resources. Coping theory is a broad field of study, typically categorized into two main parameters:

- 1) *Focus-oriented theories (trait and state)* – These theories emphasize the internal resources and mental capacities of an individual, helping to evaluate how effectively they can adapt to a situation based on their traits or current state.

2) *Approach-oriented theories (micro-analytic and macro-analytic)* – These theories focus on the nature of coping mechanisms, ranging from concrete actions to abstract strategies, and assess the specific processes involved in coping.

Together, these theories offer a comprehensive view of how individuals navigate stress, examining both internal resources and the concrete versus abstract nature of coping strategies (Carver, Scheier, & Weintraub, 1989).

Coping Theory: There are some Coping Theories which were often used to explain how a person copes.

Repression-Sensitization Theory: This theory suggests that coping operates along a bipolar dimension, with repression at one end and sensitization at the other. People who use repression as a coping mechanism tend to deny or ignore the presence of a stressor to minimize its impact. In contrast, sensitizers tend to react with heightened awareness, excessive worry, and obsessive thoughts when confronted with stress (Cohen & Lazarus, 1979).

Monitoring and Blunting Theory: This theory proposes that cognitive processes can be employed to reduce the impact of a stressful stimulus. Blunting strategies, such as denial, restructuring, and distraction, help individuals overlook temporary stressors. Monitoring strategies, like information processing and emotional regulation, are more effective for managing ongoing stress and anxiety (Cohen & Lazarus, 1979).

Model of Coping Modes (MCM): An extension of the monitoring-blunting theory, the MCM links to the repression-sensitization model and introduces the idea of cognitive avoidance. This theory posits that individuals tend to avoid stressful situations and interpret them as ambiguous, thereby distancing themselves from stressors (Cohen & Lazarus, 1979).

Macro-analytic state-oriented theories: Among the earliest macro-analytic theories is Freud's (1926) concept of defence mechanisms. Another influential approach is the model developed by Richard Lazarus and Susan Folkman, which states that successful coping mechanisms are linked to the emotional functions associated with the problem. Lazarus identified eight emotional functions that most individuals use for active coping, which are:

- 1) *Self-Control* – where we try to control our emotions in response to stress.
- 2) *Confrontation* – where we face the pressure and retaliate to change the situation and bring it back to our favour.
- 3) *Social support* – where we talk to others and look for social connections to help us survive a difficult time.
- 4) *Emotional distancing* – where we stay indifferent to what is going on around and prevent the distress from controlling our actions.
- 5) *Escape and avoidance* – where we deny the existence of stress as a coping response.
- 6) *Radical acceptance* – where one resorts to unconditional self-acceptance for adapting to adversity.
- 7) *Positive reappraisal* – where we seek to find the answer in the struggle and grow from it.
- 8) *Strategic problem-solving* – where we implement specific solution-focused strategies to get through the tough time and redirect our actions accordingly.

Mental health research on coping has revealed a strong neurobiological connection between stress and adjustment. Numerous experiments and reviews have shown that the stress management strategies we employ can help restore physiological functions at the molecular level in the body (Scheier & Carver, 1985).

Lazarus and Folkman introduced the concept of cognitive appraisal and reappraisal. According to their theory, coping with stress involves a complex process of thinking and assigning meaning to the stressor. They explained this process through the stress cycle, in which an individual's perception of a stressful situation determines how they will cope with it (Anshel, 1996; Roth & Cohen, 1986).

Positive Coping Strategies: Lazarus conceptualized positive coping strategies which may be explained as effective or positive coping strategies which include:

Support System: According to Lazarus and Folkman, having a reliable support system during tough times can make it easier to overcome stress. Supportive coping is particularly beneficial for individuals facing depression, substance abuse, grief, and isolation. Simple actions like having group discussions, calling a friend, talking to a therapist, or sharing daily problems with family can help individuals manage life stressors without becoming overwhelmed (Folkman & Lazarus, 1980).

Relaxation: While it may seem challenging to relax in stressful situations, daily relaxation practices can help train the mind to remain calm. Techniques such as breathing exercises, meditation, progressive muscle relaxation, or listening to calming music are effective in promoting mental calmness (Folkman & Lazarus, 1980).

Physical Wellness: Good physical health is key to coping effectively. Positive coping mechanisms include activities like yoga, cycling, brisk walking, and other forms of regular exercise, which help release endorphins and support the body's circulatory system (Folkman & Lazarus, 1980).

Maladaptive Coping Responses: In contrast to positive coping strategies, a negative coping mechanism and harming well-being have also been suggested (Bippus & Young, 2012). Examples of maladaptive coping include:

Escape and Avoidance: Freud identified defence mechanisms like escape, denial, and restraint as ways to absorb mental energy. While temporarily ignoring a

problem may seem helpful, it is more beneficial to acknowledge the issue and address it directly.

Unhealthy Comfort Zones: Engaging in excessive comforting habits like overeating, watching television, or spending hours on the internet as a response to stress can be counterproductive. These behaviours offer a temporary sense of relief but fail to resolve underlying issues and can increase distress.

Emotional Numbing: Emotional numbing involves distancing oneself from relationships and communication to avoid getting hurt, a behaviour that can lead to social isolation and risky actions, such as substance abuse. This form of avoidance reinforces negative cycles of withdrawal and further isolation.

Types of Coping Strategies

1) *Problem-Focused Coping:* Problem-focused coping involves directly addressing the source of stress by developing effective strategies to reduce strain and implementing specific actions to resolve the issue. This approach is generally seen as a positive coping strategy, as research indicates that it can reduce long-term stress levels (Ventura et. al., 2010). It focuses on dealing with the stressor itself, such as solving a problem or managing a situation, rather than alleviating emotional distress. However, it may not always be effective for all types of stressors. For example, strategies designed for dealing with chronic pain may not apply when dealing with a work deadline. Moreover, if the perceived threat is very high, problem-focused coping may not be effective, as excessive stress has been found to negatively affect cognitive functioning and the ability to process information (Ventura et. al., 2010).

2) *Emotion-Focused Coping:* Emotion-focused coping aims to reduce emotional distress caused by stressors without directly addressing the source of stress. This coping strategy includes reappraising the situation, seeking reassurance from others, and focusing on one's strengths (Ventura et. al., 2010). The main goal is to manage emotional strain through methods such as avoidance, distancing, and wishful thinking. One common emotion-focused strategy is cognitive reappraisal, which involves changing how one perceives a situation without altering its objective

reality. For example, a stressed person may focus on how much worse the situation could be by comparing themselves to others in more difficult situations, a process known as "downward social comparison." Other strategies may include distraction through physical exercise, meditation, or seeking emotional support. While emotion-focused coping can be helpful in some situations, it may be counterproductive in others. For instance, denying the severity of a chronic health issue may reduce anxiety initially but can become problematic during treatment or rehabilitation (DeLongis et. al., 2007).

3) *Avoidance-Focused Coping*: Avoidance coping involves efforts to avoid dealing with a stressor by not thinking about the problem, distracting oneself, or engaging in behaviours like drinking, using drugs, or removing oneself from the stressful situation. While it may offer short-term relief, avoidance coping is generally considered maladaptive, especially in chronic stress situations such as school-related stressors. Research indicates that individuals who rely on avoidance coping tend to experience higher levels of strain in the long run. Studies also suggest that people with higher neuroticism or those prone to negative emotions are more likely to use maladaptive coping strategies, partly because they have less confidence in their ability to effectively solve problems. This lack of hope may reduce their motivation to address the stressor directly. Additionally, recent research highlights the importance of positive emotions in moderating the harmful effects of stress, suggesting that positive emotions can help buffer the negative impact of stressors on overall well-being (Ventura et. al., 2010). Avoidance coping ultimately tries to avoid confronting the stressor or its emotional consequences (Moos, 1990).

Mental health

Mental health refers to a state of well-being that allows individuals to manage life's challenges, realize their potential, learn effectively, work productively, and contribute to their communities. It is both inherently valuable and essential to overall well-being. Mental health is influenced by a range of factors, including individual, family, community, and societal elements, which can either safeguard or threaten it. While many individuals demonstrate resilience, those facing adversity such as

poverty, violence, disability, or inequality are at a higher risk of developing mental health issues (WHO, 2022). Although many mental health conditions can be treated effectively and at a relatively low cost, global health systems remain inadequately funded, leading to significant treatment gaps. Even when care is available, it is often of poor quality. Additionally, people with mental health conditions frequently encounter stigma, discrimination, and violations of their human rights (WHO, 2022).

Mental health issues are the leading cause of health-related disabilities among children and adolescents globally (Erskine et. al., 2015) and represent a major health challenge of the 21st century (WHO, 2018). Over the past decades, researchers have increasingly focused on understanding mental health and well-being during childhood and adolescence (Polanczyk et. al., 2015). These problems impose a substantial burden on both individuals and society, leading to significant disruptions in areas such as family dynamics, work performance, quality of life, and the broader social environment (Bastiaansen et. al., 2005). Economically, mental health disorders result in considerable direct and indirect costs for society (Olesen et. al., 2012).

Resilience theories highlight the importance of perceived control and social support in enabling individuals to adapt effectively to difficult circumstances (Walsh, 2012). Parents of children with special health needs often express feelings of helplessness and a lack of adequate support (Florian & Findler, 2001). This loss of control can be exacerbated as healthcare systems take on a more significant role in managing their child's care. Maintaining a sense of control is vital for alleviating stress and protecting the mental health of these parents (Weiss, 2002).

Childhood and adolescence are pivotal periods for mental health, marked by rapid brain growth and development. During this time, children and adolescents develop cognitive and social-emotional skills that influence their future mental health and prepare them for adult responsibilities in society (WHO, 2018). The quality of their environment significantly impacts their well-being and development. Negative early experiences such as exposure to violence, a caregiver's mental illness, bullying, or poverty in homes, schools, or digital spaces can heighten the risk of developing mental health issues.

Mental health conditions, including childhood epilepsy, developmental disabilities, depression, anxiety, and behavioural disorders, are significant contributors to illness and disability among young people. Globally, 8% of children and 15% of adolescents experience a mental disorder, yet most do not seek or receive the care they need. Suicide ranks as the third leading cause of death among 15-29-year-olds. Failing to address mental health and psychosocial development in children and adolescents has long-term consequences that extend into adulthood, reducing opportunities to lead fulfilling lives (WHO, 2017).

Psychopathological Disorder (Childhood and Adolescence):

- 1) *Attention-Deficit/Hyperactive Disorder (ADHD):*** Attention-deficit/hyperactivity disorder (ADHD) is a developmental condition characterized by ongoing symptoms of inattention, hyperactivity, and impulsivity. Individuals may predominantly exhibit symptoms of inattention, primarily show symptoms of hyperactivity and impulsivity, or experience a combination of both types (NIMH, 2011).
- 2) *Autism Spectrum Disorder (ASD):*** The complex developmental disease known as ASD has an impact on a person's behaviour, social interactions, communication, and learning. Beginning early in life, autism spectrum disorder (ASD) is a complicated neurological and developmental disorder that impacts a person's behaviour, interactions with others, communication, and learning. The structure and operation of the brain and nervous system are impacted by ASD. ASD is referred to as a developmental disorder since it impacts development. A person may have ASD for the rest of their life (Lord et. al., 2020).

Neurodevelopmental Disorder:

A group of diseases known as Neurodevelopmental Disorders (NDDs) are defined by Abnormal Central Nervous System Development that results in brain dysfunctions later in life. These disorders may be linked to neuropsychiatric issues or impaired language, learning, motor function, or nonverbal communication (Dymen

et. al., 2020). Its known but frequently unidentified aetiology, which is connected to either genetic or environmental factors, causes it to occur throughout the foetal or neonatal developmental window (Morris-Rosendahl, 2020). The Diagnostic and Statistical Manual of Mental Disorders (DSM-5, American Psychiatric Association, 2013) and the International Classification of Diseases 11th Revision (ICD-11) classify neurodevelopmental disorders into the following categories: communication, attention deficit, hyperactivity, learning, and visual-motor disorders.

Neurodevelopmental disorders (NDs) encompass a range of conditions that affect brain development, leading to difficulties in social, cognitive, and emotional functioning. The most common NDs include (May et. al., 2019): Autism Spectrum Disorder (ASD) and Attention-Deficit/Hyperactivity Disorder (ADHD). These disorders typically manifest during developmental stages, making them most noticeable in toddlers, children, and adolescents. However, NDs can persist into adulthood, and in some cases, individuals may remain undiagnosed until adulthood (Masuda et. al., 2019).

Neurodevelopmental disorders (NDDs) are a group of conditions that typically emerge early in life, characterized by developmental deficits that impair personal, social, academic, or occupational functioning (Mary et. al., 2017). These disorders vary widely, ranging from specific limitations in learning or executive function control to more global impairments in social skills or intellectual abilities. Initially, considered to be categorically defined, recent dimensional approaches to assessing symptoms show a spectrum of severity, often without clear boundaries distinguishing them from typical development (APA, 2022).

The definitions of many of these disorders have been redefined over the years. However, it wasn't until the 21st century that research and literature on these conditions began to expand rapidly, attracting significant media attention. Some neurodevelopmental disorders raise the question of whether they are conditions that emerged more recently, such as anorexia, or whether they have existed for thousands of years, like schizophrenia (Matthew et. al., 2014). Among many, the present study selected ADHD and Autism and will explain in detail as follows.

Attention-Deficit/Hyperactive Disorder (ADHD) or Attention Hyperactivity Disorder (ADHD): ADHD is a psychiatric disorder recognized for its impact on children's ability to function. Individuals with ADHD exhibit patterns of excessive inattention, hyperactivity, or impulsivity that are developmentally inappropriate. Previously, Attention Deficit Disorder (ADD) and attention deficit hyperactivity disorder (ADHD) were considered separate diagnoses, but the DSM IV merged them into a single disorder with three subtypes: predominantly inattentive, predominantly hyperactive, or combined type (Milichap, 2008).

ADHD is a neurodevelopmental disorder characterized by significant levels of inattention, disorganization, and/or hyperactivity-impulsivity. Inattention and disorganization involve difficulties in staying on task, appearing not to listen, and misplacing materials needed for tasks, at levels inconsistent with the individual's age or developmental stage. Hyperactivity-impulsivity includes excessive activity, fidgeting, difficulty staying seated, interrupting others, and an inability to wait—symptoms that are disproportionate for their age or developmental level (APA, 2022). ADHD is often comorbid with conditions such as conduct disorder and oppositional defiant disorder, both considered "externalizing disorders." These conditions frequently coexist in childhood. ADHD can persist into adulthood, affecting social, intellectual, and professional functioning (Howard, 2022).

ADHD typically manifests in childhood, with the requirement for many symptoms to appear before the age of 12 highlighting the importance of early clinical presentation (Renate et. al., 2020). However, determining childhood onset has been challenging in the past, and an earlier age of onset is not always clearly indicated. Since adults often have inconsistent recollections of their childhood symptoms, it is essential to gather additional information. ADHD cannot be diagnosed before the age of 12 without symptoms present. If symptoms that resemble ADHD first emerge after age 13, they are more likely attributed to another mental disorder or the cognitive effects of substance use. Additionally, the disorder must be evident in more than one setting (APA, 2022).

Although delays in language, motor, or social development often co-occur with ADHD, these delays are not exclusive to the disorder. Emotional dysregulation or impulsivity is commonly observed in both children and adults with ADHD (Erin et. al., 2016). People with ADHD often report being easily irritated, quick to anger, and emotionally over reactive. Their academic or professional performance may suffer, even if there is no diagnosed learning disability. Deficits may be present in various neurocognitive areas, including working memory, set shifting, response inhibition, reaction time variability, vigilance, and planning/organization (Ana et. al., 2023). However, the sensitivity and specificity of these tests are not sufficient to serve as definitive diagnostic markers.

Before the age of four, it can be difficult to distinguish ADHD symptoms from the wide range of normal behaviours, although many parents may first notice excessive motor activity in their toddler (McAndrew et. al., 2024). ADHD is most commonly diagnosed when inattention becomes more noticeable and prevalent during primary school. The condition remains largely stable through early adolescence, although for some individuals, it may worsen as antisocial behaviours emerge. While many individuals with ADHD experience a decrease in overt motor hyperactivity during adolescence and adulthood, impulsivity, poor planning, restlessness, and inattention continue to affect them. A significant portion of children with ADHD experience ongoing impairments into adulthood (Carla et. al., 2017).

Population surveys indicate that ADHD affects approximately 7.2% of children worldwide, although prevalence rates vary significantly across countries, ranging from 0.1% to 10.2% in children and adolescents (Elie et. al., 2022). The prevalence is higher in specific populations, such as foster children or those in correctional settings. In a cross-national meta-analysis, ADHD was found to affect 2.5% of adults. ADHD is more common in males than in females in the general population, with a ratio of about 2:1 in children and 1.6:1 in adults. Females are more likely to primarily exhibit inattentive symptoms. Differences in ADHD symptom severity between sexes may be attributed to varying genetic and cognitive factors (APA, 2022).

For mothers, the expectation of a healthy child is often challenged when a diagnosis of disability is made, whether in infancy or later in life. This diagnosis can significantly impact a mother's happiness and well-being (Ritu et. al., 2016). It may trigger a range of psychological responses in parents, particularly mothers, who often experience it as a crisis requiring substantial psychological adjustment. In India, most individuals with ADHD and similar conditions have traditionally been cared for by their families. However, in modern society, this home-based care has led to numerous negative consequences (Ritu et. al., 2016).

Although numerous studies indicate that genes have a significant impact, researchers are still unsure of the exact origin of ADHD. ADHD most likely stems from a confluence of variables, just like many other diseases. Researchers are examining how the brains of individuals with ADHD differ from those without the illness in terms of neurobiology and brain development in addition to genetics. Additionally, they are researching environmental factors such as social situations, diet, and brain traumas that may raise the likelihood of having ADHD (NIMH, 2011).

Symptoms of ADHD: According to the National Institute of Mental Health (2011), based on their specific symptoms, a person can be diagnosed with one of three types of ADHD:

- 1) *Inattentive:* Mostly symptoms of inattention but not hyperactivity or impulsivity
- 2) *Hyperactive-impulsive:* Mostly symptoms of hyperactivity and impulsivity but not inattention
- 3) *Combined:* Symptoms of both inattention and hyperactivity and impulsivity

Prognosis of ADHD: ADHD symptoms must begin in childhood (before age 12). Symptoms often continue into the teen years and adulthood. The criterion for a diagnosis differs slightly based on age

- 1) Children up to 16 years must show at least six symptoms of inattention, hyperactivity and impulsivity, or both.

- 2) Adults and youth over 16 years must show at least five symptoms of inattention, hyperactivity or impulsivity, or may be both.

Diagnosis of ADHD: To be diagnosed with ADHD, a person's symptoms must also:

- 1) Occur for at least 6 months
- 2) Be present in two or more settings (for example, at home, at work, in school, or with friends)
- 3) Interfere with or impair social, school, or work functioning

ADHD symptoms can be like those of stress, sleep problems, anxiety, sadness, and other health problems or conditions. A health care provider needs to do a thorough evaluation to determine the cause of symptoms, make a diagnosis, and identify effective treatments (APA, 2022).

Primary care providers sometimes diagnose and treat ADHD, or they may refer the person to a mental health professional. During an evaluation, a provider usually (NIMH, 2011):

- 1) Examine the person's mental health and medical history, including their mood and past or current health conditions.
- 2) Look at the person's current or, if an adult, childhood behaviour and school experiences. To obtain this information, the provider may ask for permission to talk with family, friends, partners, teachers, and others who know the person well and have seen them in different settings to learn about behaviours and experiences at home, school, or elsewhere.
- 3) Uses standardized behaviour rating scales or ADHD symptom checklists to determine whether the person meets the criteria for a diagnosis of ADHD.
- 4) Administers psychological tests that look at cognitive skills, such as working memory, executive functioning (abilities such as planning and decision-making), visual and spatial abilities, or reasoning. Such tests can help identify psychological or cognitive (thinking-related) strengths and

challenges and identify or rule out possible learning disabilities. (Benjamin et. at., 2015: DSM - TR).

Treatment of ADHD: ADHD has no cure, but available treatments can help alleviate symptoms and enhance daily functioning. Typical treatments include medication, psychotherapy, and behavioural interventions. For children, treatment often involves educating parents and implementing school-based programs. Researchers are investigating new approaches, like cognitive training and neuro-feedback, though these are typically considered after medication and psychotherapy have been explored. Many individuals benefit from a combination of these treatment methods (APA, 2022).

Psychotherapy and behavioural interventions for ADHD can vary in approach and are often combined with medication and other strategies for parents, families, and educators. Incorporating therapy into an ADHD treatment plan can help individuals better handle daily challenges, build self-confidence, and control impulsive or risky behaviours (NIMH, 2011).

According to NIMH (2011), several psychosocial interventions have been shown to help manage symptoms and improve functioning.

- 1) Behavioural therapy helps a person change their behaviour. It might involve practical assistance, such as organizing tasks or completing schoolwork, learning social skills, or monitoring one's behaviour.
- 2) Cognitive behavioural therapy helps a person become aware of attention and concentration challenges and work on skills to improve focus and organization and complete daily tasks (for instance, by breaking large tasks into smaller, more manageable steps).
- 3) Family and marital therapy helps family members learn to handle disruptive behaviours, encourage behaviour changes, and improve interactions with children and partners.

Therapy for children and teenagers involves active participation from parents. Sessions that focus solely on the child tend to be more effective in addressing symptoms of anxiety or depression that may accompany ADHD, rather than managing the core symptoms of the disorder (NIMH, 2011).

School-based programs: Many children and teens with ADHD benefit from school-based behavioural interventions and academic accommodations. These interventions may include behaviour management plans or teaching organizational and study skills in the classroom. Accommodations can involve preferential seating, reduced classwork, and extended time for tests and exams (NIMH, 2011). Schools often provide these accommodations through a 504 Plan, or for students eligible for special education, an Individualized Education Plan (IEP).

Cognitive training: Cognitive training approaches involve repetitive use of specific programs or activities over several weeks to enhance functions like memory or attention. The exercises are adjusted based on the person's progress (APA, 2022). While cognitive training has been shown to modestly improve the skills being practiced, such as memory, attention, inhibition, planning, and cognitive flexibility in individuals with ADHD, these improvements typically do not extend to core symptoms like impulsivity and hyperactivity (Benjamin et. al., 2015).

Neuro-feedback: Neuro-feedback is a non-invasive method that uses an electronic device to monitor and record a person's brain activity, offering immediate feedback to aid in self-regulation. The device measures brain activity through techniques like EEG or fMRI scans, providing the information back to the individual, often through a computer screen or visual cues. This feedback enables people to learn how to regulate their brain activity, with the goal of directly influencing related behaviours. The idea is that, with repeated real-time data, individuals can modify their internal brain activity, leading to observable changes in behaviour and cognition (Benjamin et. al., 2015).

Neurodevelopmental disorders can disrupt social and economic routines, often affecting the daily functioning of the entire family. Parents typically devote their time and energy to managing behavioural issues, which can lead to their well-being becoming a secondary priority. In addition to the demands of caregiving, parents may experience emotions such as frustration, depression, hopelessness, and emotional sensitivity (Elisa & Patrizia, 2022). Mothers of children with mental and neurological impairments often report a high burden and poor quality of life, according to a comprehensive review on the topic (Reis et. al., 2020).

While many parents cope effectively with these challenges, there are instances where taking on additional responsibilities results in a heavy caregiving load (Goudie et. al., 2014). Numerous studies have shown that raising a child with a neurodevelopmental disorder (NDD) can lead to both psychological and physical health problems for parents, including chronic conditions like back pain and migraines (Brehaut et. al., 2004; Lach et. al., 2009). Higher rates of distress and depression are also linked to this caregiving role. Notably, the severity of the disorder or specific NDD characteristics do not appear to be directly associated with these health issues (Brehaut et. al., 2009). This suggests that parents and children with various medical conditions may experience similar health outcomes and share common needs. Although little is known about changes in the health of parents of children with NDD at the population level, the range of health challenges these parents face presents a significant public health concern.

Research indicates that mothers caring for a child with intellectual and developmental disabilities often face economic disadvantage, limited social and psychological support, a higher likelihood of experiencing stressful life events, and an increased risk of functioning within an unhealthy family environment (Embregts et. al., 2021). Caregivers of children with disabilities frequently report higher levels of stress, depression, and general health concerns. Both Autism Spectrum Disorder (ASD) and ADHD are chronic developmental disabilities that manifest early in childhood, with the recovery process requiring substantial human and material resources for both disorders (Sarah et. al., 2020).

Autism Spectrum Disorder (ASD)

Autism Spectrum Disorder (ASD) is a neurological and developmental disorder that affects how individuals interact with others, communicate, learn, and behave. Although ASD can be diagnosed at any age, it is considered a "developmental disorder" because symptoms typically emerge within the first two years of life (NIMH, 2011). According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), a guide used by healthcare providers to diagnose mental disorders, individuals with ASD often experience:

- 1) Difficulty with communication and social interaction
- 2) Restricted interests and repetitive behaviours
- 3) Symptoms that impact their ability to function in school, work, and other areas of life

ASD is referred to as a "spectrum" disorder due to the wide variation in the types and severity of symptoms experienced. People of all genders, races, ethnicities, and socioeconomic backgrounds can be diagnosed with ASD. Although ASD is typically a lifelong condition, treatments and services are available that can improve symptoms and daily functioning.

Signs and symptoms of ASD: The list below gives some examples of common types of behaviours in people diagnosed with ASD (NIMH, 2011). Not all people with ASD will have all behaviours, but most will have several of the behaviours listed below.

According to APA, 2013, autism spectrum disorder mostly affects

- 1) *Social communication and social interaction behaviours* which may include:
 - a) Making little or inconsistent eye contact
 - b) Appearing not to look at or listen to people who are talking
 - c) Infrequently sharing interest, emotion, or enjoyment of objects or activities (including infrequently pointing at or showing things to others)

- d) Not responding or being slow to respond to one's name or to other verbal bids for attention
 - e) Having difficulties with the back and forth of conversation
 - f) Often talking at length about a favourite subject without noticing that others are not interested or without giving others a chance to respond
 - g) Displaying facial expressions, movements, and gestures that do not match what is being said
 - h) Having an unusual tone of voice that may sound sing-song or flat and robot-like
 - i) Having trouble understanding another person's point of view or being unable to predict or understand other people's actions
 - j) Difficulties adjusting behaviour to different social situations
 - k) Difficulties sharing in imaginative play or in making friends
- 2) *Restrictive/repetitive behaviours* may include:
- a) Repeating certain behaviours or having unusual behaviours, such as repeating words or phrases (a behaviour called echolalia)
 - b) Having a lasting intense interest in specific topics, such as numbers, details, or facts
 - c) Showing overly focused interests, such as with moving objects or with parts of objects
 - d) Becoming upset by slight changes in a routine and having difficulty with transitions
 - e) Being more sensitive or less sensitive than other people to sensory input, such as light, sound, clothing, or temperature
- 3) People on the autism spectrum also may have many strengths, including:
- a) Being able to learn things in detail and remember information for long periods
 - b) Being strong visual and auditory learners
 - c) Excelling in math, science, music, or art

ASD Assessment: According to the National Institute of Mental Health (2011), healthcare providers diagnose autism spectrum disorder (ASD) by assessing a person's behaviour and developmental history. ASD is generally reliably diagnosed by the age of 2. Early diagnosis is crucial because the sooner ASD is identified, the sooner treatments and services can be provided.

ASD Diagnosis: *The diagnosis process in young children is typically a two-stage process:*

Stage 1: General Developmental Screening During Well-Child Check ups

Every child should receive regular well-child check ups with a paediatrician or early childhood healthcare provider. The American Academy of Paediatrics recommends that all children be screened for developmental delays at their 9 months, 18 months, and 24 months or 30 month visits, with specific autism screenings at the 18 months and 24 month check ups. Children who are at high risk for ASD or other developmental issues may undergo additional screenings. Considering the experiences and concerns of caregivers is an important part of the screening process. The healthcare provider may ask questions about the child's behaviours and evaluate those responses alongside information from autism-specific screening tools and clinical observations. If developmental differences in behaviour or functioning are noted, the provider may refer the child for further evaluation.

Stage 2: Additional Diagnostic Evaluation

Early and accurate diagnosis of ASD is crucial, as it provides insight into a child's unique strengths and challenges. Early detection also helps caregivers determine the most appropriate services, educational programs, and behavioural therapies. A team of healthcare providers with experience in diagnosing ASD will carry out the diagnostic evaluation. This team may include child neurologists, developmental-behavioural paediatricians, speech-language pathologists, child psychologists and psychiatrists, educational specialists, and occupational therapists (NIMH, 2011).

The diagnostic evaluation is likely to include:

- 1) Medical and neurological examinations
- 2) Assessment of the child's cognitive abilities
- 3) Assessment of the child's speech and language abilities
- 4) Observation of the child's behaviour
- 5) An in-depth conversation with the child's caregivers about the child's behaviour and development
- 6) Assessment of age-appropriate skills needed to complete daily activities independently, such as eating, dressing, and toileting
- 7) Questions about the child's family history

ASD is a complex disorder that sometimes occurs with other illnesses or learning disorders, the comprehensive evaluation may include blood tests and a hearing test. The outcome of this evaluation may result in a formal diagnosis and recommendations for treatment (Benjamin et. al., 2015).

Diagnosis in Older Children and Adolescents: Caregivers and teachers are often the first to notice symptoms of autism spectrum disorder (ASD) in older children and adolescents, particularly those who are in school. In these cases, the school's special education team may conduct an initial evaluation and recommend that the child undergo further assessment by their primary healthcare provider or a specialist in ASD. Caregivers may discuss the child's social challenges with healthcare providers, including difficulties with subtle communication. These issues may include trouble understanding tone of voice, facial expressions, or body language. Older children and adolescents may also struggle with interpreting figures of speech, humor, or sarcasm and may find it difficult to form peer relationships (NIMH, 2011).

Treatment Options Available for ASD:

Treatment for Autism Spectrum Disorder (ASD) should begin as soon as possible after diagnosis. Early intervention is crucial because appropriate care and services can help reduce difficulties while promoting the development of new skills and building on existing strengths. Since individuals with ASD may experience a

wide range of challenges, there is no one-size-fits-all treatment. Therefore, working closely with healthcare providers to identify the most suitable combination of treatments and services is essential for effective management of the condition (NIMH, 2011).

A health care provider may prescribe medication to treat specific symptoms. With medication, a person with ASD may have fewer problems with:

- 1) Irritability
- 2) Aggression
- 3) Repetitive behaviour
- 4) Hyperactivity
- 5) Attention
- 6) Anxiety and depression

Behavioural, Psychological, and Educational Interventions for ASD:

People with Autism Spectrum Disorder (ASD) may be referred to healthcare providers who specialize in behavioural, psychological, educational, or skill-building interventions. These programs are often highly structured and intensive, involving not only the individual but also caregivers, siblings, and other family members (NIMH, 2011). Such programs can help people with ASD:

- 1) Learn social, communication, and language skills
- 2) Reduce behaviours that interfere with daily functioning
- 3) Build upon existing strengths
- 4) Acquire life skills needed for independent living

The core features of ASD include persistent deficits in social communication and social interaction across various contexts. These deficits can involve difficulties with social reciprocity, nonverbal communicative behaviours used in social interactions, and skills necessary for building, maintaining, and understanding relationships (Lach et. al., 2009).

For a diagnosis of ASD, these social communication difficulties must be accompanied by restricted and repetitive patterns of behaviour, interests, or activities

(Ronan, 2018). Although the current presentation of the disorder must cause significant impairment, the diagnostic criteria may also be met based on historical information. This is because symptoms can evolve with development, and compensatory mechanisms might mask or minimize their expression (NIMH, 2011).

Specifiers in Autism Spectrum Disorder (ASD):

In diagnosing Autism Spectrum Disorder (ASD), specifiers are used to describe individual clinical characteristics and to provide a more detailed and personalized diagnosis. These specifiers help medical professionals note specific features of ASD, such as:

- 1) With or without accompanying intellectual impairment
- 2) With or without accompanying structural language impairment
- 3) Associated with a known genetic or other medical condition or environmental factor
- 4) Associated with a neurodevelopmental, mental, or behavioral problem

Specifiers that describe the specificity of autistic symptoms allow for a more accurate clinical picture of the individual. For example, many individuals who were once diagnosed with Asperger's Syndrome would now be diagnosed with ASD without intellectual or language impairment (APA, 2022).

Intellectual and/or language disabilities, such as delayed language development or slow speech, are common in individuals with ASD (Luyster et. al., 2008). Even individuals with high or average intelligence may have an uneven skill set, often exhibiting a significant gap between cognitive abilities and functional skills.

For example, Theory of Mind deficits—the inability to understand the perspective of others—are often observed in individuals with autism, though not universally. Additionally, challenges related to central coherence (the ability to see the "big picture" rather than focusing on details) and executive function deficits (such as difficulties with planning, organization, and flexible thinking) are common, though they are not unique to ASD (Damian & Jens, 2022).

Motor deficiencies are often noticeable, including clumsiness, unusual motor behaviours (e.g., tiptoe walking), and an irregular gait. Compared to other conditions like intellectual developmental disability, children and adolescents with autism spectrum disorder are more likely to exhibit challenging and disruptive behaviours, such as self-harming actions like head banging and wrist biting (Penelope et. al., 2016).

Males are diagnosed with Autism Spectrum Disorder (ASD) three to four times more frequently than females, and females often receive a diagnosis later in life (Antonio et. al., 2022). In clinical samples, females are more likely than males to exhibit both epilepsy and accompanying intellectual developmental disabilities. This could indicate that girls without intellectual disabilities or language delays may go unrecognized due to more subtle manifestations of social and communication difficulties. While females with ASD face similar social comprehension challenges as males, they may demonstrate better reciprocal conversation, be more likely to share interests, integrate verbal and nonverbal behaviours, and adjust their behaviour depending on the context (Fletcher et. al., 2008; Mosher et. al., 2013).

In some females, the process of concealing or masking autistic behaviours—such as mimicking the appearance, speech patterns, or demeanour of socially successful women—can make the diagnosis more challenging (Lai et. al., 2015). On average, females tend to exhibit fewer repetitive behaviours compared to males (Helene et. al., 2023), and their interests, while still intense, may be more socially acceptable or "normative" (e.g., interests in singing, acting, or horses). Research has shown that gender variation rates in Autism Spectrum Disorder (ASD) are higher among affected individuals than in the general population, with greater variance observed in females than in males (Antonio et. al., 2022).

Neurodevelopmental disorders are more common in males than females (May et. al., 2019), with differences potentially attributed to genetics, biology, and various risk factors. While conditions like Autism Spectrum Disorder (ASD) are more prevalent in males, research indicates that there is not a significant gender difference in the types of symptoms presented. The exact cause of neurodevelopmental

disorders remains unclear (Bale et. al., 2010), though current research suggests both biological and environmental factors contribute. Genetic predispositions and hormones may interact with external risk factors like stress, illness, or trauma, triggering the onset of these disorders (Bale et. al., 2010).

Examples of neurodevelopmental disorders include Autism Spectrum Disorder (ASD), Attention-Deficit Hyperactivity Disorder (ADHD), epilepsy, intellectual disabilities, and various sensory and motor impairments, such as cerebral palsy. Some disorders overlap, as seen in children with epilepsy, where ASD occurs in 22%, ADHD in 33%, and behavioural/emotional problems in 30-50%. Many individuals with ASD also experience intellectual developmental disorders, and children with ADHD often have specific learning disorders (Valerie et. al., 2019).

Neurodevelopmental disorders often co-occur with other mental and behavioural disorders that have onset during childhood. For example, communication disorders and autism spectrum disorder (ASD) can be associated with anxiety disorders, ADHD may co-occur with oppositional defiant disorder, and tics can overlap with obsessive-compulsive disorder (NIMH, 2011).

For many neurodevelopmental disorders, the clinical presentation includes behaviours that are more frequent or intense than those typically observed in children of the same developmental age and gender. Additionally, there may be deficits or delays in achieving expected developmental milestones. For instance, autism spectrum disorder (ASD) is diagnosed when social communication deficits are accompanied by excessively repetitive behaviours, restricted interests, and insistence on sameness (APA, 2022).

Research on the prevalence of neurodevelopmental disorders in children aged 2 to 9 years highlights that ADHD and ASD are the most common conditions. The study found that one in every eight children in this age range has at least one neurodevelopmental disorder (Reis et. al., 2020).

Relationship between Dependent Variables

Quality of Life and Depression

Depression affects one's emotions, thoughts, and behaviour, which has an effect on one's quality of life, particularly for carers (DeokJu Kim, 2017). Depression has a substantial negative impact on the quality of care and affects a person's behaviour, emotions, and cognitive abilities (Tanaka et. al., 2015). Negative self-evaluation is the root cause of depression, which makes it hard to go about daily tasks because it leaves one feeling exhausted and unmotivated. Additionally, it could result in physical discomfort and even suicidal thoughts and actions (Beck, 1986). Hence, it is important to seek solutions to relieve such symptoms and to improve the health of family caregivers of a person with a disability to protect their mental health and to ensure that they lead a healthy family life.

Maternal depression has been linked to paternal depression, a lack of speech development in children, and the child's enrolment in special education services. Similarly, paternal depression is associated with the severity of autistic symptoms in the child and maternal depression (Kutuk et. al., 2021). Research indicates that parenting stress negatively impacts the early learning outcomes of autistic children (Osborne et. al., 2008) and is strongly correlated with the development of depressive symptoms and a decline in quality of life for parents of children with high-functioning pervasive developmental disorders (Suzumura, 2015).

A large-scale cohort study revealed that caregivers of children with ASD face a higher risk of mortality and experience significantly reduced survivorship (Fairthorne et. al., 2014). In addition to high levels of stress, parents of children with ASD are at an increased risk of mental health issues, including elevated depressive symptoms and psychological distress (Bromley et. al., 2004).

Parent management, which reflects parenting behaviour, fully accounted for the link between ADHD and depression in younger children but not in older children (Ostrander & Herman, 2006). Notably, the parent-child relationship has been largely overlooked in exploring how ADHD progresses to depression. To address this gap,

the current study directly examines the role of three potential mediators in the connection between ADHD and depression (Biederman et. al., 1991).

Caregiving is closely linked to caregiver depression, which can have significant consequences for both the caregiver and the person receiving care. Depression contributes additional stress to the living environment, which can negatively affect the functioning of the patient (Zhang & Wu, 2021). Depression is a common and serious medical condition that affects how a person feels, thinks, and acts. It typically causes persistent feelings of sadness or a loss of interest in once enjoyable activities. Depression can lead to a variety of emotional and physical problems and can reduce a person's ability to function both at work and at home. For a diagnosis of depression, symptoms must persist for at least two weeks. The severity of depression symptoms can vary, and they may include: changes in appetite (unrelated to dieting), weight loss or gain, trouble sleeping or oversleeping, increased fatigue, purposeless physical activity (such as hand-wringing or pacing), or slowed movements and speech (observable by others), feelings of worthlessness or guilt, difficulty concentrating, thinking, or making decisions, and thoughts of death or suicide (APA, 2022).

In an ideal situation, positive interactions within the family promote healthy behaviours, self-worth, effective coping strategies, and overall well-being. As social beings, humans naturally seek social connections and a sense of belonging, which significantly contributes to their well-being (Patricia, 2017). However, being in stressful environments can negatively affect an individual's well-being. One potential source of stress is a strained family relationship. Protective resources, such as social support from family members, have been linked to increased feelings of self-worth, optimism, emotional resilience, and a sense of purpose in life. Additionally, this support can contribute to financial stability and improve both mental and physical health (Iryna & Tracy, 2021).

Depression significantly reduces the quality of child care, as it often leads to negative self-evaluation and low self-esteem, making it difficult to perform everyday tasks. Depression can drain energy and motivation, further complicating the

caregiver's ability to care for others (Elena et. al., 2019). Self-esteem is a key factor in how individuals cope with adversity. Rosenberg defined self-esteem as a subjective evaluation of oneself, suggesting that high self-esteem reflects self-acceptance and respect, as well as the belief that one is a valuable person. Self-esteem is a personal evaluation that can be expressed either positively or negatively, influencing how individuals view themselves as capable, important, successful, and valuable. Self-esteem plays a crucial role in fostering a healthy mind set and personality, ultimately guiding individuals toward self-realization (Smith et. al., 2017).

Self-esteem, as a component of self-concept, involves recognizing oneself as a valuable individual. It serves as a mediator for various daily life stressors, acting as both a social resource for individuals with depression and an internal resource that shields them from negative influences in stressful environments (DeokJu Kim, 2017). However, families caring for a member with a disability often experience a decline in self-esteem due to the challenges they face. Low self-esteem can create a harmful cycle where individuals are hesitant to seek help and isolate themselves socially, further intensifying the caregiving burden. On the other hand, individuals with strong self-esteem tend to experience less stress, as they are better equipped to protect themselves from psychological challenges and respond to situations in a more positive manner (Peter & Henry, 2023). Therefore, it is crucial to find ways to support families in improving their self-esteem to enhance their ability to cope with caregiving challenges.

Quality of Life and Anxiety

Anxiety is an emotional response characterized by feelings of tension, worried thoughts, and physical changes such as increased blood pressure. People with anxiety disorders often experience recurring intrusive thoughts or concerns and may avoid situations due to fear. Studies have shown that families of children with disabilities face significant sources of stress and anxiety, including the child's care and education needs, societal attitudes and judgments related to disability, and uncertainty about the child's current and future status (Ozkan, 2002). Research indicates that parents of

children with disabilities experience more stress, higher levels of anxiety, lower self-confidence, higher stigma, and lower self-esteem, compared to parents of children without disabilities. These parents also report lower marital harmony (Cantwell, Muldoon & Gallagher, 2015; Ali & Hassiotis, 2012; Uguz & Toros, 2004; Glidden & Schoolcraft, 2003; Coiro, 2003). The presence of a child with a disability in the family is a significant emotional burden, creating a stressful life experience that requires continuous coping efforts from all family members.

Research indicates that children's ADHD and anxiety symptoms may impact specific aspects of the parent-child relationship rather than broadly affecting it. These effects can vary depending on whether the other condition is present. Notably, the combination of higher levels of inattention and anxiety in children, rather than elevated symptoms in either domain alone, predicts negative parenting outcomes, such as reduced parental confidence (Chan et. al., 2022).

It is important to screen caregivers for both signs and symptoms of anxiety. Differentiating between these signs and symptoms can be challenging, as anxiety and depression share common characteristics such as poor concentration, insomnia, restlessness, and loss of appetite, and they often coexist (Akkerman et. al., 2005; Gatzoyia, 2014).

Although most studies have found no direct relationship between caregiver "burden" and limitations in activities of daily living (ADL), there is a clear association between caregiver burden and depressive symptoms. Overall, caregivers often experience significant burden and distress. However, no study has yet investigated the prevalence and determinants of anxiety and depression in a representative community sample of family caregivers of individuals with neurodevelopmental disorders (Theng et. al., 2023).

Caregivers of children with autism experience a higher level of burden and a lower quality of life across all four domains of quality of life compared to caregivers of children without disabilities. Findings suggest that different childhood conditions lead to varying effects, highlighting the need for adequate parental support when

providing interventions for children with disabilities (Geetanshi, 2021). Caregivers of children with ADHD and ASD experience particularly high levels of burden, with those caring for children with ASD reporting significantly higher levels of stress compared to caregivers of children with acquired brain injuries (Higginson et. al., 2010). Studies have shown that caregiver burden in ADHD is strongly associated with comorbid psychiatric symptoms (Beecham & Knapp, 1992). The unmet needs of caregivers, particularly in terms of social contact, mental health challenges, appropriate daytime activities, personal safety, and communication, are closely linked to the caregiving burden for both ADHD and ASD.

Caregivers of children with ADHD are tasked not only with parenting but also with managing their child's challenging behaviours. In addition to these responsibilities, they must cope with negative public perceptions and questioning from other family members (Ho et. al., 2011). Studies have found that hopelessness is a common experience among caregivers of children with ADHD (Laugesen & Groenkjaer, 2015). Identifying factors related to hopelessness in these caregivers can help inform the development of intervention programs, which would support the well-being of both caregivers and their children with ADHD. A majority of caregivers reported that caring for their child with a disability negatively impacted their economy (70%), physical health (65%), social life (64%), and future aspirations (81%). The study further indicates a high level of psychological distress and a significant overall burden among caregivers of children with neurodevelopmental disorders (NDD) in rural Nepal (Hans, Hanne & Kristen, 2021).

Caregivers of children with attention deficit-hyperactivity disorder (ADHD) and autism spectrum disorder (ASD) experience higher levels of stress compared to caregivers of typically developing children, but there is limited research evaluating the quality of life for these caregivers. Caregivers of children with both ADHD and ASD reported higher odds of difficulty in making decisions together as a family and facing challenges in solving family problems collectively. This suggests that caring for children with ADHD and ASD may significantly impact caregivers' quality of life (Sari, Sara, & Sarah, 2023). Furthermore, caregivers of children with autism

experience higher levels of burden, with about 47.2% reporting severe levels of stress. These caregivers also reported significantly lower quality of life, particularly in physical functioning and energy/fatigue, compared to caregivers of typically developing children (Magda & Osama, 2017).

The presence of psychiatric disorders in parent, the child's school attendance, the duration since the diagnosis of autism, and the child's medication use all influence the quality of life (QOL) of caregivers. Autism significantly affects the QOL of caregivers, and interventions that take these factors into account—whether they positively or negatively impact caregivers' quality of life—can potentially improve their well-being (Borte, Hatice & Erhan, 2018). Similarly, caregivers of children with ADHD experience impairment in all WHOQOL domains, except for the physical domain, which is comparable to the impact seen in caregivers of diabetic patients. This suggests that ADHD negatively affects caregivers' QOL in a manner similar to other chronic conditions. These findings highlight the importance of including caregiver quality of life in treatment strategies and the need for future studies with larger sample sizes to compare how QOL is affected across various chronic disorders (Elisa, Laysan & Paula, 2016).

Caregivers from low-income families and those caring for children aged 6-12 years reported significantly higher levels of burden. A positive correlation was found between the severity of autism and the burden of care, with caregivers experiencing an increasing decline in quality of life as the severity of symptoms grew. The study concluded that caregivers of children with autism spectrum disorder (ASD) face high levels of caregiving burden and impaired quality of life (Amit, Vivek & Puwan, 2020). Additionally, compared to parents of children with physical disabilities and typically developing children, parents of children with ASD showed significant impairments in all four domains of quality of life—Physical, Psychological, Social, and Environmental—as measured by the WHOQOL-BREF. These findings highlight the need for healthcare professionals to develop targeted support groups and psychosocial intervention programs to assist families of children with ASD (Vaithi & Vimala, 2014).

The study found that caregiving stress was positively correlated with depression, and both financial and psychological stress had a significant negative correlation with self-esteem. Moreover, depression and self-esteem were negatively correlated, suggesting that caregiving stress, despite the family's acceptance of the disability, continued to cause significant stress due to the chronic care requirements of the individual. This ongoing psychological burden led to a loss of self-esteem, which ultimately contributed to depression. The findings highlight the importance for caregivers to seek professional help in managing their stress, as continued stress can exacerbate both emotional and psychological challenges (Kim, 2017).

Research suggests that social support may play a key role in alleviating caregiving difficulties, though findings are mixed. The emotional support from family and friends can help reduce subjective caregiver burden, and that families engaged in educational courses perceive less stress compared to those who are not (Heru et. al., 2004). However, stigma associated with mental illness, particularly the societal disregard for patients and their caregivers, can exacerbate caregiving stress. The negative beliefs and attitudes surrounding illness can not only increase the burden experienced by caregivers but also influence how caregivers perceive their caregiving responsibilities (Struening et. al., 2001). These findings suggest that improving social support and addressing societal stigma can potentially reduce caregiver burden.

Research suggests that caregivers' beliefs and attitudes towards illness are strongly linked to their perceived caregiving burden. These beliefs (Chakrabarti & Gill, 2002), are evaluative judgments that caregivers make regarding the demands of the caregiving situation and their available coping resources. Such beliefs often serve as a critical determinant of the subjective burden experienced. For instance, caregivers' perceptions of an illness can significantly affect their burden, and past experiences with healthcare services can influence how caregivers view their role (Ogilvie et. al., 2005).

Research finding highlights that illness beliefs—such as caregivers' perception of their control over the patient's symptoms—are closely tied to their level of

caregiving burden (Perlick et. al., 1999). Caregivers who feel they have control or influence over their loved one's symptoms tend to report lower burden levels, whereas those who perceive their loved one as not trying to manage their condition may experience higher levels of stress and burden. Additionally, study evinced that there is a positive relationship between caregivers' belief that the patient is not attempting to improve and the level of caregiving burden (Karp & Tanarugsachock, 2000). This dynamic extends to siblings as well, with those who feel that the patient could influence their condition but is not making the effort to do so experiencing greater burden and emotional strain, including stigma, worries, and fears (Greenberg et. al., 1997).

This research suggests that the way caregivers perceive illness and their role can significantly impact their well-being, emphasizing the importance of addressing caregivers' beliefs and attitudes in support programs.

Quality of Life and Caregiver Burden

One factor that influences Quality of Life is the caregiving burden, which is described as a load or responsibility (Merriam-Webster, 2024). Caregivers are individuals who assist others in managing daily activities due to their inability to care for themselves. Informal caregivers, who perceive their role as emotionally and psychologically taxing, are particularly susceptible to experiencing subjective caregiver burden, which can negatively affect their physical and mental well-being. Informal caregiving refers to non-professional, unpaid support given to individuals with long-term care needs by family, friends, neighbours, or others, often fulfilling a significant portion of the care requirements (Tough et. al., 2022). Examples include children, the elderly, individuals with chronic illnesses, and those with disabilities. Social workers, medical professionals, friends, family, and clergy can serve as caregivers, assisting in settings such as hospitals, healthcare facilities, or homes (NCI Dictionary of Cancer Terms, 2024).

Numerous studies on carers have documented the wide range of difficulties they face, such as detrimental effects on their mental and physical health, issues with

their relationships with other family members, difficulties at work, and financial limitations brought on by income loss (Sherman et. al., 2008). Primary carers encounter many difficulties and see a decline in their standard of living (Bruder, 2016).

Caregiver burden refers to the emotional distress caregivers experience as a result of providing care. This burden is unique to each caregiving situation and can range from anxiety and depression to other emotional or general responses (Given et. al., 2001). Caregiving burden encompasses several areas, including physical (Fletcher et. al., 2008; Mosher et. al., 2013; Osse et. al., 2006; Stenberg et. al., 2010), psychological (Braun et. al., 2006; Deshields et. al., 2012; Grunfeld et. al., 2004; Mosher et. al., 2013; Osse et. al., 2006; Song et. al., 2011; Stenberg et. al., 2010; Williams & McCorkle, 2011), social (Deshields et. al., 2012; Goldstein et. al., 2004; Song et. al., 2011), and financial (Deshields et. al., 2012; Song et. al., 2011; Yun et. al., 2005) aspects. Physical burdens such as sleep disturbances, fatigue, and pain are commonly experienced by caregivers.

For assistance with their physical, social, and emotional needs, a disadvantaged kid often looks to their family, particularly the mother (Neely & Dia, 2008). A kid with a neuro-developmental disability is very challenging for parents to care for, and they are more likely to experience additional psychopathologies including anxiety and depression (Peter & Monica, 2021). Studies have shown that anxiety and despair affect as many as 68% and 52% of these moms, respectively (Swapnajeet et. al., 2023). Mothers are known to experience greater rates of depression as a result of the strain of balancing the needs of their children with home responsibilities (Saltanat et. al., 2023).

When raising children with neurodevelopmental disorders (NDDs) and emotionally demanding behaviours, parents' experiences are typically not based on traditional parenting techniques (Williams & Murray, 2015). The bulk of care for children with intellectual and developmental disabilities is provided by mothers, including community-based care and coordination of care needs with doctors. Mothers are therefore more vulnerable to burnout and stress (Lafferty et. al., 2016).

Mothers who care for children outside the traditional norms of motherhood often face oppression and marginalization. Both mothers and their children are forced to navigate the world as outsiders due to this exclusion. Parents caring for children with disabilities encounter various personal, social, and structural challenges, which can be intensified and require significant effort to manage (Williams & Murray, 2015). Unrealistic societal expectations of parenting can lead to feelings of disconnection and vulnerability (Brock, 2014; Fernandes & Robertson, 2019; Robertson, 2014). One of the primary goals of parenting is to raise a "good" child. However, mothers of children with complex neurodevelopmental disorders (NDDs) are often described as being marginalized, as their parenting experiences do not align with conventional expectations. These children, with their behavioural differences, challenge the typical "text" of mothering (Carpenter & Austin, 2007). Despite their efforts to engage in social activities, mothers face limitations imposed by societal standards of what defines a good mother and child (Robertson, 2014). Families may experience feelings of shame and exclusion when their child behaves in ways that deviate from societal norms (Carpenter & Austin, 2007). As a result, medical issues often remain unresolved, and families receive minimal support. Children who display disruptive behaviour are frequently rejected, as their actions contradict social or moral expectations. The narratives of these mothers are viewed as "troublesome" and their ability to manage their children's issues is often labelled as inadequate (Austin & Carpenter, 2008).

Mothers of children with neurodevelopmental disorders (NDDs) often face apathy and disengagement from friends, family, and healthcare professionals (Austin & Carpenter, 2008). These mothers, dealing with unusual and unexplained symptoms in their children, struggle to obtain proper treatment, support, and care, which often requires the involvement of multiple systems. Due to a lack of medical experience and understanding of how to address complex medical and behavioural issues, parents who raise concerns with healthcare providers often feel uncomfortable, rejected, and overlooked (Fernandes & Robertson, 2019). Consequently, medical problems remain unresolved, and families receive minimal assistance. Children exhibiting disruptive behaviour that deviates from societal or moral standards often

face rejection as well. According to Austin and Carpenter, mothers' experiences are seen as socially "troublesome" and they are regarded as "troubled" for their inability to manage their children's challenges effectively.

Three prominent modern theoretical models explain how social connections influence the relationship between caregiver stress and health. The first is the buffering model, which suggests that social interactions act as a moderating factor, lessening the negative impact of caregiver stress on health. Although this concept has yet to be fully proven, several studies have demonstrated that social support can reduce the harmful effects of objective caregiver burden—such as the time spent caregiving—on subjective burden, as well as on caregiver distress and depression. It is believed that social support and high-quality relationships—those that are reciprocal, supportive, and trusting—equip caregivers with resources to perceive their situation as less stressful, while also providing practical assistance to reduce caregiving burdens and promote healthier behaviours (Brooke & Nancy, 2017).

It remains uncertain whether social support, or social relationships in general, can alleviate the negative effects of subjective caregiver burden on health, despite research suggesting that it may protect caregivers from experiencing caregiving strain. The second model, the degradation model, posits that relationships suffer due to the subjective caregiver burden, which, in turn, harms health (Susan, 2012). For example, the additional responsibilities of caregiving in a partnership can cause stress and strain, ultimately deteriorating the quality of the relationship. The third model, the counteractive model, offers an alternative to the degradation model. It suggests that individuals become more resourceful within their existing social networks under stress. Applied to caregiver burden, this model hypothesizes that caregiving may prompt individuals to mobilize their current resources, increasing both perceived and actual social support, which can have positive effects on health. However, there is currently no empirical evidence to support the counteractive model in the caregiving context (Brinkhof et. al., 2022).

Up until now, a lot of studies have focused on the impact of caregiving on carers. These studies have shown that carer burden is measurable and comprises both

objective and subjective elements. Furthermore, some antecedent features have been linked to higher carer load in previous studies. These variables include the care recipient's age, race, and income; the caregiver-care recipient relationship; the care recipient's residence; the care recipient's disease characteristics; and the care recipient's needs (Hughes et. al.,1999). Research on demographic factors has shown that younger carers bear a greater burden than older carers (Fitting & Rabins, 1985), while gender has a variable relationship with burden (Miller & Cafasso, 1992).

Children with developmental delays and disabilities are more likely to face poor mental, physical, and emotional well-being, as well as learning challenges. In India, where there is a stigma surrounding childhood mental illness and limited understanding of such conditions, community learning programs focused on children with neurodevelopmental disabilities (NDDs), such as autism, are crucial. These programs can raise awareness and reduce stigma. Early detection and intervention can help alleviate stress on families, reduce the burden on the individual, and lessen the societal impact (Renuka et. al., 2017). Caregivers, especially mothers, often report inadequate sleep, lack of exercise, irregular and unhealthy eating habits, and neglecting their own health needs (Lisa, 2021). These behaviours have been linked to clinical anxiety, depression, social isolation, increased stress, and a diminished quality of life. Additionally, the family's socioeconomic status can heighten the risk of psychological issues among mothers of children with cognitive impairments (Borst et. al., 2010).

Children with neuro-developmental disorders benefit most from policies and programs that address the overall burden of psychiatric morbidities associated with poor child outcomes (Mahbub et. al., 2022). Research on the consequences of raising children with NDD and their susceptibility to various psychopathologies in India is lacking (Purva et. al., 2022). Closing this gap is essential since the mother's health has a direct impact on her child's health and the family's health (Asfana & Komal, 2023).

Caregivers of children with autism experience a higher level of burden and a lower quality of life across all four domains of quality of life, compared to caregivers

of children without disabilities. Research suggests that the effects of caregiving vary depending on the specific childhood condition, highlighting the importance of providing adequate parental support during interventions for children with disabilities (Geetanshi, 2021). Caregivers of children with ADHD and autism spectrum disorder (ASD) report very high levels of burden, with the burden being significantly higher in the ASD group compared to those caring for children with acquired brain injury (Higginson et. al., 2010). Studies also show that caregiver burden for ADHD is significantly associated with comorbid psychiatric symptoms (Beecham & Knapp, 1992). The unmet needs of caregivers significantly contribute to their burden, with these needs being closely related to factors such as social contact, major mental health issues, suitable daytime activities, safety, and communication difficulties for both ADHD and ASD caregivers.

While some families create stronger ties with each other and employ a variety of strategies to provide successful care for their child or family member with a disability, other families experience higher levels of stress, conflict, and discontent among their members (Mathew et. al., 2020). Increasing family tensions because of low self-esteem, despair, anger, and unhappiness on the inside; on the outside, show up as physical strain, time constraints from childcare and job, and financial issues (Nicholas et. al., 2022). Extreme and ongoing family disputes and tensions brought on by unresolved feelings and emotions have the potential to eventually cause the family to drift apart. In varying degrees, the majority of families with a handicap family member deal with stress and depression symptoms as a result of their caregiving duties (Elizabeth, 2023).

It has also been shown that the load is increased by the disease characteristics of the care recipient. It has been demonstrated that certain types of caring duties increase workload. According to Gottlieb and Rankin (1994), carers who assist patients with behavioural problems and/or everyday living activities are under more stress than those who assist with other care needs.

Quality of Life and Coping Strategies

Coping is defined as the cognitive and behavioural efforts made to manage external and internal demands that are perceived as overwhelming or exceeding one's available resources. Early conceptualizations, such as those by Lazarus & Folkman, highlighted coping as a reaction to stressful events, focusing on managing or regulating responses to these challenges. More contemporary definitions (Skinner & Wellborn, 1994; Compas et. al., 2001), broadened the understanding of coping by emphasizing the proactive nature of coping efforts, including the regulation of emotions, thoughts, behaviours, and even physiological responses to stressors.

Findings also showed that mothers of children with ADHD tend to use problem-focused coping more often than emotion-focused coping when dealing with depression, anxiety, and stress. Bailey's study also found that problem-focused coping was more commonly used by mothers of children with ADHD than emotion-focused coping (Bailey, Barton & Vignola, 1999). Similarly, another study revealed that mothers were more likely to employ rational/problem-focused strategies, which were found to be more effective for mothers of children with ADHD (Bailey, 1999).

Parents who use emotion-focused coping strategies tend to experience higher stress levels compared to those who adopt problem-focused strategies. As a result, families generally cope better when they follow problem-focused strategies rather than emotion-focused ones (Knussen & Sloper, 1992).

Emotion-focused coping was most commonly used by parents of children with ASD (Sivberg et. al., 2002; Smith et. al., 2008). On the other hand, parents of children with ASD frequently employed problem-focused coping mechanisms (Pepperell et. al., 2018). Qualitative research also indicated that parents of children with ASD used both problem-focused and emotion-focused coping strategies (Gona et. al., 2016) that are consistent with earlier findings (Lin et. al., 2008).

There is a notion of coping as "conscious volitional efforts to regulate" these aspects in response to stress (Compas et. al., 2001), further acknowledging that coping processes can be both internal (emotional and cognitive regulation) and

external (behavioural responses and environmental adjustments). These more recent definitions share several key features:

- 1) Reaction to Stress: Coping is inherently a response to stress—whether acute or chronic—reinforcing the idea that coping efforts arise in reaction to perceived challenges or demands.
- 2) Intentional Effort: Coping involves purposeful and goal-directed actions, indicating that individuals consciously mobilize resources and strategies to manage stress.
- 3) Self-Regulation: There is a growing emphasis on the regulation aspect of coping, where individuals not only manage stressful situations but also regulate their emotions, thoughts, behaviours, and physiological states to maintain balance.

Overall, contemporary definitions of coping have expanded the scope of its processes beyond mere management, incorporating the regulation of multiple aspects of an individual's experience to adapt to stress. This broadened perspective on coping is particularly relevant in understanding how individuals navigate complex stressors, including caregiving situations, and manage their well-being under pressure.

Managing a wider range of functions, including emotion, behaviour, cognition, physiology, and the environment, is now included in the concept of coping. The fundamentals of coping and the subtypes that best capture the range of coping mechanisms remain controversial despite this increasing consensus. Skinner and colleagues (2003) pointed out that although more than 400 coping subtypes have been studied, the process of determining the structure of coping has not progressed rapidly. As a result, even while there has been considerable progress in clarifying the conceptualisation of coping in its widest sense, there is still confusion regarding the structure and subtypes of coping.

Coping refers to the use of psychological resources and strategies to address, modify, or manage stressful situations or crises. Raising a child with intellectual and developmental disabilities presents a significant crisis. The way parents react to the stresses of caregiving is influenced by various factors, including their perception of the crisis, the support available from family and community, and the structure of their family.

A family's capacity to cope is influenced by the members' personalities, financial situation, educational attainment, problem-solving abilities, and spirituality. Parental adjustment is also influenced by social support and strong marital ties (Thwala, Ntinda & Hlanze, 2015; Emerson, 2003; Fazil, Wallace & Singh, 2004). Coping strategies aim to balance family functioning, lessen the cause of stress or negative emotions, and preserve or improve family resources. Efforts to ignore or minimise the situation are less adaptive than techniques that are explicitly targeted at coping with the source of stress, such problem-solving and information-seeking.

Folkman & Lazarus (1985) suggested that coping with stress is a dynamic process, with coping strategies evolving over time and in different contexts to meet the changing demands of stressful situations. Previous research has shown that positive coping strategies are linked to better mental health outcomes, while negative strategies are associated with maladaptive mental health effects (Lazarus & Folkman, 1984; Skinner & Zimmer-Gembeck, 2007; Taylor & Stanton, 2007). Similar patterns have been observed among parents of children with ASD. Factors such as the child's age and symptom severity (Gray, 2006; Ingersoll & Hambrick, 2011), the parent's personality (Ingersoll & Hambrick, 2011), and family functioning (Altiere & von Kluge, 2009) have been found to influence parenting stress. Additionally, adaptive coping strategies among parents of children with ASD are positively related to lower levels of depression and anxiety, while maladaptive strategies are negatively associated with these symptoms (Benson, 2011; Smith et. al., 2008).

Although there is a wealth of research on stress coping strategies, variables, and outcomes connected to ASD (Benson 2011; Grey 2006; Hayes and Watson 2012), it is less clear how parents and carers cope with ASD in various contexts and

individuals. The dynamic and stressor-dependent nature of coping has been highlighted in earlier research, indicating that general coping frameworks as previously developed might not be universally applicable to all parents and carers of children with ASD (Pakenham et. al. 2005; Skinner & Zimmer-Gembeck 2007). This makes it a crucial area for additional research. Nevertheless, there are currently few concluding assessments on the nature of stress coping in parents and other carers of children with ASD.

Quality of Life and Coping Mechanisms: Data from several studies show that while emotion-focused coping strategies are positively associated with more maladaptive mental health outcomes in parents of children with an NDD (Hassall, Rose, & McDonald, 2005; Hastings et. al., 2005), problem-focused and social support-seeking coping strategies are positively associated with lower parental stress and higher positive moods (Arzani, Valizadeh, Zamanzadeh, & Mohammadi, 2015; Guralnick, 2012). The parenting of children with ADHD exhibits similar trends: research has demonstrated a negative correlation between anxiety symptoms and adaptive and maladaptive coping strategies, and a positive correlation with depression symptoms (Theule, Wiener, Rogers, & Marton, 2010).

According to some researchers, the actions of kids with ADHD cause parents to become more stressed, which leads to bad parenting practices (such inconsistent discipline and physical punishment) that encourage the kids' inappropriate behaviour. This clarifies the connection between children's ADHD symptoms and parenting stress (Muñoz-Silva et. al., 2017; Patterson, 2002). Children's externalising behaviour problems have a greater influence on parenting stress than the challenges they face (Mackler et. al., 2015).

Carers use a range of coping strategies to manage a patient's handicap and the various caring duties at hand. The caring role may also be influenced by the nature of the partnership. For example, the caring duties of a spouse differ from those of a parent (Elena, 2021). Cultural traditions and socioeconomic standing might also have an impact on the type of caregiving role. For instance, caring for the other family

members is the main duty of an adult female in Western countries. If these duties change as a result of this woman's illness, there may be a substantial caregiving load.

Appraisal is the main component in the so-called stress-appraisal-coping paradigm, which can be used to describe the caregiving process (Chakrabarti & Gill 2002). Caregiving can be viewed as a stressor in life, and how an individual responds to this stressor is influenced by both their personal characteristics and the circumstances of the caregiving situation. The patient's condition, the quantity of labour they have to do, their own psychological well-being, and their evaluation of the patient's support network are all elements that influence a caregiver's ability to manage a patient's illness. Other noteworthy associations have been discovered between these mediating traits and the specific coping mechanisms employed by carers.

First, among other things, Chakrabarti & Gill (2002) distinguish between emotion-focused and problem-focused coping strategies. The patient's increased social activity, positive communication, and quest for additional information about the condition are typically components of problem-focused approaches. Emotion-focused strategies include avoidance, coercion, compliance, resignation, seeking spiritual help, and drug and alcohol use. Two more flexible methods are engaging in conversations with friends and engaging in personal interests.

There is a favourable correlation between carers' financial status and the information they search for. Collusion, coercion, and seeking spiritual assistance are associated with patient age, marital status, and duration of sickness. Higher levels of patient dysfunction are associated with caretakers having fewer friend discussions (Choy et. al., 2022). Higher caring load scores are negatively correlated with positive communication. Illness unawareness is associated with positive communication, talking to friends, and less frequent but greater levels of social connection. Carers who have more access to social assistance are less likely to engage in collusion (Choy et. al., 2022).

Managing the ambiguity of mental illness and leading a "normal" life were the primary concerns of family members. It was found that caring for patients at different stages of their illness involved different roles and responsibilities. First, the relative has to cope with the uncertainty of the diagnosis, which means they have to be on guard, risk losing their trust, allowing the illness to take over, and try to make sense of the patient's behaviour. During this phase of the patient's illness, the caregiver's goal is crisis management; hence, coping strategies may involve assessing one's own strengths, focussing on the illness, and being cautious (Rose et. al., 2002).

In the second stage of the illness, the focus shifts to managing the patient's condition. Family members must navigate their losses, process their grief, and assess their responsibilities. As a result, the primary objectives of the caregiver during this phase are containment and control (Laura & David, 2018). Coping strategies at this stage often involve setting boundaries with the patient, maintaining therapeutic engagement, and using common sense. In the third stage, the focus of care transitions to the patient's perception of reality and available options. There may be efforts to restore connections, hope, stability, growth, and a sense of resolution. During this phase, caregivers strive to achieve some sense of normalcy for the patient. Coping strategies may include dealing with stigma, minimizing losses, changing perspectives, and taking on roles as a communicator, teacher, and advocate. The goal for caregivers is to help the patient regain a semblance of normalcy during this stage of the illness (Susan & Stephen, 2021). Psychological coping strategies include emotional responses (crying, denial, upset), cognitive responses (positive thinking, information, problem-solving), and behavioural responses (hobbies and action-oriented pursuits). Lastly, social coping strategies include social support, community resources, professional support, spiritual support, respite care, and group/self-help groups (Huang et. al., 2008). These are known coping strategies used by carers. These are a few instances of physical coping mechanisms.

Furthermore, it has been demonstrated that the family and carers of people with severe mental illness can affect how the illness progresses and the chance of recurrence; for this reason, it is essential to consider the coping strategies of that

person or family (Rudnick, 2004). Supporting the well-being of carers and assisting them in navigating support systems and coping mechanisms can ultimately improve family dynamics and benefit the person with a significant mental illness (Crowe & Lyness, 2014).

Best practices will be guided and informed by an understanding of the coping strategies used by carers for individuals with a diagnosis of a severe mental illness. According to research, people with serious mental illnesses who have carers are more unlikely to relapse and have better health (Romi & Melamed, 2007; Crowe & Lyness, 2013; Bland & Foster, 2012; Solomon & Draine, 1995; Williams et. al., 2014).

There is a lack of research on how carers manage the caregiving burden despite the growing number of carers as a result of the deinstitutionalisation of mental health care, despite the fact that numerous other studies have emphasised the significance of offering pertinent and evidence-based interventions to support the psychosocial wellbeing of carers of individuals diagnosed with severe mental illness (Ho et. al., 2005) based on resilience theory (Green, 2002) as well as stress and coping theory (Lazarus, 1993). According to the stress and coping hypothesis, a person must first determine how they have evaluated a circumstance or transaction—have they deemed it stressful, unimportant, or benign-positive? (Eisdorfer, 1981; Lazarus, 1993).

Coping mechanisms used by parents of ADHD children and parents of typical children were compared in a study for children with ADHD carers. Parents of children with hyperactivity who were referred to a clinic were found to be less able to cope with their children's behavioural issues and to be generally less successful than parents of children who were not referred to a clinic. Woodward and associates looked at child and family factors related to the clinical referral of pervasively hyperactive children versus non-clinic-referred pervasively hyperactive children living in the same geographic area (Woodward et. al., 1997). Furthermore, compared to children in the community, clinic-referred children were far more likely to receive

forceful discipline (screaming, threatening, and slapping), and parental control was less successful.

In a study by Woodward and colleagues, it was found that parents of hyperactive children were less attuned to their children's needs and were less effective at managing their children's behaviour compared to parents of healthy children (Woodward et. al., 1998). Children whose parents struggled more with managing behavioural problems were 3.3 times more likely to be hyperactive, and 2.5 times more likely to be hyperactive if their parents employed harsh and aggressive disciplinary methods. Bailey and colleagues observed that mothers of children with ADHD tended to use more indirect coping strategies, such as seeking support and avoiding direct confrontation, compared to mothers of typically developing children (Bailey et. al., 1999). The study highlighted that mothers of children with ADHD used coping strategies more frequently, suggesting that the continuous need to monitor, manage, and cope with their child's behaviour is particularly draining on both their physical and psychological resources.

Coping among Parents of Children with ADHD: Study evinced the relationship between coping strategy and familial quality of life and emotion-focused coping strategies were associated with a poorer quality of life (Cappe et. al., 2016). Study compared cognitive coping strategies of mothers of children with ADHD and those with ASD (Predescu & Şipoş, 2013). The coping strategy of the mothers of children with ADHD that negatively impacted their overall family quality of life was the "blame others" strategy. The connection between coping strategies and depression symptoms in parents was found to correlate with depression ratings on a scale (McKee et. al., 2004) that higher levels of depression were linked to more avoidant-focused coping, less adaptive-focused coping, and reduced seeking of social support. Fathers showed an avoidant-focused coping which was significantly associated with depression.

Coping among Parents of Children with ASD: Several studies examined the relationship between coping strategies and parental stress such as stress proliferation, perceived stress as a threat or loss, and global parental stress. Of the five types of

tools used, three highlighted the negative impact of emotion-focused coping on stress. Parents who used emotion-focused coping tended to perceive their experiences as threats or losses (Cappe et. al., 2017). Additionally, there was a link between parental stress and coping, with increased use of coping strategies correlating with higher stress levels. Wang and associates found similar results with negative coping, while active coping was associated with lower stress levels as it was used more frequently (Dabrowska & Pisula, 2010). Moreover, parents who employed problem-focused coping tended to view their experiences as a challenge. Benson's study identified three significant effects of coping strategies on stress proliferation: the use of disengagement, engagement, and cognitive reframing was linked to an increase in stress proliferation (Cappe et. al., 2017).

A study on coping strategies for parents of children within the autism spectrum (ASD) identified two main dimensions of coping techniques: emotion-focused coping, which aims to manage emotional distress related to the problem, and problem-focused coping, which involves taking action to address the problem causing the distress (Haytham, 2022). Additionally, there has been limited evaluation of the effectiveness of the various coping technique questionnaires used in existing literature. A multifactorial study suggested that coping strategies influence the quality of life by interacting with perceived stress, other transactional variables, and a range of individual and environmental factors (referred to as "antecedents"). Parental characteristics such as age, gender, marital status, and employment status have been found to impact the experiences of parents with children diagnosed with ASD.

In a review of coping mechanisms used by parents of children with ASD, problem-focused coping and social support were the most common techniques (Lai & Oei, 2014). They also found connections between these coping mechanisms and specific traits of both the parents and the children. Parents of children with ASD tend to employ active-avoidance coping strategies more frequently compared to parents of typically developing children (Lai et. al., 2014). Similarly, Pisula and Kossakowska discovered that parents of children with ASD scored higher on the escape-avoidance coping scale than parents of typical children. Dabrowska and Pisula (2010) further

noted that parents of children with ASD reported lower scores in seeking social support compared to parents of typically developing children.

Quality of Life (QoL) can be influenced by several factors and is an important aspect of general well-being. The emotional and behavioural reactions of mothers to having a child diagnosed with a mental illness are often shaped by the level of emotional distress they experience and the cognitive coping strategies they employ (Elena & Rexana, 2013). Various psychological assessments have been used to measure parents' emotional discomfort (Profile of Affective Discomfort), cognitive coping strategies (Cognitive-Emotional Regulation Questionnaire), and family QoL (Family Quality of Life Survey). The two groups did not show significant differences in terms of QoL or mental discomfort. Coping mechanisms such as positive refocusing, positive re-evaluation, and catastrophizing were used by mothers of children with ASD and were found to significantly correlate with their overall assessment of family quality. The results suggest that adaptive coping strategies are linked to a higher family quality of life, whereas maladaptive strategies are associated with lower QoL (Silvia et. al., 2022).

A systematic evaluation was conducted to assess the coping mechanisms used by parents of children with Attention Deficit Hyperactivity Disorder (ADHD). ADHD symptoms often interfere with family life, and as a result, parents of children with ADHD utilize a range of coping strategies. The aim of this systematic review was to compile a comprehensive list of the coping mechanisms employed by these parents, identify the most commonly used instruments for measuring coping mechanisms, and explore the variables that influence how parents cope with the challenges of raising a child with ADHD (Francesco & Rosa, 2020).

Coping strategies are assessed using a variety of instruments. Research has shown that compared to parents of typically developing children, parents of children with ADHD are more likely to use avoidant-focused coping strategies (Charles et. al., 2005). Additionally, mothers of children with ADHD are found to use more indirect coping methods and actively seek out more support compared to mothers of typically developing children (Moutafi, 2023). This review highlights the importance

of investigating the coping strategies of parents of children with ADHD, as it is crucial to help them develop healthier coping mechanisms and provide access to resources for support (Francesco, 2020).

CHAPTER-II

REVIEW OF LITERATURE

REVIEW OF LITERATURE

Neurodevelopmental disorders encompass a wide range, from specific learning or executive function difficulties to more generalized impairments in social skills or intellectual abilities. Previously thought to be clearly defined, modern approaches to measuring these symptoms now show a spectrum of intensity, often without a clear boundary between typical and atypical development (APA, 2022).

Due to their disruption of social and economic norms, neurodevelopmental diseases frequently impact the daily functioning of the entire family. As parents devote their time and energy to correcting misbehaviour, activities that support their own wellbeing are neglected. Furthermore, irritability, sadness, pessimism, and emotional hypersensitivity are displayed (Elisa & Patrizia, 2022). Mothers of children with mental and neurological disorders express significant burden and a low quality of life, according to a comprehensive study on the topic (Reis et. al., 2020).

Since quality of life is seen as a crucial outcome of chronic health conditions but lately gained popularity and been suggested for clinical care and clinical studies (Puka et. al., 2020). Quality of life (QOL) is an important outcome for the monitoring and treatment of neurocognitive developmental disorders and disabilities (NDD) as well as for understanding the difficulties and experiences of patients and their families. It is a complex construct that captures how each individual subjectively views their degree of independence, social functioning, psychological well-being, and physical health (Conway et. al., 2020).

Since neurocognitive developmental disorders and disabilities (NDD) are marked by impairments or comorbidities in many domains of function, it should not be surprising that children with NDD and their families experience lower quality of life (QOL) than peers (Puka et. al., 2020). Therefore, QOL measures transcend a one-dimensional focus on symptoms and are not interchangeable with diagnostic instruments that evaluate symptoms or inadequacies (Conway et. al., 2020).

The quality of life of primary caregivers is most impacted in the physical health domain, where it typically scores the lowest. Key predictors of caregiver

quality of life include family type and the caregiver's knowledge of the child's condition (Aparna, Naim, & Pooja, 2019). Parents of children with disabilities are often more likely to experience heightened levels of stress, which in turn negatively affects their quality of life (Browne & Bramston, 1998). Studies suggest that approximately 35% to 53% of parents of children with disabilities may struggle with depression, although the literature suffers from small sample sizes and inconsistencies in measurement methods (Olsson & Hwang, 2001). According to Veisson (1999), research on depression among parents of children with disabilities produces conflicting results, with some studies reporting higher levels of depression and others finding no difference compared to parents of typically developing children (Glidden & Schoolcraft, 2003). Furthermore, researchers (Sanini, Brum & Bosa., 2010) emphasize that the ongoing and continuous caregiving role of mothers can act as a significant stressor, potentially leading to depression.

Prior research indicates that compared to other carer types, parents of children with ASDs had worse QOL scores in the majority of categories. Perhaps since parents are usually the child's primary carers, this conclusion was reached in a Saudi Arabian study. Surprisingly, in the categories of social functioning and emotional well-being, brothers of children with ASDs did the poorest. The Saudi Arabian culture's strong familial bonds may be the cause of this, as siblings are expected to actively participate in their care, which puts a lot of stress on those siblings who look after one another (Al-Jabri et. al., 2021).

Caregivers' socio-demographic factors significantly influence their quality of life. However, it remains unclear whether older caregivers have a poorer quality of life (Lima et. al., 2022). Female caregivers often report lower quality of life, which may be attributed to traditional family roles across various cultures (Hsia et. al., 2020; Cohen et. al., 2021). Caregivers facing lower socioeconomic status, lower education levels, and unemployment, or financial difficulties tend to experience higher rates of depression and anxiety, as well as lower quality of life scores, whether the individual they care for has mental or non-mental illnesses (Grover et. al., 2017; Geng et. al., 2018; Ribe et. al., 2018). Studies examining the effect of caregiving

duration on quality of life have yielded mixed results (Ukpong et. al., 2021). Caregivers' psychological factors, such as self-esteem and psychological distress, are also strongly linked to their quality of life. Common forms of psychological distress among caregivers include anxiety and depression (Grover et. al., 2017; Stanley et. al., 2017). The quality of life of caregivers of children with neurodevelopmental disorders is an important area of study, as it acknowledges their health and well-being while highlighting the daily challenges they face due to their child's health conditions, illness, or treatment (Gislaine et. al., 2019).

Quality of Life and Depression

Research findings revealed that parents of children with ADHD reported poorer family QoL and higher levels of parental depression and anxiety (Cussen et. al., 2012). QoL between patients with psychiatric disorders and a control group showed that patients with mental illnesses were less satisfied with their lives compared to those in the normal control group (Akvardar et. al., 2006). A systematic review of coping strategies in parents of children with ADHD, noting that ADHD's impact is profound not only on the patients but also on their families (Craig et. al., 2020). The caregiving role often leads to family, marital, and parental issues, reduces parenting efficacy, and increases parental stress (Danckaerts et. al., 2010). Additionally, feelings of guilt that accompany ADHD caregiving increase vulnerability to depression (Johnston & Mash, 2001) and result in a worsened quality of life (Faraone et. al., 2005).

Caregivers of children with mental and behavioral disorders face significant challenges, including a higher prevalence of depression and lower quality of life compared to those of children without such conditions. Studies indicate that caregivers' quality of life is further impacted by socioeconomic factors, such as lower education, financial problems, and unemployment, which are associated with higher levels of depression and anxiety (Grover et. al., 2017; Geng et. al., 2018; Ribe et. al., 2018).

Zanin & Batista (2012) assessed anxiety, depression, and quality of life in caregivers of children with neurodevelopmental disorders and found that 49% of caregivers experienced anxiety, while 31% had depression. The study also revealed that caregivers had a low quality of life, exacerbated by the physical and emotional toll of caregiving. The routine demands of care contribute to stress, worry, sadness, and insomnia, along with physical symptoms like hypertension and muscle soreness, underscoring the need for healthcare and mental health support for these caregivers.

Study highlights the significant risk of depression among family caregivers of children with disabilities, particularly focusing on both parents and grandparents (Chen et. al., 2023) and found that 34.8% of the total sample screened positive for depression, with 11.1% experiencing moderate to severe depression. Among parents, 11.3% were screened for moderate to severe depression, while 10.3% of grandparents were affected. It was also showed that mothers (38.2%) had a higher risk of depression compared to fathers (24.3%), and grandmothers (38.6%) faced a higher risk than grandfathers (21.1%). The main factors are depression for both parents and grandparents along with family cohesion and the availability of barrier-free environments, emphasizing the importance of supportive family dynamics and accessibility in reducing the risk of depression. Additionally, it identified intergenerational differences in how depression risk was influenced by factors like caregiver education, children's sleep problems, mood swings, and house ownership, highlighting the need for targeted interventions that consider the specific needs of both parents and grandparents caring for children with disabilities.

The study among caregivers of children with intellectual disabilities revealed that 79% of caregivers were at risk of clinical depression, even though none had been previously diagnosed by a clinician. The high prevalence of depression risk was attributed to financial stress, social isolation, loss of friendships, and the stigma associated with caring for a child with intellectual disabilities (Dzienkowski et. al., 1996). In addition, family units have become smaller (Dzienkowski et. al., 1996) and the rate of marriage break down has increased (Raina et. al., 2004) with increases in the magnitude of responsibility on the intellectual disability in small nuclear families.

There was a positive significant correlation between unemployment and depression risk, as caregivers who were unemployed faced additional emotional and financial strain. Inadequate community-based resources, such as insufficient schools for intellectually disabled children and lack of adequate medical facilities, compounded the financial burden on caregivers. The emotional impact of caregiving was also reflected as nearly half (44.7%) of the caregivers at risk of depression were married, suggesting a lack of emotional support from spouses. It confirmed that gender was a significant factor, with female caregivers being more vulnerable to depression, aligning with findings from other researches.

It is also important to note that the economic situation in Kenya dictates that people work long hours with little pay especially if they are in nonskilled employment. This coupled with the fact that there are few institutions or organizations that school or take care of the intellectually disabled makes the role of caregivers enormous. The caregivers are usually the mother of the child, elderly family members, or the unemployed members of the family who do not normally plan to be caregivers (Eicher & Batshaw, 1993) but find the need unavoidable. The caregivers do not receive preparation for this role and find it very demanding (Eicher & Batshaw, 1993) than other carers (Raina et. al., 2004). Further, the carer works involuntarily (Raina et. al., 2004) and people with poor socioeconomic status usually have no financial assistance and their perception of lack of control in their lives hampers their physical and psychological health (Krause, 1994). The relationship between caregiving and health is described generally in terms of stress. Stressors in the context of caregiving are the difficult circumstances and problems. Such demands and obstacles exceed or push to the limit the caregivers' capacity to adapt (Dzienkowski et. al., 1996).

The common factors are child's behavior (King et. al., 1999), child's temperament (Beckman et. al., 1983), severity of the disability (Friedrich et. al., 1986), low self-esteem (Pearlin et. al., 1981; Sloper & Turner, 1993), poor social support (King et. al., 1999; Friedrich et. al., 1986), communication ability, specific cognitive or sensory impairments, sex, and age of the patient (Frey et. al., 1989).

Factors that may prevent psychological distress in mothers of intellectual disabled persons are positive belief system, noncritical family network (Frey et. al., 1989), skill of stress management, family functioning (Ransom et. al., 1992), support from the spouse (Friedrich et. al., 1979), and using specific stress management strategies (Frey et. al., 1989).

The complex interplay of economic, social, and emotional factors is reflected in the mental health of caregivers. The study found that 5.9% of individuals had depression, 45.1% of participants said they had little to no carer strain, and 45.1% said they had mild to moderate carer burden. Just 2.0% had severe burden, and only 7.8% had moderate to severe burden. Carer depression and carer load were significantly positively correlated, with higher levels of carer depression being linked to higher levels of carer burden.

An autism morbidity is higher in men than in women (Lerthattasilp et. al., 2015), with a roughly 5:1 ratio, the majority of autistic patients whose carers took part in the study were men (84.3% vs. 15.7% female). Depression and anxiety in parents and carers of children with autism spectrum disorder (ASD) reflect that 2% of control parents/caregivers and 22% of patients had a history of mental health issues (Mohammed & Mansour, 2013). Decreased maternal depression symptoms contributed to an improvement in children's quality of life (Riyo, Takashi & Yosuke, 2022).

Psychological empowerment of parents of autistic children is advised due to the low quality of life and depression symptoms experienced by parents (Hoshang & Siavah, 2017). The carer's ongoing and permanent caregiving is considered as a significant stressor, potentially leading to depression (Sanini, Brum & Bosa, 2010; Gatzoyia, 2013).

The participants' level of quality of life was medium, and the results indicated statistically significant differences in quality of life between the participants. These differences were caused by the parents' relationship with autistic children, which favoured them, the gender of the autistic child, which favoured males, and the

severity of the disability, which favoured the mild group. The study suggested that in order to improve the quality of life for parents of autistic children, particularly mothers, authorities in the care and support centres for children with autism spectrum should be made aware of the need to offer training programs and activities to them (Khaled, 2016).

Quality of Life and Anxiety

Caregivers of children with autism spectrum disorder (ASD) and Attention-Deficit/Hyperactivity Disorder (ADHD) face significantly higher levels of stigma, burden, depression, anxiety, and a poorer quality of life compared to caregivers of typically developing children. Notably, caregivers of children with ASD experience these challenges to a greater extent than those caring for children with ADHD (Romany & Doaa, 2021).

Anxiety, a common emotional response to perceived threats, is frequently seen among caregivers, particularly due to the constant stress of caregiving. It is characterized by feelings of tension, worried thoughts, and physical symptoms such as increased blood pressure. While occasional anxiety is normal, chronic and severe anxiety may indicate psychiatric conditions, like generalized anxiety disorder. In caregivers, anxiety is often triggered by the pressures of caregiving.

Caregivers must be carefully assessed for signs and symptoms of anxiety, as they often overlap with other conditions, such as depression. Both anxiety and depression share symptoms like poor concentration, insomnia, restlessness, and loss of appetite, and they frequently occur together. Given the high demands of caregiving, anxiety, and depression can significantly impact a caregiver's health and daily functioning, leading to a decline in personal health status (Akkerman et. al., 2005; Northouse et. al., 2012).

Given these challenges, it is essential for caregivers to be regularly screened for both anxiety and depression, and for interventions to be developed to support their mental and emotional well-being. In comparison to parents without any disabled children, research has shown that parents of disabled children experience

higher levels of stress, anxiety, and low self-confidence, stigma, and marital harmony (Cantwell, Muldoon & Gallegher 2015; Ali & Hassiotis, 2012; Uguz & Toros, 2004; Glidden & Schoolcraft, 2003; With & Coiro, 2003).

According to certain research, not every parent of a child with ASD has higher stress levels and more signs of anxiety and despair. Family hardiness, which was inversely correlated with depression, is one example of a resilience feature that certain families exhibit (Weiss, 2002). The mental health and wellbeing of parents of autistic children may be protected by perceived social support (Ekas et. al., 2010; Weiss et. al., 2013; Zablotsky et. al., 2013; Whitehead et. al., 2015; Drogomyretska et. al., 2020), psychological resilience (Bitsika et. al., 2013), religious beliefs (Ilias et. al., 2018), effective coping skills (Zablotsky et. al., 2013), and involvement in parental support groups (Kerr & McIntosh, 2000).

According to a study among parents of children with intellectual disabilities, anxiety and depression were substantially higher in mothers (89%) than fathers (77%); 13% mothers had both anxiety and depression, 33% had anxiety, and 40% had depression whereas 42% fathers suffered from anxiety, 31% from depression, and 3% from both. Parental gender and psychiatric diagnoses of anxiety, were significantly correlated (Azeem et. al., 2013).

The Becks Anxiety Inventory (BAI) was used for assessing anxiety, sadness, and caregiving stress, older carers were more susceptible to carer burden, lower levels of anxiety was associated with higher socioeconomic position, a high anxiety was correlated with number of children with disabilities (Barutcu et. al., 2021).

Study evinced that anxiety and depression among parents of children with intellectual and developmental disorders (IDD) was strongly associated with increased levels of both anxiety and depression (Scherer, Verhey, & Kuper (2019). Specifically:

- 1) Higher levels of depression were linked to lower household income (80% of studies) and a higher degree of impairment in the child (78% of studies).

- 2) One-third (31%) of parents of children with IDD exceeded the clinical cut-off score for moderate depression, compared to only 7% of parents of children without IDD.
- 3) Similarly, 31% of parents of children with IDD also reached the cut-off score for moderate anxiety, compared to 14% of parents of children without IDD.

These findings highlight the significant emotional and mental health challenges faced by parents of children with IDD, particularly in relation to household income and the severity of the child's impairment. Addressing these factors could be key to improving the mental well-being of these parents.

Research estimated the prevalence and contributing factors of psychological issues among mothers of autistic children which included occupation, number of siblings, educational attainment, and marital status (Ruqayyah & Asma (2018). Additionally, mothers of children with autism diagnoses are far more likely to suffer from psychological illnesses than general population, and highly suggested social assistance and psychological treatment for them.

Quality of Life and Caregiver Burden

Evidences have been found in the length of caregiving effects on quality of life (Ukpong et. al., 2021) which strongly correlated with the psychological and intrinsic characteristics of carers such as psychological distress and self-esteem (Grover et. al., 2017; Stanley et. al., 2017).

Numerous studies on carers have documented the wide range of difficulties they face including the detrimental effects on their mental and physical health, issues with their relationships with other family members, difficulties at work, and financial limitations brought on by income loss (Sherman et. al., 2008). Primary carers encounter many difficulties and see a decline in their standard of living (Bruder, 2016).

Quality of life (QoL) for caregivers is often closely linked to caregiver burden, which may mediate the relationship between caregivers and their quality of

life. A study investigated the mediating effect of caregiver burden on caregivers' QoL, focusing on both patient and caregiver characteristics and found that significant predictors of caregivers' QoL included carer health status, income, whether spouses provided patient care, the length of the patient's hospital stay, the amount of time spent providing care each day and the degree of patient education (Jeong et. al., 2015).

Caregivers commonly experience psychological distress, including anxiety and depression. Socio-demographic factors also play a significant role in caregivers' quality of life (QoL), although the impact of age on QoL remains inconclusive (Lima et. al., 2022). Female caregivers often report poorer QoL, possibly due to the traditional family roles they occupy in various cultures (Hsia et. al., 2020; Cohen et. al., 2021).

Several studies have identified patient-dependent factors that can predict caregivers' QoL. Some mental illnesses such as psychosis, mood disturbances, aggression and suicidal attempts, contribute to a greater caregiving burden and lower QoL for caregivers (Ukpong & Ibigbami, 2021). Research has shown that a significant proportion of mothers of children with neurodevelopmental disorders suffer from anxiety and depression, with up to 68% and 52% of them experiencing these issues, respectively (Swapnajeet et. al., 2013). Additionally, mothers tend to have higher depression rates due to the strain of balancing their children's needs with household responsibilities (Saltanat et. al., 2023).

Caregivers of children with ADHD and autism spectrum disorder (ASD) experience significantly high levels of burden, with those caring for children with ASD reporting a greater burden compared to those caring for children with acquired brain injury (Higginson et. al., 2010). Studies also indicate that caregiver burden for ADHD is closely linked with comorbid psychiatric symptoms (Beecham & Knapp, 1992). Unmet needs, particularly in areas such as social contact, mental health issues, appropriate daytime activities, safety, and communication, are significantly correlated with an increased caregiver burden for both ADHD and ASD. Parents

being the carers for children with ADHD have to contend with unfavourable public opinions and enquiries from other relatives (Ho et. al., 2011).

Raising a child with developmental disabilities is a crisis event for families, and how parents respond to the stresses of caregiving depend on several factors that influence their coping abilities. The coping care giving burdens include family members' personality traits, financial status, education, problem-solving abilities, spirituality, strong marital relationships and social support systems are also crucial in determining parent's adjustment to these challenges (Thwala et. al., 2015; Hlanze, 2015; Emerson, 2003; Fazil et. al., 2004). Mother usually provide the majority of care for children with developmental and intellectual disabilities, coordinating community-based care and medical requirements and places them at higher risk for stress and burnout (Lafferty et. al., 2016).

A study on the quality of life (QoL) of carers of children with and without disabilities showed statistically significant lower quality of life scores in all domains for carers of children with impairments (Ritu & Shweta, 2020).

The absence of primary care contribute overload, to the carers which calls for increased public funding for the treatment of these illnesses. Prevention provided by a support program should directly address the needs of carers and indirectly improve the care provided to individuals with disabilities and other family members by lessening the effects of burden and improving the quality of life of carers (Barros et. al., 2019).

The majority of carers stated that taking care of their impaired child had a detrimental impact on their social life (64%), physical health (65%), economic (70%), and future goals and expectations (81%) which made them experience substantial levels of psychological anguish and overall load (Hans, Hanne, and Kristen, 2021). The quality of life of carers may be impacted by raising children with ASD and ADHD (Sara & Sari, 2023). Although there is little study on the quality of life of carers, it has been well recognised that those who care for children with attention deficit-hyperactivity disorder (ADHD) and autism spectrum disorder (ASD)

endure higher levels of stress than those who care for children who are having normal growth.

About half of autistic carers (47.2%) had a severe level of load, according to a prior study comparing carers of autistic and control groups. Autistic carers reported a considerably worse quality of life in terms of energy/fatigue and physical functioning, exhibit worse QoL and higher levels of burden (Magda & Osama, 2017). The constant problem like length of time since the child's autism diagnosis, the child's medication use, the mother or father's mental health condition, and the child's school attendance pushing carers to stress. Carers' quality of life is impacted by autism may be improved or lifted up by treatment interventions (Borte, Hatice, & Erhan, 2018). There is a need for more extensive research in the future that compares the effects of various chronic illnesses on the carer's physical and mental health including AUD and ADHD.

The burden of care for carers and the degree of autism were found to be positively correlated. The caregiver's quality of life deteriorates as symptom intensity rises (Amit, Vivek & Puwan, 2020), and carers of children with ASD experience a high burden of care and a reduced quality of life.

Parents of children with autism spectrum disorder demonstrated considerable impairment in all four domains (physical, psychological, social, and environmental) when compared to parents of children with physical disabilities and normal children (Vaithi & Vimala, 2014). The findings will assist medical practitioners in creating suitable support groups and psycho-social intervention programs for families of children with autism spectrum conditions. The mothers of the ASD and ADHD carers score higher than average on stigmas, burden, anxiety, sadness, and a lower quality of life. Moreover, this situation is worsened for ASD carers than for ADHD carers as carers of people with ASD face greater challenges than carers of those with ADHD (Romany & Doaa, 2021).

Quality of Life and Coping Strategies

Folkman and Lazarus (1985) suggested that general stress coping is a dynamic process in which coping strategies evolve over time and across different situations to address the changing demands of stressful events. Previous studies on stress coping have found that positive coping strategies are linked to adaptive mental health outcomes, while negative strategies are associated with maladaptive outcomes (Lazarus & Folkman, 1984; Skinner & Zimmer-Gembeck, 2007; Taylor & Stanton, 2007). Similar trends have been noted among parents of children with ASD, with factors such as the child's age and severity of symptoms (Gray, 2006; Ingersoll & Hambrick, 2011), parent personality (Ingersoll & Hambrick, 2011), and family functioning, (Altiere & von Kluge, 2009) impacting parenting stress. Additionally, adaptive coping strategies are positively linked to lower levels of depression and anxiety, while maladaptive strategies tend to worsen these symptoms (Benson, 2011; Smith et. al., 2008). Research on coping strategies, stressors, and outcomes related to ASD caregiving has been extensively studied (Benson, 2011; Cappe et. al., 2017).

However, it is less clear how parents and carers deal with ASD in various contexts (Grey, 2006; Hayes and Watson, 2012). The dynamic and stressor-dependent nature of coping has been highlighted in earlier research, indicating that general coping frameworks as previously developed might not be universally applicable to all parents and carers of children with ASD (Pakenham et. al. 2005; Skinner and Zimmer-Gembeck 2007). This makes it a crucial area for additional research. Nevertheless, there are currently few concluding assessments on the nature of stress coping in parents and other carers of children with ASD.

Elena & Rexana (2013) conducted a comparative study in a sample of the Romanian population on the quality of life, emotional distress, and cognitive coping methods of moms of children with ASD and ADHD. They found no discernible differences between the two groups in terms of emotional distress or quality of life. Positive refocusing, positive re-evaluation, and catastrophising were the coping mechanisms used by moms of children with ASD that showed a strong correlation with the overall appraisal of the family quality. The findings imply that a higher

family quality of life is associated with the application of adaptive coping mechanisms, whereas the opposite is true for dysfunctional ones.

Francesco and Rosa (2020) examined coping mechanisms used by parents of children with attention deficit hyperactivity disorder (ADHD) in a comprehensive review. When the symptoms of attention deficit hyperactivity disorder (ADHD) interfere with family life, parents of these children employ a variety of coping mechanisms. They discovered that parents of children with ADHD employed more avoidant-focused coping mechanisms than parents of regular children. Mothers of ADHD children utilised more indirect methods and sought out far more help than parents of regular children.

Given the context-dependent nature of stress coping outlined by Lazarus and Folkman (1985), it is important to approach the application of general coping models with caution when comparing distinct cultural groups, such as Western and Asian parents of children with ASD. Cultural perspectives on collectivism versus individualism may shape how parents cope with stress. Asian parents, who tend to value group benefits, might be more inclined towards collectivistic problem-focused coping strategies while Western European parents may prioritize individual gain, might prefer individualistic, self-focused coping strategies, such as passive appraisal or *avoidance* (Chun et. al., 2006; Sawang et. al., 2006; Oyserman et. al., 2002; Markus & Kitayama, 1991). Cultural worldviews can significantly influence how the individual approach and manage stress (Sawang et. al., 2006).

Studies have suggested that problem-focused coping is linked to positive mental health outcomes, which may imply that Asian parents of children with ASD could experience a reduced risk of psychological maladjustment compared to their Western European counterparts (Taylor & Stanton, 2007; Uchino, 2006; Kawachi & Berkman, 2001). However, Asian parents are also observed to internalize their stress, potentially avoiding discussions about personal problems to "save face" (Kim et. al., 2001; Luong et. al., 2009). Additionally, they may place excessive emphasis on their child's academic performance, exacerbating their own stress when their children underperform (Lam & Mackenzie, 2002). Therefore, a deeper understanding of how

individual differences affect parental and caregiver coping mechanisms in the context of ASD-related stress is crucial for assessing the outcomes of coping strategies (Chun et. al., 2006).

Although the diagnostic prevalence of ASD is increasing, current research on parental and caregiver coping among Asian populations remains limited, primarily focusing on Asian parents residing in the United States or East Asian countries like China and Taiwan (Luong et. al., 2009; Wang et. al., 2022). Given the influence of individualism and collectivism on general stress coping, as well as the growing prevalence of ASD in Asian populations, it is essential to consider cross-cultural differences when developing coping strategies tailored to the needs of diverse populations (Oyserman et. al., 2002; Sawang et. al., 2006).

The rising prevalence of children diagnosed with ASD raises concerns about the mental health and well-being of families, as well as the availability and effectiveness of support systems for those managing the challenges of raising a child with ASD (Hayes & Watson, 2013; Lin et. al., 2008; Moh & Magiati, 2012). It is crucial for healthcare providers to first gain an understanding of how different groups of parents and caregivers cope with caregiving stress in order to effectively allocate coping resources (Pakenham et. al., 2005). By gaining insight into the individual and cultural nuances, healthcare providers can better support parents and caregivers by offering tailored ASD-related stress coping resources (Chun et. al., 2006).

Studies have explored the psychosocial outcomes of caregiving, highlighting the challenges faced by caregivers compared to non-caregivers. Older adult caregivers, for example, report increased stress and depression, as well as lower levels of subjective well-being and self-efficacy (Pinquart & Sörensen, 2003; Revenson et. al., 2016). Informal caregiving can also affect social activities and marital dynamics (Matthews, 2018). Specific health conditions, such as dementia, can lead to unique challenges, including exposure to physical or verbal aggression (Dodge & Kiecolt-Glaser, 2016). In terms of physical health, caregiver stress has been associated with changes in endocrine and immune functioning in both elderly and younger caregivers (Vedhara et. al., 1999, 2002). For instance, chronically

elevated salivary cortisol levels have been linked to poorer immunity (Pruessner et. al., 1999), and young parents caring for children with developmental disabilities have been shown to have a poorer antibody response to influenza vaccination (Gallagher et. al., 2009).

Caregivers or parents reported more physical health issues and higher levels of psychological discomfort, perceived stress, anxiety, and depression than non-caregivers (Lovell et. al., 2012). Some health issues such as headaches, arthritis, high blood pressure, stomach ulcers, and back injuries are also linked to carer stress in carers between the ages of 35 and 76 (Sawatzky & Fowler-Kerry, 2003).

Many studies highlight the psychological and physical challenges faced by caregivers, some caregivers cope effectively without showing negative impacts (Cohen et. al., 2002; Garity, 1997). Positive outcomes have also been identified. Spousal caregivers of cancer patients have reported enhanced relationships, a sense of personal growth, and feelings of satisfaction (Li & Loke, 2013). Similarly, informal caregivers of patients with amyotrophic lateral sclerosis have noted both positive and negative experiences (Sandstedt et. al., 2018). Young carers, in particular, report feeling proud of their role, gaining valuable skills, and becoming more mature and independent (Cass et. al., 2010). These findings suggest that not all caregiving outcomes are detrimental, and that resilience can foster effective coping, allowing individuals to adjust successfully. In this review, coping is seen as a process leading to adjustment, where adjustment refers to the psychophysiological outcomes of coping. Positive adjustment is defined as an adaptive response to challenges, which spans physical, interpersonal, cognitive, emotional, and behavioural domains (Larsen & Lubkin, 2009). The term "adjustment" is used here as it captures a range of terms related to caregiving outcomes, and is commonly employed in this field.

Many studies offer theoretical explanations for caregiver outcomes based on the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984), which defines coping as a dynamic process involving "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands." In this process, coping responses typically fall into three categories: problem-focused

coping (which involves actions to change the relationship between the person and their environment), emotion-focused coping (which involves actions to change the meaning of that relationship, such as avoidance, distraction, or minimization), and cognitive coping (which influences stress and emotions through reappraisal of the person-environment relationship) (Lazarus & Folkman, 1984). Haley and colleagues (1987) found that appraisal and coping responses were significant predictors of outcomes in adult dementia caregivers. Similarly, caregiving factors, cognitive appraisal, coping strategies, and available coping resources have been shown to predict adjustment in adult multiple sclerosis (MS) caregivers (Pakenham, 2001).

The use of problem-focused coping is generally associated with better caregiver adjustment compared to emotion-focused coping (Pakenham, 2001). Branscum (2011) suggests that the negative effects of caregiving in adults can be mitigated with adequate social support and the use of problem-focused coping. However, defining psychological concepts like coping and adjustment can be challenging in any population, and the TSC model has been critiqued for oversimplifying and not accounting for the situational nature of coping (Schwarzer & Schwarzer, 1996). Some researchers have expanded on this by adopting multi-dimensional approaches, emphasizing that the effectiveness of coping strategies may vary depending on the specific situation and stressor (Carver et. al., 1989). In a similar vein, Skinner (2007) proposed 12 "families" of coping based on their function and contribution to adaptation. Additionally, the concepts of allostasis and allostatic load provide a well-accepted explanation for adjustment at the physiological level, highlighting how different health outcomes arise from underlying mechanisms (McEwen, 1998; Sterling & Eyer, 1988). These concepts have been applied in models of adjustment to study the physical impact of caregiving (Vedhara et. al., 1999, 2002).

Depression and Anxiety

It has been demonstrated that maternal depression impacts the psychological, intellectual, and emotional development of the kid and may raise the infant's risk of malnourishment and physical and mental health problems. A fulfilling life for

children with disabilities depends on the family's general functioning, resources, and support system (Majnemar et. al., 2007). When compared to carers of children with normal development, carers of children with ADHD and autism reported higher levels of burden, sadness, anxiety, and stress as well as a significant decline in their quality of life (Pecor et. al., 2021).

The psychological burden experienced by carers of children with ASD was found to be predicted by factors about the child and parents, as well as society-level issues. Stress, anxiety, and depression were found to be indicated by the number of co-occurring conditions (Zablotsky et. al., 2013), the severity of autism symptoms (Picardi et. al., 2018), and the emotional and behavioural issues of children (Estes et. al., 2013; Falk et. al., 2014; Zhou et. al., 2019).

Other factors that were linked to depression in parents included mothers' age (Falk et. al., 2014), self-stigma (Werner & Shulman, 2013; Chan & Lam, 2018), perceived limit-setting skills, and inadequate coping mechanisms (Whitehead et. al., 2015). Higher levels of parental stress are usually predicted by the father's age (Falk et. al., 2014) and financial pressure (Zablotsky et. al., 2013; Falk et. al., 2014; Ilias et. al., 2018) which link to children not attending school and poor-quality interactions within the extended family (Derguy et. al., 2016). Autism-related public stigma (Grey, 2002; Chan and Lam, 2017) creates anxiety and despair. Children with autism symptoms are likely to have seizures, depression, poorer family ties, less social support and family mastery (Puka, Widjaja & Smith, 2017).

Research evinced the connections between the clinical characteristics of children with autism spectrum disorder (ASD) and the carer's burden, anxiety and depression levels (Baykal et. al., 2018) that the severity of autistic symptoms and the intensity of the carer's depressive symptoms were significant predictors of the overall carer burden ratings. The language development problems of ASD were the main symptoms that affected the carer's burden, the severity of depressed symptoms, and the carer's burden which harmed the quality of psychosocial interventions offered to carers (Baykal et. al., 2018).

Depression and Caregiver Burden

It has been demonstrated that higher levels of carer stress or depression impair parenting skills (Cummings & Davis, 1994), which can have a detrimental effect on the physical and mental health of the kid (Olfson et. al., 2003; Lushin & O'Brien, 2016). Researchers discovered that parenting stress was strongly directly linked to the emergence of depressive symptoms and a decline in the quality of life for parents of children with high-functioning pervasive developmental disorders (Suzumura, 2015) and inversely related to the successful outcomes of early learning processes of autistic children (Osborne et. al., 2008).

The impact of raising a child with ASD on parents and families is profound and multifaceted, much like the disorder itself. Meeting the significant care needs of children with ASD demands considerable time, effort, and patience. These challenges are compounded by the severity and chronic nature of ASD, the presence of extensive developmental and physical comorbidities, and limitations within health services in providing accessible, integrated, and intensive interventions for individuals with ASD. The far-reaching effects of having a child with ASD are evident in the wide range of parental domains that are affected (Vohra et. al., 2014).

One of the most extensively studied aspects of the burden faced by families of children with ASD is parenting stress, which refers to the distress arising from the demands of parenting and is typically measured through parent self-report questionnaires. A recent meta-analysis revealed that parenting a child with ASD is associated with higher levels of stress compared to parenting a typically developing child or a child with another disability, such as Down syndrome, cerebral palsy, or intellectual disability (Hayes et. al., 2013).

Two surveys were utilised in a study on carer burden on autistic children: the 12-item Zarit Burden Interview and a socio demographic questionnaire. Out of the 77 respondents, the majority were female (n = 56, or 72.3%), moms of children with ASD (n = 49, or 64.3%), and identified as Christian, according to the data. The majority were employed and had either finished secondary school or a postsecondary

education. Of the carers, only 24.9% indicated no to mild burden, 33.8% reported severe burden, and 41.6% reported mild to moderate burden (van Niekerk et. al., 2023).

A study conducted in Taiwan revealed that 60% of mothers of children with autism exhibited severe depression, as assessed by the Centre for Epidemiologic Studies Depression Scale (CES-D). Factors contributing to caregiver depression included high levels of the child's behavioural problems, early onset of autism, low functioning in the child, insufficient social support for caregivers, and the caregivers' own illnesses or disabilities. Additionally, many families of children with autism reported experiencing high levels of caregiving burden (Stuart et. al., 2009; Mugno et. al., 2007). A significant positive correlation was found between depression and caregiving burden. Other notable correlations were between the burden and the time since diagnosis, the number of the child's problems, and the number of hours caregivers spent with their children daily. Furthermore, the burden was significantly associated with the child's communication problems and inappropriate, repetitive behaviours. A later study found that while the prevalence of depression and the severity of the burden on caregivers were relatively low in their sample, the factors contributing to burden, such as the time since diagnosis, the child's problems, and communication and behavioural issues, were significant (Tiraya & Thamanard, 2015).

Other factors that were linked to depression in parents included mothers' age (Falk et. al., 2014), self-stigma (Werner & Shulman, 2013; Chan & Lam, 2018), perceived limit-setting skills, and inadequate coping mechanisms (Whitehead et. al., 2015). Higher levels of parental stress were predicted by the father's age (Falk et. al., 2014) and financial pressure (Zablotsky et. al., 2013; Falk et. al., 2014; Ilias et. al., 2018). Higher levels of parental stress were also linked to children not attending school and poor quality of interactions within the extended family (Derguy et. al., 2016). Anxiety and despair have been linked to autism-related public stigma (Grey, 2002; Chan & Lam, 2017).

Research on the relationship between depression and the stress of caring for individuals with intellectual disabilities in Korea was carried out in 2017 by Nam and Park. The data used in this study, which includes secondary analysis, came from the 2011 Survey on the Actual Conditions of Individuals with Developmental Disabilities conducted by the Ministry of Health and Welfare of Korea. The most severe handicap was shown in the first grade, when all depression and caregiving stress assessments were significantly greater. The strain of caregiving was often higher for co-residents, parents, the unemployed, female carers, and people with health conditions. Carer characteristics like spouse relationships, health problems, and perceptions of the time and cost required in giving care have all been connected to depression.

The presence of an individual with a disability, such as cerebral palsy (CP) or other neurodevelopmental disorders, can have significant impacts on the entire family. Families of individuals with CP often face heightened psychological anxiety and financial stress, with parents experiencing time pressure and difficulties in maintaining social and cultural activities. According to a study by Park and Nam (2018), the frequency of depression among parents supporting individuals with CP was notably higher than previous findings. Specifically, 38.2% of respondents scored ≥ 16 on the Centre for Epidemiological Studies Depression Scale, indicating a significant prevalence of depression. The study found that parents of preschool-aged children spent more time caregiving than those supporting adults, and those caring for adults reported less time pressure. While caregiving time did not directly predict depression, the study emphasized that increased time pressure was strongly linked to a higher risk of depression among caregivers.

A study examining the epidemiological profile of children with disabilities and their primary caregivers (PCs) assessed depression severity, caregiving burden, and family dysfunction. The results showed that the median age of the PC was 37 years, with 72.7% of caregivers being mothers. The study found that 22.7% of caregivers experienced depression, 43.6% experienced burden, and 11.8% reported family dysfunction. Caregiving strain and burden were associated with depression

and anxiety symptoms both cross-sectional and with worsening symptoms five years later (Fernanda et. al., 2016). Sleep quality was identified as a mediator in these relationships, with caregiving demands and associated sleep disruptions contributing to depression and anxiety in caregivers (Anna et. al., 2010). Furthermore, mothers of children with autism experienced moderate to extreme caregiver burden, and there was a positive correlation between depressive symptoms and caregiver burden (Lin et. al., 2007). Factors contributing to caregiver burden included the severity of the child's symptoms, the number of life problems faced by the caregiver, and a low level of support received by the caregiver (Fernanda et. al., 2016).

Depression and Coping Strategies

Stress can cause adverse effects when it is too strong and exceeds the adaptive capacity of the individual, thus, prolonged stress increases the risk of mental disorders such as anxiety disorders and depression (Kay & Tasman, 2006). Coping with stress is undertaken in a stressful situation (Heszen-Niejodek, 2000). Dealing with stress is known as a process, strategy, or style of coping (Heszen-Niejodek, 2000; Strombek-Milczarek & Talarowska, 2011). Coping styles are defined as an individual's established and typical approaches to dealing with problems, and coping strategy related to personal reactions in a particular situation (Kay & Tasman, 2006).

In the cognitive-transactional model, coping with stress is a continual cognitive and behavioural effort to deal with external and internal demands which are assessed as excessive or overwhelming (Ogińska-Bulik & Juczyński, 2008). The effect of stress on depression triggers the subsequent phases of the disease (Sariusz-Skapska et. al., 2003). Stressful life events can cause or exacerbate depression, depending on the individual's personality traits (Sariusz-Skapska et. al., 2003; Benedysiuk & Tartas, 2006). Stressful life experiences and ways of dealing with them predispose to mood disorders, and the onset and course of depression remain in important relationships with coping strategies (Sariusz-Skapska et. al., 2003). Shortage of coping resources contributes to the deterioration of the quality of life and adversely affects the health status (Fredrickson & Joiner, 2002),

Available studies of associations between stress and the onset of depression propounded significant life events like loss or overstrain trigger or change in the course of depression (Sariusz-Skapska et. al., 2003). The stressful life events associated with the onset of affective disorders in different studies range from several to 100% (Heim & Nemeroff, 2001; Brown & Anderson, 1991) such as the death of a loved one, marital and family conflicts, tragedy, changes in family status, interpersonal conflicts, difficult family situation, problems with children, and health problems (Sariusz-Skapska et. al., 2003; Benedysiuk & Tartas, 2006)

Reports confirm the link between environmental stress in childhood and the future occurrence of affective disorders (Heim & Nemeroff, 2001; Brown & Anderson, 1991) that indicates that children exposed to severe adverse experiences are more likely to develop depression and/or anxiety disorders in later life (Heim & Nemeroff, 2001). Induced persistent CNS sensitization as a consequence of severe stress is the biological basis of the development of depression and anxiety disorders (Heim & Nemeroff, 2001; Brown & Anderson, 1991).

Depressive women chose fewer active ways of coping strategies (Kossakowska., 2012). Persons with major depressive disorder showed differences in ways of coping with stress from persons with mental illness samples (Benedysiuk & Tartas, 2006), and more use of the strategy of cognitive avoidance and acceptance/resignation. Patients with depression usually use the emotion-oriented style and less frequently use the task-oriented style and avoidance when compared with the control group. Emotions-oriented style positively correlated with the severity of depression (Pu et. al., 2011).

Patients treated for depressive disorders in stressful situations use coping strategies based on behavioural disengagement and problem denial, and have more difficulties in positive reinterpretation of stressful events compared to healthy people. Women and men do not significantly differ in preferred ways of coping with stress (Orzechowska et. al., 2013)

Coping strategies and Caregiver Burden

Coping is defined as a dynamic process involving cognitive and behavioural efforts to manage specific external and internal demands that are perceived as overwhelming or exceeding an individual's resources. It encompasses psychological resources and coping strategies that assist in eliminating, modifying, or managing a stressful event or crisis. Raising a child with intellectual and developmental disabilities creates a crisis that requires adaptive responses. How parents cope with the stress of raising such a child depends on several factors, such as their interpretation of the situation, the support available from family, community resources, and the family's overall structure.

Various aspects, including personality traits, financial status, educational level, problem-solving skills, and spirituality, all play a significant role in influencing a family's ability to cope with the challenges. Additionally, strong marital relationships and social support systems are crucial in determining how parents adjust to the demands of caregiving (Thwala, Ntinda & Hlanze, 2015; Emerson, 2003; Fazil et. al., 2004).

Caregiving experiences can vary significantly depending on the context, particularly when raising a child with neurodevelopmental disorders (NDDs). These challenges often go beyond the typical stresses of caregiving and include unique difficulties such as managing complex medical, behavioural, and developmental needs. In addition to these challenges, caregivers may also face social isolation, psychological distress, and feelings of exclusion.

Stigma surrounding disabilities can amplify these struggles, leading to negative societal attitudes and further isolation. Discriminatory or inequitable policies can compound these issues, limiting access to necessary resources and support. As a result, caregivers of children with NDDs may experience heightened emotional burdens, which can significantly affect their mental health and overall well-being (Thrush et. al., 2014; Vadivelan et. al., 2020; Carnevale et. al., 2008).

Autism spectrum disorder (ASD) and attention-deficit/hyperactivity disorder (ADHD) are both neurodevelopmental disorders that have seen an increase in prevalence in recent years. Children with ASD typically face challenges in social interaction, communication, and display repetitive, stereotypical behaviours, alongside delays in verbal language development (APA, 2013). In contrast, ADHD is characterized by persistent patterns of inattention, hyperactivity, and impulsivity, which can significantly affect a child's ability to focus and engage in tasks (APA, 2013).

Both disorders can have highly variable effects on the child's daily functioning, and these challenges extend to their caregivers as well. The impact of ASD and ADHD can be broad, influencing educational, social, and behavioural aspects of a child's life. As a result, multidisciplinary management is critical for addressing the diverse needs of children with these disorders. Treatment approaches typically include educational support, psychological interventions, behavioural therapies, and, in some cases, pharmacological treatments as recommended by most European guidelines (Fridman et. al., 2017). These combined strategies aim to enhance the child's functioning and improve quality of life for both the child and their caregivers.

Parents of children with developmental disabilities, including autism spectrum disorder (ASD) and attention-deficit/hyperactivity disorder (ADHD), face unique and significant challenges that can result in high levels of distress and negative psychological outcomes. These challenges are often linked to difficulties in communication, managing unpredictable and aggressive behaviours, limitations in self-care, and the lack of respite due to the absence of appropriate substitute caregivers. The emotional and mental toll on parents can be profound, leading to increased caregiver burden and distress. There is increasing recognition of the stigma and strain placed on caregivers raising children with ASD and ADHD. Research has highlighted that the psychological and emotional burdens on caregivers are not only significant but also distinct across the two disorders. For example, the caregiving experience for parents of children with ASD may involve unique stressors related to

social communication deficits, while parents of children with ADHD may struggle more with managing impulsivity and hyperactivity. While both conditions contribute to caregiver distress, the extent and nature of suffering differ, as noted by Cadman and associates (2015), emphasizing the need for tailored support and interventions for caregivers based on the specific challenges posed by each disorder.

According to the results of a study, problem-focused coping and carer burden are significantly positively correlated. People who actively work to address and change the causes of a problem or stressor are said to be engaging in problem-focused coping. It takes a lot of work and repeated tries to cope with this kind of situation. The primary components of problem-focused coping are adopting proactive measures, seeking out other people's assistance, waiting for the right moment, accepting, planning, minimising other conflicting activities, and reinterpreting. Problem-focused coping is a common strategy adopted by carers of children with special needs to manage the numerous issues and stressors they encounter daily (Vinothkumar et. al., 2022).

Most researchers asserted that problem-focused coping will reduce carer strain. The findings of our study, however, go counter to earlier findings and suggest that employing problem-focused coping mechanisms will put more stress on carers. It is possible that problem-focused coping is not always effective and may possibly have negative consequences. The effectiveness of problem-focused coping depends on the caregiver's ability to control the source of the stressor. If a person cannot control a source of stress, all efforts and attempts will be in vain, and coping techniques may not be effective (Carver, 2011).

Research consistently indicates that emotion-focused and avoidant coping strategies are linked to increased caregiver burden. Both of these coping styles are considered dysfunctional and often used by caregivers as ways to escape the stressors associated with their caregiving role.

Emotion-focused coping, which involves managing emotional responses to stress rather than addressing the stressors themselves, has been found to exacerbate

caregiver burden. This coping strategy may lead to an intensification of the emotional distress that caregivers feel, contributing to negative outcomes such as anxiety, depression, and overall diminished well-being (Kim, 2007; Li et. al., 2021). Dysfunctional emotion-focused coping can trap caregivers in a cycle of emotional distress without providing real relief or solutions.

Similarly, avoidance coping, which involves denying or minimizing stressors to temporarily alleviate emotional discomfort, is another maladaptive coping strategy. While it may offer short-term emotional relief, avoidance coping can ultimately worsen the long-term consequences of caregiving by failing to address the root causes of stress. Avoidance coping is more commonly used by individuals who experience higher levels of emotional instability, but research has shown that it can escalate caregiver burden and emotional distress over time (Barmann, 2015; Menati et. al., 2020; Vinothkumar et. al., 2022).

These findings underscore the importance of promoting more adaptive coping strategies, such as problem-focused coping, that can help caregivers better manage the stressors of caregiving and reduce the negative impacts on their mental and physical health.

Fairfax and others (2019) examined the relationship between coping strategies and psychological aspects of quality of life (QoL). The study highlighted that adaptive coping strategies such as problem-focused coping, which aims to address the underlying stressors were positively associated with better psychological outcomes in terms of QoL. However, due to the variability in how coping strategies were measured across studies, it was difficult to categorize these strategies definitively. On the other hand, maladaptive coping strategies, like emotion-focused coping, which often involves managing emotional responses rather than tackling the stressor itself, were found to have a negative correlation with psychological aspects of QoL.

Further support for these findings comes from studies involving families of children with intellectual disabilities, which found that caregivers' well-being was

enhanced when they employed problem-focused coping strategies. Conversely, caregivers who relied on emotion-focused strategies generally reported poorer psychological well-being. These findings underscore the importance of fostering adaptive coping mechanisms to improve caregivers' psychological health and quality of life, particularly for families managing the complex needs of children with disabilities (Colman et. al., 2019).

In contrast, four studies discovered that a lower overall quality of life (QoL) (psychological and physical health combined) was associated with both adaptive and maladaptive approaches. According to this, caretakers who employ coping strategies more frequently which may be both adaptive and maladaptive may also have a greater need to cope, which means they are under more stress and hence require coping techniques. This bolsters the need for prospective studies that could assess quality of life (QoL), coping strategies, and stresses (such the complexity of caring). The findings support the hypothesis that psychological quality of life may be positively connected with adaptive or constructive coping strategies among parents of children with chronic illnesses (Colman et. al., 2019).

It appears that problem-focused coping and seeking out social support are the most often employed strategies by parents of children with ADHD. Therefore, as part of their intervention efforts, healthcare practitioners should encourage healthy coping mechanisms and assist parents in finding family members, experts, or associations who can support them (Francesco et. al., 2020).

Anxiety and Caregiver Burden

Seventy-two caregivers of dependent older relatives were recruited in a medium–long stay hospital. Socio-demographic variables, number of basic activities of daily living (ADLs) attended, hours of surveillance, burden, and anxiety were collected from caregivers. Trajectory analysis was used to analyse the relationship between variables. Of the caregivers, 36.1% had subjective burden and 14.9% had anxiety. Subjective burden was positively associated with the number of basic ADLs attended, the hours of surveillance, and the cognitive impairment of the care

recipient. Anxiety was also positively associated with subjective burden. Subjective burden mediated the effects of the number of basic ADLs attended, hours of surveillance and the cognitive impairment of the care recipient on anxiety. The levels of subjective burden and anxiety in caregivers debuting in hospital care are elevated, showing the need for these caregivers to be cared for. Subjective burden is a possible risk factor for anxiety, independent of the objective burden; it may suffer the effects of objective burden on anxiety (Margaritia et. al., 2019). Both disorders were associated with a high level of caregiver burden, but it was significantly greater in ASD. In both groups, caregiver burden was mainly explained by the affected young person's unmet need. Domains of unmet need most associated with caregiver burden in both groups included depression/anxiety and inappropriate behaviour. Specific to ASD were significant associations between burden and unmet needs in domains such as social relationships and major mental health problems (Cadman et. al., 2012).

Caregiver burden had a significant direct effect on anxiety (59.1% of the total effect), while indirect effects accounted for 40.9%. Cognitive fusion was the only significant mediator between caregiver burden and anxiety, accounting for 20.8% of the total effect. Additionally, experiential avoidance – both alone and when preceded by cognitive fusion – significantly mediated the relationship between caregiver burden and reduced engagement in values-driven actions (Han et. al., 2025). Some studies found that not all caregivers of children with ASD experience increased stress levels and elevated depression and anxiety symptoms. Some families display traits of resilience, such as family hardiness, which was inversely associated with depression (Weiss, 2002).

Anxiety and Coping Strategies

Studies were conducted on 42 parents of children with ASD who were enrolled at a specialized clinic for children with hearing and speech difficulties. They used the Depression Anxiety Stress Scales (DASS), the Coping Orientation to Problems Experienced (COPE) inventory, and a demographic questionnaire which included questions on satisfaction with life and social support received. The respondents reported no clinically elevated levels of stress, depression or anxiety. However, the

mothers reported more stress and anxiety-related symptoms than did the fathers. The results showed that coping strategies of positive reinterpretation and growth were positively correlated to higher perceived social support and greater satisfaction with life, and were negatively correlated with depression and anxiety. Perceived social support was highly negatively correlated with anxiety. Strategies of acceptance were used significantly more often by individuals with a higher level of education (Demsar & Bakracevic, 2021).

Significantly higher levels of stress and depression were reported among parents who perceived their needs as being unmet or extremely unmet as addressed by societal acceptance as compared to parents who reported adequate levels of needs met by social acceptance. Employed parents and parents with a higher level of perceived friends' support had less symptoms of stress, anxiety, and depression (Alibekova et. al., 2022).

Mothers and fathers of children with ASD carry a huge caregiving burden in the form of objective difficulties, subjective distress, and symptoms of depression and anxiety. This study added to our understanding of the factors that are associated with burden. Given that caregiving burden and stress may affect service utilization and reduce the effectiveness of interventions for young children with ASD, identifying and understanding factors related to the parental burden is important for designing effective interventions aimed at its reduction (Osborne et. al., 2008).

Studies conducted with correlation analysis in the group with ADHD revealed that parental stress correlated significantly with social support and with children's emotional problems. In the ASD group, parental stress also correlated significantly with children's sleep and behavioral problems. Moreover, multiple regressions showed that confidant support was a significant predictor of parenting stress in both clinical groups. The findings provide new insights to consider social support as a fundamental part of treatments for parenting stress in mothers of children with ASD and ADHD (Pardo et. al., 2024).

CHAPTER-III

STATEMENT OF THE PROBLEM

STATEMENT OF THE PROBLEM:

A group of diseases known as neurodevelopmental disorders (NDDs) are defined by abnormal CNS development that results in brain dysfunctions later in life. These disorders may be linked to neuropsychiatric issues or impaired language, learning, motor function, or nonverbal communication (Parenti et. al. 2020). Its known but frequently unidentified aetiology, which is connected to either genetic or environmental factors, causes it to occur throughout the foetal or neonatal developmental window (Morris-Rosendahl, 2020). The Diagnostic and Statistical Manual of Mental Disorders (DSM5, American Psychiatric Association, 2013) and the International Classification of Diseases 11th Revision (ICD-11) classify neurodevelopmental disorders into the following categories: communication, attention deficit, hyperactivity, learning, and visual-motor disorders.

Caring for children with autism spectrum disorders (ASDs) is challenging and affects family life. ASDs are neurological complex conditions impairing social interaction and communication, such as difficulties to respond to social interactions or deficits in understanding nonverbal communication (Hoefman et. al., 2014). Moreover, persons diagnosed with an ASD have restricted behavioural functions, such as stereotype behaviour or inability to adjust to new situations (Strock, 2007). Children with ASDs often exhibit more than one of these core ASD symptoms and many also suffer from associated symptoms, such as severe tantrums or sleep problems (Aman 2004; Couturier et. al., 2005). Moreover, health in general of these children is lower than that of typically developing children (Gurney et. al. 2006; Kuhlt-hau et. al., 2013). The cause of ASD is unknown. Premature birth, bleeding during pregnancy, toxemia, and viral infections are only a few of the problems that have occasionally been reported during pregnancy or childbirth. Research on family members indicates that there might be a broader autism phenotype in which less severe symptoms are inherited, and studies on twins and families indicate that the heritability is over 90%. The brain system linked to social cognition, the limbic system, which includes the frontal lobes, cerebellum, medial temporal lobe, and other regions, have been implicated in neurobiological investigations. Particularly, the

amygdala may be involved in impairments related to joint attention, motor imitation, empathy, and social stimulus orientation (Wilson & Scarper, 2017).

Individuals with ASD experience a variety of emotional and behavioural problems that include externalizing and internalizing behaviours such as anxiety, depression, somatization, rule-breaking, aggression, self-harm, inattention, hyperactivity, impulsivity, and abnormal thought. Moreover, these symptoms change as the child grows and vary in severity. The prevalence of problem behaviour in children with ASD was found to range from around 71% to 94.0% (Chandler et. al., 2016 ; MC Tiernan et. al., 2007). These figures are at least three times higher compared to an earlier study conducted in Malaysia, where the reported prevalence was considerably lower, at 24.2%. While problem behaviour was found to be independent of age and gender (Chandler et. al., 2016), several factors have been linked to problem behaviours in ASD, including having comorbid intellectual disability, impaired adaptive functioning, language impairment, as well as medical comorbidities such as seizures, gastrointestinal and sleep disorders (Hartley et. al., 2010; Esteves et. al., 2021). Moreover, except for hyperactivity, these behaviour problems tend to persist from adolescence through adulthood, indicating their chronic nature (Rattaz et. al., 2011).

A chronic pattern of extreme inattention and/or hyperactivity-impulsivity that lasts for at least six months is known as attention-deficit/hyperactivity disorder (ADHD). A few symptoms must have existed before the age of twelve. Additionally, there must be a functional impairment in at least two contexts (e.g., school, home). ADHD is thought to affect 5%–9% of school-age children, with boys and children from poorer socioeconomic backgrounds being more likely to experience it (Scarpa & Wilson, 2013). According to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, for diagnosing this disorder, having six specific functional and behavioural symptoms of lack of attention, hyperactivity, and impulsivity for 6 months before the age of 12 is necessary (Ghanizadeh, 2007).

Until recently, the lack of appropriate approaches for new born and early childhood has hindered growth. Recent technological developments have made it

possible for us to assess how well a baby's brain functions. Scientists can now more clearly understand how changes at the neurological level relate to changes at other levels of description, such as behaviour or cognition. (D'Souza, 2016). Furthermore, EEG and neuroimaging methods may help detect important early indicators of NDDs of uncertain origin (such as autism and attention-deficit/hyperactivity disorder) before the behavioural symptoms appear later in development. The developmental methods that oppose the static neuropsychological approach are the dynamic systems approach, the developmental systems approach, and neuro-constructivism. These developmental theories hold that interactions between multiple subsystems functioning within a particular context led to the process of self-organization that is development (Karmiloff-Smith et. al., 2016).

Neurodevelopmental illnesses often affect the day-to-day functioning of the entire family because they disrupt social and economic norms. Activities that promote their own well-being take a backseat as parents focus their time and energy on rectifying misbehaviour. In addition, feelings that surface include annoyance, melancholy, hopelessness, and emotional hypersensitivity (Gilberg et. al., 2019). Mothers of children with mental and neurological impairments report high burden and bad quality of life, according to a comprehensive review on the topic (Reis et. al., 2020).

Providing care for individuals with disabilities is associated with a variety of negative experiences (Fazree et. al., 2021). Quality of life (QOL) is an important outcome for the monitoring and treatment of neurocognitive developmental disorders and disabilities (NDD), as well as for understanding the experiences and difficulties faced by patients and their families. According to Conway and associates (2020), it is a complex construct that captures how each individual subjectively evaluates their degree of independence, social functioning, psychological well-being, and physical health. Because NDD is marked by impairments or comorbidities in multiple domains of function, it is not surprising that children with neurocognitive developmental disorders and disabilities (NDD) and their families experience lower quality of life (QOL) than peers (Puka et. al., 2020). Therefore, QOL measures go

beyond a one-dimensional emphasis on symptoms and are not equivalent to diagnostic techniques that evaluate symptoms or inadequacies. (Conway et. al., 2020).

Caregiving load and quality of life (QoL) may be positively correlated, and this could have a moderating effect on carer relationships. In a 2015 study, the mediating role of carer burden on carers' quality of life was examined. The study looked at carer load as a mediator between patient and carer characteristics and the determinants of carers' QoL. Surveys, interviews, and a review of the literature were used in this investigation. With caregiving acting as a mediating factor, carer health status, income, spouses providing patient care, and length of hospital stay were found to be significant predictors of carers' quality of life. Carers' Quality of Life was only directly predicted by the amount of time they spent providing care each day and the degree of patient education (Jeong et. al., 2015).

One aspect of general status and well-being that may be impacted by a number of variables is the Quality of Life (QoL). The emotional and behavioural responses of mothers to having a child diagnosed with a mental illness vary based on the level of emotional distress and the cognitive coping mechanisms employed (Elena & Rexana, 2013). A variety of psychological tests have been used to evaluate the parents' emotional discomfort (Profile of Affective discomfort), cognitive coping mechanisms (Cognitive-Emotional Regulation Questionnaire), and quality of life (Family Quality of Life Survey). The two groups did not differ significantly in terms of QOL or mental discomfort. Positive refocusing, positive re-evaluation, and catastrophizing were the coping mechanisms used by the mothers of ASD children, and they showed a significant correlation with the overall appraisal of the family quality. According to the findings, employing adaptive coping mechanisms is associated with a higher family quality of life, whereas the opposite is true for maladaptive coping mechanisms (Silvia et. al., 2022).

Caregivers of children with autism experience higher level of burden and lower level of quality of life on all the four domains of quality of life as compared to the caregivers of children without disability and findings indicate different effect as a

consequence of different childhood conditions and also the need to provide adequate parental support when providing intervention to their children with disabilities (Geetanshi, 2021). Caregivers with ADHD and ASD have very high levels of burden and are significantly higher in the ASD group when compared with acquired brain injury (Higginson et. al., 2010). Studies found that the caregiver burden for ADHD (Beecham & Knapp, 1992) is significantly associated with comorbid psychiatric symptoms. The unmet need is significant to endorse the burden of the caregiver which was significantly correlated with the burden for both disorders concerning social contact, major mental health problems, appropriate daytime activities, the safety of self and communication (Akbari et. al., 2018).

A mother expects her child to be born healthy but the diagnosis of a child as disabled during infancy or in later stages takes a heavy toll on her happiness and well-being. Diagnosis can precipitate a range of psychological responses in parents thereby, constituting a crisis for mothers and demanding extraordinary psychological adjustment. In India, the majority of such persons have traditionally been cared for by their families. In today's modern society, this home-based care has resulted in many adverse consequences. Factors such as changes in the social system (e.g. breaking up of joint families) and the economic system (e.g. unemployment, inflation) have contributed to the stress that parents of special children experience. Parents of children with ADHD and Autism may find themselves burdened with a lifelong responsibility of caring for their children and diminished attention to their own health. Other than this, lack of knowledge about disorder, lack of treatment, and if treatment is available, it is unaffordable, adds the stress. This leads to deterioration of quality of life of parents in different domains such as economic, social, educational, and psychological (Jain et. al., 2019). In the Indian context, mothers take the sole responsibility for raising and caring for a child with a disability. Given other responsibilities that mothers typically have about maintaining stability for their family, the additional responsibility of providing significant levels of care for their child indefinitely may task parents' ability to maintain balance in their own lives. This may lead to stress for parents which could compromise their ability to effectively care for their child. Hence, female caregivers tend to have poorer Quality

of Life due to traditional family roles in different cultures (Hsia et. al., 2020; Cohen et. al., 2021). There is a higher prevalence of depression or anxiety and lower Quality of Life scores related to lower socioeconomic status, lower education, and unemployed or financial problems among caregivers of individuals with mental and non-mental illness (Grover et. al., 2017; Geng et. al., 2018; Ribe et. al., 2018).

When mothers care for children outside of the conventional discourses of motherhood, they experience oppression and marginalisation. Mothers and their offspring acquire the skill of navigating the world as the "other," and this marginalisation applies to both groups. It can take a lot of work to overcome the intrapersonal, interpersonal, and structural constraints that parents of children with disabilities must deal with (Currie & Szabo, 2020). The unrealistic parenting expectations can lead to disconnection and vulnerability (Brock, 2014; Fernandes & Robertson, 2019; Robertson, 2014). Mothers who care for children with complex neurodevelopmental disorders (NDDs) were described by Carpenter and Austin (2007). These writers discussed how atypical experiences of parenting are marginalised and how children with behavioural differences upend the popular "text" (Carpenter & Austin, 2007) of mothering. Mothers make an effort to participate in social settings and activities, but they are limited by societal expectations of what constitutes a good mother and kid (Robertson, 2014). Families may feel ashamed and excluded if their child is engaging in abnormal activity that is accepted by society (Carpenter & Austin, 2007). As a result, medical problems were not well resolved, and families received little assistance. Rejection also occurred to children whose disruptive, bothersome behaviour deviated from social norms or moral standards. Mothers' stories are socially "troublesome" and are viewed as "troubled" because they are unable to properly manage their children's problems (Austin & Carpenter, 2008). Caregivers of child with NDDs suffer from significant physical and mental stress (Ansari et. al., 2016). Multisystem participation was required because mothers who were dealing with unusual and unexplained disease presentations in their children reported difficulty getting treatment, support, and assistance. Parents who voiced concerns to healthcare providers felt uneasy, rejected, and shunned because of

medical inexperience and a lack of knowledge in handling complex medical and behavioural issues (Abegaz et. al., 2019).

Having a child with developmental disabilities creates a crisis event, how parents respond to the stresses of raising their child with special needs depends on a wide variety of factors influencing their ability to cope, such as their interpretation of the crisis event, the family's sources of support, community resources, and family structure. The personality characteristics of the family members, their financial status, educational level, problem-solving skills, and spirituality all influence a family's ability to cope. Strong marital relationships and social support also help determine parent adjustment (Thwala et. al., 2015; Hlanze, 2015; Emerson, 2003; Fazil et. al., 2004). For children with developmental and intellectual disabilities, mothers provide the majority of care, including community-based care and coordination of requirements with doctors. Mothers are therefore more vulnerable to stress and burnout (Lafferty et. al., 2016). Research has indicated that up to 68% and 52% of these mothers, respectively, suffer from anxiety and despair (Swapnajeet et. al., 2013). Due to the pressure of juggling their children's requirements with household duties, mothers are known to have higher rates of depression (Saltanat C et. al., 2023).

Caregiving of children with Autism Spectrum Disorder (ASD) is reported to be more stressful and challenging compared to parenting children with typical development or other developmental disabilities (Pandey et. al., 2018; Valicenti et. al., 2015). These challenges include behavioural problems, financial difficulties, stigma, and lack of awareness within the community (Zakaria et. al., 2023). Problematic behaviours are among the most commonly cited predictors of caregiver stress and burden (Tomanik et. al., 2004; Marsack et. al., 2019). Other significant predictors of caregiver burden include the severity of ASD symptoms, lower levels of perceived social support, low financial status, caregiver parenting skills, and the presence of medical comorbidities in caregivers (Athari et. al., 2013; Mohamad et. al., 2018). Studies examining the bidirectional relationship between child behaviour and caregiver stress suggest that child behaviours can exacerbate parental stress,

which in turn can worsen the child's behavioural issues (Baker et. al., 2003). Parent-child interactions are found to vary across different life stages and types of behavioural problems (Woodman et. al., 2023). Additionally, Del Bianco and colleagues noted that perceived parental stress and maladaptive parenting strategies in families of children with ASD might stem from difficulties in understanding atypical behaviours and non-verbal communication. The interaction between these communication challenges and parental distress can create a cascade effect, impacting the parent-child relationship (Mazzarini & Nacinovich, 2021).

A family is a social system where one member's disorder can disrupt the entire dynamic, potentially worsening the problems within the family and creating new challenges. The behaviours associated with a chronic condition like ADHD can destabilize the family's foundations. Moreover, health systems often focus primarily on the symptomatic treatment of children, without addressing the needs of the family, leaving caregivers unsupported. If caregivers' needs are not adequately met, and interventions are not tailored to address their challenges, both the caregivers' physical and mental health may suffer, and the children may be deprived of the appropriate care they need. Nurses play a crucial role in supporting family caregivers, helping them become qualified and empowered, and shifting the caregiving approach beyond simply caring for the patient to a more holistic, supportive model for the family as a whole (Wood, 2007).

Numerous studies on caregivers have highlighted the extensive challenges they face, including the negative effects on their physical and emotional well-being, strained relationships with other family members, work-related difficulties, and financial burdens due to loss of income (Sherman et. al., 2008). Primary caregivers, in particular, encounter various obstacles and experience significant impairments in their quality of life (Bruder, 2016). Caring for children with special needs demands a great deal of time, effort, and patience, which often leads to psychological distress, depression, anxiety, and other mental or physical health issues among parents (Bromley et. al., 2004; Hamlyn-Wright et. al., 2007; Khanna et. al., 2011; Kuhlthau et. al., 2010). Additionally, many parents face financial difficulties due to high out-

of-pocket health care costs, underemployment, or job loss (Bromley et. al., 2004; Hamlyn-Wright et. al., 2007; Kuhlthau et. al., 2005, 2010). It is not surprising that parents of children with ASD often feel overwhelmed by the demands of caregiving (Khanna et. al., 2011; Stuart & McGrew, 2009).

Behavioural problems in children significantly affect family adaptation, including quality of life and psychological well-being. Parents often feel helpless, overwhelmed, and frightened by these behaviours, leading them to question their parenting abilities. Feelings of guilt arise due to their perceived inability to manage these challenges. Parents of children with ASD and ADHD face a unique set of difficulties in providing care, as these conditions present complex and ongoing challenges that require significant emotional and practical adjustments.

Studies have indicated that families of children with ADHD face more challenges compared to families of healthy children. These challenges include increased stress, a more conflicted family environment, and the use of harsh disciplinary methods, which may involve violence and inappropriate interactions. Other difficulties include marital conflicts, parents' distress, greater financial burdens, depression, and aggressive or inappropriate behaviour toward other children as a result of the pressures imposed by caring for a child with ADHD. Furthermore, these families may struggle with a lack of coping skills, reduced social and family support, uncertainty in managing the child's condition, negative feelings, and the stigma associated with ADHD. As a result, some parents may conceal the diagnosis and avoid seeking proper treatment for their child. The mental strain of raising children with ADHD can also strain marital relationships, and these challenges affect not only the children but also their families and society at large (Powell et. al., 2010; Savundranayagam et. al., 2011).

According to Folkman and Lazarus (1985), general stress coping is a dynamic process, where coping strategies evolve over time and across different contexts to meet the changing demands of stressful situations. Previous research has shown that positive coping strategies are linked to adaptive mental health outcomes, while negative coping strategies are associated with maladaptive outcomes (Lazarus

& Folkman, 1984; Skinner & Zimmer-Gembeck, 2007; Taylor & Stanton, 2007). Similar patterns have been observed among parents of children with Autism Spectrum Disorder (ASD). For example, factors such as the child's age and symptom severity (Gray, 2006; Ingersoll & Hambrick, 2011), parent personality (Ingersoll & Hambrick, 2011), and family functioning (Altiere & von Kluge, 2009) have been shown to influence parenting stress. Additionally, among parents of children with ASD, the use of adaptive coping strategies has been found to have a positive relationship with lower levels of anxiety and depression, while maladaptive coping strategies are linked to higher levels of these symptoms (Benson, 2011; Smith et. al., 2008).

Research on coping strategies related to stress in parents and caregivers of children with Autism Spectrum Disorder (ASD) has been extensively explored (Benson, 2011; Gray, 2006; Hayes & Watson, 2012). However, the way that parents and caregivers cope with the challenges of ASD varies significantly across different individuals and situations, making it a complex and evolving area of study. Previous research has highlighted the dynamic and stressor-dependent nature of coping, suggesting that generalized coping frameworks may not apply uniformly to all parents and caregivers of children with ASD (Pakenham et. al., 2005; Skinner & Zimmer-Gembeck, 2007). Despite the growing body of research, comprehensive reviews on the nature of stress coping among parents and caregivers of children with ASD remain limited. Parents adopt various coping strategies that are both positive and negative to manage the psychological stress associated with raising a child with ASD. Coping behaviours differ based on factors such as marital and socioeconomic status, and these strategies can either alleviate or exacerbate distress. Parents also rely on diverse support systems, both formal and informal, to help them cope. Strengthening these support networks can significantly improve the well-being of parents and caregivers (Lai & Oei, 2014).

Caregivers use a variety of coping strategies to manage the challenges associated with a patient's disability and their caregiving responsibilities. The type of relationship between the caregiver and the patient, such as whether the caregiver is a

parent or spouse, can significantly influence the caregiving role (Elena, 2021). Social status and cultural norms also impact the caregiving experience. The caregiving process can be understood through the stress-appraisal-coping model, where appraisal plays a crucial role in how caregivers perceive and react to the stressor of caregiving (Chakrabarti & Gill, 2002). In this context, caregiving can be seen as a life stressor, and how a caregiver copes with it is influenced by their personal traits and the caregiving environment. Factors such as the patient's condition, the caregiver's workload, their psychological health, and the available support system all play a role in determining a caregiver's ability to manage the stress. Different coping strategies are employed, with problem-focused strategies aiming to address the issue directly—such as increasing the patient's social activity, improving communication, or seeking more information about the illness—while emotion-focused strategies may include avoidance, resignation, seeking spiritual support, or using substances. More adaptable coping strategies may involve socializing with friends or engaging in personal hobbies.

Parents of clinic-referred children with hyperactivity were coping less effectively and struggled more with improving their children's behavioral issues compared to parents of non-clinic-referred children. Additionally, children referred to clinics were more likely to experience aggressive disciplinary actions, such as shouting, threatening, and physical punishment, while parental control was less effective in these families compared to those with non-clinic-referred children (Woodward et. al., 1997).

The symptoms of attention deficit hyperactivity disorder (ADHD) disrupt family life, and parents of children with the disorder use a range of coping strategies. A systematic assessment of coping strategies used by parents of children with ADHD was carried out. This systematic review's goals were to identify the most widely used tools for measuring coping strategies, create a list of coping strategies used by parents of children with ADHD, and look into the factors influencing parental coping (Francesco & Rosa, 2020).

Adaptive coping strategies were positively associated with psychological aspects of quality of life in a number of reviewed studies, but it was difficult to classify strategies with certainty due to variations in how coping was measured. However, one study discovered a negative relationship between maladaptive coping strategies and psychological aspects of quality of life (Fairfax et. al., 2019). Several research including families of children with intellectual disabilities provide additional support for these findings; however, these studies were not included in our analysis since the children's situations frequently did not fit our inclusion criteria for paediatric professional therapies. According to these researches, using problem-focused coping techniques increased carer well-being, while using emotion-focused strategies decreased it (Colman et. al., 2019).

Family care and other duties that parents are supposed to perform are crucial in helping these kids manage their disorders. Additionally, some of the researchers had first-hand experience addressing the requirements of family carers of children with autism and ADHD. Families are always enquiring about their child's issue, the progression and signs of the illness, medications, and the overall approach to raising these kids. The requirements of carers for these youngsters in Mizoram have not yet been evaluated by any study.

Numerous researches have been carried out to assess the burden and quality of life of parents; however, few studies have provided socio demographic predictors of the quality of life of parents with autism and ADHD. In Mizoram, there is a dearth of substantial study on the stress that parents of special needs children bear. Understanding the in-depth realities of carers' problems, mental health, quality of life, and family relationships is the primary goal of this research.

OBJECTIVES: The study adopted the following for the objectives:

- 1) To assess the level of quality of life of the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.
- 2) To assess the level of depression in the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.
- 3) To assess the level of anxiety in the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.
- 4) To assess the level of burden in the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.
- 5) To assess the coping strategies of the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.
- 6) To examine the relationship between burden, quality of life, depression, anxiety and coping strategies among three groups - the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.

HYPOTHESES

- 1) There will be the highest quality of life for the parents of normal mentally healthy children, followed by parents of children with Autism, and parents of children with ADHD.
- 1) There will be the highest level of depression among the parents of children with Autism, followed by parents of children with ADHD, and parents of normal mentally healthy children.

- 2) There will be the highest level of anxiety on the parents of children with ADHD, followed by parents of children with Autism, and parents of normal mentally healthy children.
- 3) There will be the highest level of burden on the parents of children with Autism, followed by parents of children with ADHD, and parents of normal mentally healthy children.
- 4) Parents of children with autism, and parents of children with ADHD will use avoidance and emotional coping whereas parents of normal mentally healthy children will use task-oriented coping strategies.
- 5) It is expected that burden, depression, anxiety, avoidance coping and emotional coping will have a positive relationship with each other whereas the quality of life and task-oriented coping strategy will also have a positive relationship with each other; burden, depression, anxiety, avoidance coping and emotional coping will have a negative relationship with the quality of life and task-oriented coping strategy.

CHAPTER-IV

METHODS AND PROCEDURE

METHODS AND PROCEDURE

Sample: The sample size was 120 in total, 40 parents of autism, 40 parents of ADHD and 40 parents of normal health to serve as a control group. Sample selection was done in a multi-stage procedure: (i) samples for 40 children of autism, 40 children of ADHD were selected from Gilead Special School, Child Guidance Centre, and Private clinics, District Early Intervention Centres located in Aizawl, Mizoram. The selected children were already identified having autism / ADHD by registered professionals; and (ii) parent of selected children samples comprising- 40 parents of autism, 40 parents of ADHD were identified through their children; (iii) sample of normal children were selected from Aizawl city based on the socio-demographic profile of the selected samples for 40 children of autism, 40 children of ADHD; and (iv) 40 parents of normal mental health children were identified through their children who were already identified. For the final count, 40 parents of autism, 40 parents of ADHD and 40 parents of normal mental health were used to serve as a sample. The sample selection followed a purposive sampling procedure, and the age range for the samples was 25-45 years of age.

Inclusion criteria for parents with ADHD and Autism:

- a. Parents of children having ADHD and Autism who met the criteria of ICD-11
- b. Parents aged 25-45 years
- c. Parents who are staying together
- d. Those who have given informed consent
- e. Parents with normal physical health

Exclusion criteria for parents with ADHD and Autism:

- a. Parents of children not having ADHD and Autism based on the criteria of ICD-11
- b. Parents aged below 25 and above 45 years of age

- c. Parents who are not staying together/single parent
- d. Those who do not want to give consent
- e. Parents without Normal physical health.

Inclusion criteria for parents with normal healthy control:

- a. Parents of children who are not having any psychiatric/physical problems (screened out using Mini-Mental Status Examination (MMSE))
- b. Parents aged 25-45 years
- c. Parents who are staying together
- d. Those who have given informed consent

Exclusion criteria for parents with normal healthy control:

- a. Parents of children who are having any psychiatric/physical problems. (By using Mini-Mental Status Examination (MMSE))
- b. Parents aged below 25 and above 45 years of age
- c. Parents who are not staying together/single parent
- d. Those who do not want to give consent

Psychological Tools Used:

1). Informed Consent form (Lalawmpuia, 2021) : An informed consent form was designed by the researcher, especially for this study in which the participants were informed about the purpose of the study, and expected contribution/participation from the participant, assurance of keeping their personal information confidential, purely voluntary participation and freedom to leave anytime if he/she is willing, without any penalty and that no harm will be caused on the participant. After informing all, the participants were asked for consent which suggests that if he/she is

willing to perform in the study, he/she may give consent in writing on the Informed Consent Form.

2). Socio-demographic data sheet (Lalawmpuia, 2021): A specially designed Performa containing necessary and basic information like name, age, sex, religion, marital status, education, monthly income, etc was used.

3). Mini-Mental Status Examination (Folstein et al., 1975) :

The mini–mental state examination (MMSE) is a 30-point questionnaire that is used extensively in clinical and research settings to measure cognitive impairment. The MMSE's purpose has been not, on its own, to provide a diagnosis for any particular nosological entity. Administration of the test takes between 5 and 10 minutes and examines functions including registration (repeating named prompts), attention and calculation, recall, language, ability to follow simple commands and orientation.

4). WHO Quality of Life-BREF (1996): The WHO quality of life assessment was developed by the WHOQOL group with fifteen international field centres, simultaneously in an attempt to develop a quality of life assessment that would be applicable cross-culturally. WHOQOL-BREF domains are physical health, psychological health, social relationship, environment factors. It contains a total of 26 questions. The WHOQOL-BREF should be self-administered if respondents have sufficient ability. Otherwise interviewer assisted or interview administered forms should be used. The internal consistency coefficient ranged from 0.70 to 0.75 for the domains. The test-retest reliability coefficient ranged from 0.41 to 0.79 at item level and 0.76-0.80 domain level all at $p < 0.01$.

5). Beck Depression Inventory (BDI; Beck, Steel & Brown, 1996): It was created to gauge how severe depression is. It is a 4-point rating scale with 21 items. Four categories are used for scoring: mild (0–16), moderate (17–30), and severe (31 and above). An internal consistency study showed that the students' Cronbach's alpha was .93 and the outpatients' was 0.92. The scale's validity was determined to be .98 (Beck et. al., 1996). The scores of both samples were subjected to item total correlations, which produced substantial correlations for both groups on every item.

After calculating the test-retest reliabilities, an average correlation of .93 was obtained.

The BDI-II is a widely used 21-item self-report inventory measuring the severity of depression in adolescents and adults. The BDI-II was revised in 1996 to be more consistent with DSM-IV criteria for depression. For example, individuals are asked to respond to each question based on a two-week time period rather than the one-week timeframe on the BDI. The BDI-II is widely used as an indicator of the severity of depression, but not as a diagnostic tool, and numerous studies provide evidence for its reliability and validity across different populations and cultural groups. It has also been used in numerous treatment outcome studies and in numerous studies with trauma-exposed individuals.

6). State trait anxiety inventory (STAI) (Sesti, 2000): Anxiety was assessed by the state-trait anxiety inventory (STAI-State). This scale contains 20 items on, for instance, feeling at ease or upset (Sesti,2000). Scale scores range from 20 to 80 with higher scores indicating higher levels of anxiety (Van der Ploeg et al., 1980). An STAI-State score of more than 44 defines an individual as highly anxious (Spielberger & Vagg,1984; Millar et al, 1995). Applying this cut-off level, we defined men with pre-treatment STAI-State scores equal to or below 44 as low anxiety and those with scores above 44 as high anxiety‘ whereas the range for the state anxiety was .16 to .62.

7). The Zarit Burden Interview (Zarit, Reever & Bach-Peterson, 1980): Originally a 29-item questionnaire, the Zarit Burden Interview is a widely used carer self-report tool utilised by numerous ageing organisations (Zarit, Reever & Bach-Peterson, 1980). In Zarit and associates (1980), the 29-item test is used. There are 22 items in the updated version. Using a 5-point rating system, the carer is asked to support each assertion in the interview. The possible answers are 0 (Never) through 4 (Nearly Always). Shorter versions with 1–18 items have been created for quicker administration. According to a study by Yu, Yap & Liew (2018), the 6-item version was the best short version since it had the fewest items and comparable diagnostic usefulness to the original 22-item form.

8). Coping Inventory for Stressful Situations (CISS-21; Endler & Parker, 1990):

The CISS is a self-report measure of coping reactions, which focuses on assessing basic coping behaviours or reactions. The CISS is unique in its explicit focus on distinguishing between task-oriented, emotion-oriented, and avoidance strategies. CISS is a four-factor model of human coping with adversity developed by Endler and Parker (1990) and validated by others (Avero et. al., 2003). Their construct differentiates three types of coping: emotion-oriented, task oriented, and avoidant. The CISS is a 48-item self-report inventory that measures stress coping strategies in three dimensions-namely task-oriented coping, emotion-oriented coping, and avoidance-oriented coping, each dimension itself comprising 16 items. Task-oriented coping entails treating a stressful situation as a problem to be solved, and tackling it directly as such; emotion-oriented coping aims at mitigating emotional stress, and avoidance-oriented coping styles on the postponement of dealing with current problems.

Research Design: The study aims to Correlational Design to compare parents of children with Autism, ADHD and normal mentally healthy children on quality of life, depression, anxiety, coping strategies and burden.

Procedure:

The conduction of the data collection for the present study followed the following steps: (1) construction of a Socio-demographic profile, (ii) collection of selected psychological tests, (iii) any required permission/consent for data collection was taken from the authorities of hospital, centres, homes, etc. who are taking care of the children, (iv) informing participants about the purpose of the study, expected participation, assurance of confidentiality for keeping personal information, ensuring voluntary participation and obtaining consent from the participants or the caretakers, (v) Sample selection and identification was done by employing the socio-demographic profile, and mainly purposive sampling procedure was attempted but random sampling procedure was followed as far as possible, (vi) administration of the selected psychological scales on the selected samples was done as per Ethical Principles of Psychologists and Code of Conduct of American Psychological

Association (2016) and the prescribed instructions given in the manuals were followed, (vii) the researcher took precautions on unresponsiveness on each item, etc.

The subjects were contacted personally for data collection and consent for the study was taken from them. Parents of children with Autism and ADHD were selected from different parts of Aizawl – Mizoram such as special school, district early intervention centre, support group, private clinic and hospital. They were provided the basic instructions for each test to make them understand how to perform. The tests were administered following the instructions specified in the respective test manuals. Tests were conducted with the presence of researcher (Clinical Psychologist), it was administered in individual setting, and number of session required for each participant was 2 session and duration was 2 hours.

CHAPTER-V

RESULT AND DISCUSSION

RESULT AND DISCUSSION

The present study entitled “Quality of Life, Psychological Distress and Coping Strategies of Parents of Children with Neurodevelopmental Disorder” aimed to study the impact of neurodevelopmental disorders such as ADHD and Autism on caregivers, primarily parents by comparing them across several psychological scales such as (i) Mini-Mental Status Examination (MMSE; Kurlowicz, L., & Wallace, M. (1999), (ii) The Zarit Burden Interview (Zarit, Reever & Bach-Peterson, 1980), (iii) The World Health Organization-Five Well-Being Index (WHO-5; WHO. 2024), (iv) Beck Depression Inventory (BDI; Beck, Steel & Brown, 1996), (v) Beck Anxiety Inventory (BAI; Beck et. al.,1988, and (vi) Coping Inventory for Stressful Situations (CISS-21; Endler & Parker (1990). Moreover, the correlation between the dependent variables is also estimated to understand the extent of the relationship between these variables.

Based on the available literature and theory, it was expected that the level of burden and level of depression would be highest among parents of children with Autism, followed by the parents of ADHD but high in Anxiety while the parents of normal children were lowest in burden, depression and anxiety. Quality of Life was expected to be the highest among parents of children with normal mental health. In coping mechanisms, it was hypothesized that Parents of Autism and ADHD were expected to employ more avoidance and emotional coping while parents of children with normal mental health were expected to use task-oriented coping strategies. It was also expected that burden, depression, anxiety, avoidance coping and emotional coping will have a positive relationship with each other whereas the quality of life, and task-oriented coping strategy will also have a positive relationship with each other.

The present study employed 120 samples, comprising 40 parents of autism, 40 parents of ADHD, and 40 parents of normal mental health who served as a control group. The samples were selected through a random sampling procedure. The researcher also prepared inclusion and exclusion criteria using ICD-11 and the Mini-International Neuropsychiatric Interview (M.I.N.I.).

Sample characteristics: The sample characteristics include gender, psychiatric illness, age, socio-economic status, number of offsprings, marital status, and expert professionals which were recorded with the help of socio-demographic profiles constructed by the researcher (Lalawmpuia, 2021). Equal representation of illness (ADHD, Autism, Normal), and gender (female and male) were ensured. The distribution of the socio- dempgraphic profiles of the samples including age, socio-economic status, number of offsprings, educational qualifications and professionals who diagnosed the samples are presented in Table 1.

Table- 1: Showing the distribution of socio-demographic profiles of the samples

1. Distribution of age groups among samples in percentage and numbers				
25-30 years	31 to 35 years	36-40 years	41-45 years	Total
28% (34)	35% (42)	21% (26)	15% (18)	100% (120)
2. Distribution of socio-economic status (family monthly income) among samples in percentage				
5000-15000	15001-20000	25001- 30000	30000 above	Total
22% (26)	35% (42)	30% (36)	13% (16)	100% (120)
3. Distribution of the number of offspring among the samples in percentage				
1 offspring	2 offsprings	3 offsprings	4 above offsprings	Total
23 % (28)	37% (44)	23% (28)	17% (20)	100% (120)
3. Distribution of educational qualifications among the samples				
Class X and Below	Class XII	Graduate	PG and above	Total
17% (20)	33% (40)	22% (26)	28% (34)	100 % (120)
4. Distribution of professionals who diagnosed the samples				
Psychiatrist	Clinical psychologist	Paediatrician	Physician	Total
23% (28)	35% (42)	28% (34)	14% (16)	100% (120)

(i) The distribution of age groups was presented in four groups: 28% of the respondents fall in the age range of 25-30 years, 35% of the respondents fall in the age range of 31-35 years, 21% of the respondents fall in the age range of 36-40 years and 15% fall in the age range of 41-45 years.

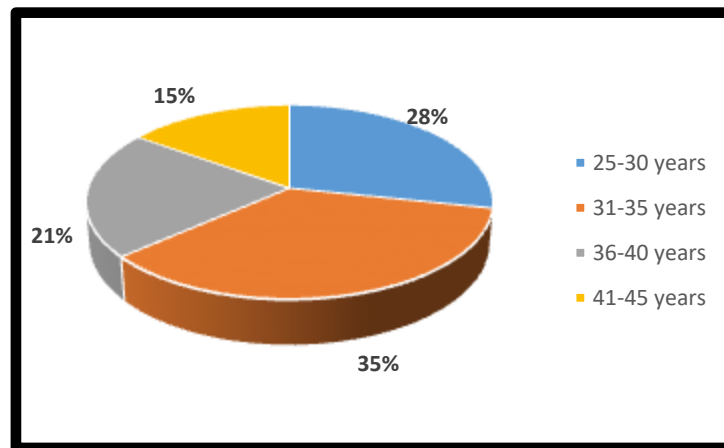


Figure- 1: *Distribution of age groups in percentage*

(ii) The distribution of socio-economic status (family monthly income) are as follows: 22% of the respondents have family monthly income between 5000 and 15000, 35% fall within the family monthly income range of 15001 and 20000, 30% have family monthly income between 25001 and 30000 and 13% have family monthly income of 30000 above.

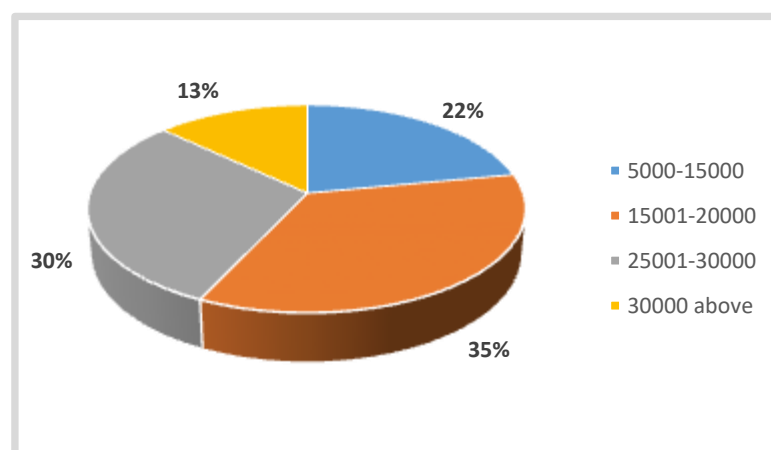


Figure 2: *Distribution of Socio-economic status (family monthly income) in percentage*

(iii). The distribution of the number of offsprings are as follows: 23% of the respondents have 1 offspring, 37% have 2 offsprings, 23% have 3 offsprings and 17% have 4 and above offsprings.

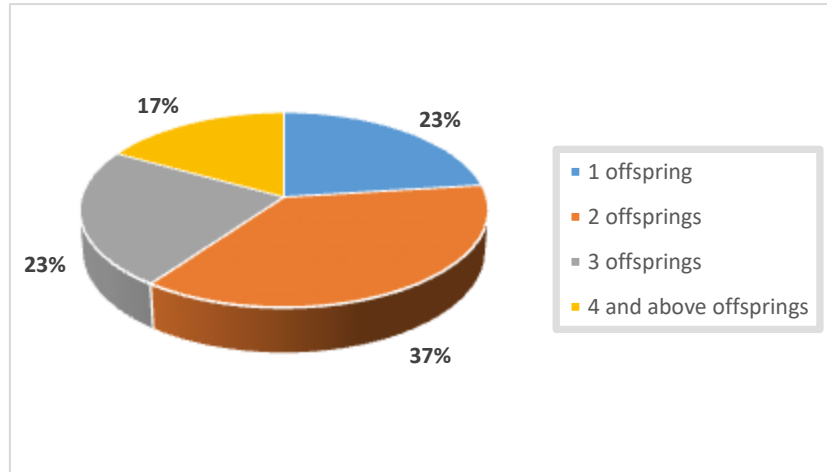


Figure 3: Distribution of the number of offsprings in percentage

(iv). The distribution of educational qualifications of the samples are presented in the following category - 17% of the respondents are Class X and below, 33% have completed Class XII, 22% are Graduates and 28% have a postgraduate degree or higher.

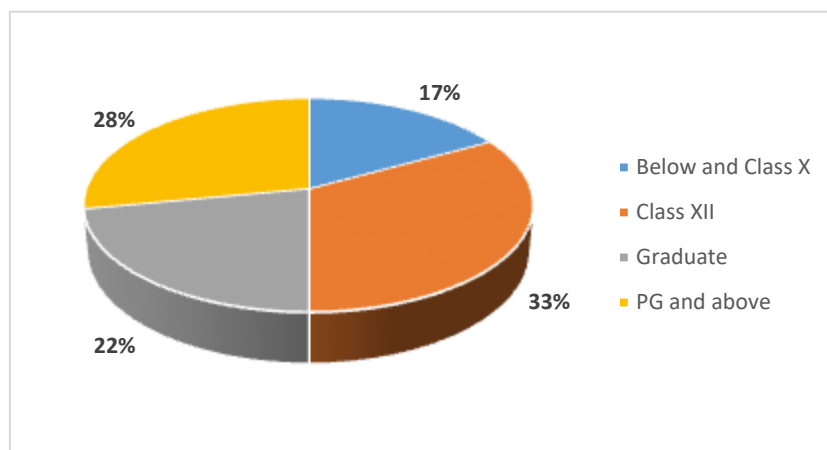


Figure 4: Distribution of the educational qualifications in percentage

(v). The distribution of professionals who diagnosed the samples are presented as follows: 23% were diagnosed by Psychiatrist, 35% diagnosed by Clinical psychologists, 28% diagnosed by Paediatrician and 14% diagnosed by Physician.

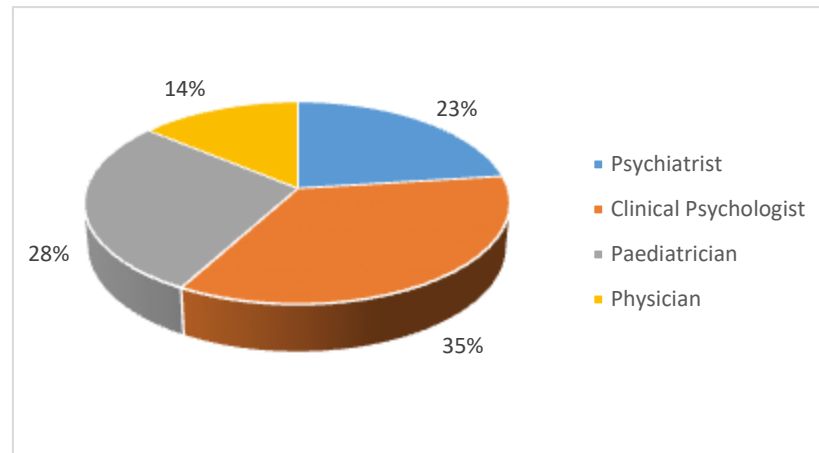


Figure 5: *Distribution of professionals who diagnosed the samples in percentage*

2. Psychometric properties of the Psychological Scales

The psychological tests used in the present study were originally constructed and standardized based on the population of another culture, and it becomes necessary to ensure its applicability for the current population investigated (Witkin & Berry, 1975). As such, the psychometric test was done to verify the authenticity of the test for the target population. The study employed some standardized psychological scales for the collection of data which were constructed for other cultures and not for the target population of the study which required checking of its applicability to the targeted population. To check the psychometric properties, the normality (Mean, SD, Kurtosis and skewness), reliability (Cronbach's Alpha) and Homogeneity (Levene and Brown-Forsythe) were computed.

The results shown in Table 2 reveal the reliability coefficients (Cronbach's alpha) of the scales for the target population (Parents with Autism, ADHD and normal mental health). The scales used for behavioural measurements were found to be highly reliable for the population under study as all coefficients are .80 and above.

Table 3 also shows that the Kurtosis and skewness were within the acceptable range (± 2), and the Homogeneity test was within an acceptable range (Levene; all non-significant) and brown Forsyth (all - significant) which, along with the reliability results, showed the trustworthiness of the scales.

The data has met the assumptions of parametric statistics (Normality, reliability and homogeneity) which suggested that parametric statistics may be used for further analysis.

Table 2: Showing the Reliability and Homogeneity of Variance of the Psychological Scales

Scales	Cronbach's α	Levene's Test	Brown-Forsythe
Quality of Life	.87	.013	.32
Depression	.85	.012	.32
Anxiety	.80	.025	.29
Task-oriented coping	.84	.023	.28
Emotion Focus Coping	.88	.032	.19
Avoidance	.87	.040	.35
Burden	.85	.020	.37

Table-3: Showing the Mean, SD, Skewness and Kurtosis of all dependent variables

Scales	Mean	SD	Skewness	Kurtosis
Quality of Life	20.24	5.09	0.77	0.65
Depression	13.52	2.90	0.68	0.63
Anxiety	29.50	5.85	0.60	0.80
Problem Focused Coping	16.39	3.80	0.79	0.61
Emotion Focused Coping	16.44	4.26	0.67	4.82
Avoidance Focused Coping	15.44	4.20	0.76	0.73
Burden	17.76	4.46	0.85	0.65

Descriptive statistics such as Mean, Standard Deviation, Skewness and Kurtosis were calculated for the whole sample (Parents of ADHD, Autistics and Normal mental health). The Skewness and Kurtosis were generated to highlight the characteristics of the distribution of each psychological scale. All psychological scales showed that the distribution approximates the normality variance as represented in Table-3.

The results of the study were displayed following the objectives of the study sequentially as follows:

Objective-1: To assess the level of quality of life of the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.

To compare the three groups- (i) Parents of Autistics (ii) Parents of ADHD (iii) Parents of normal mental health, the descriptive statistics and post-Hoc mean comparison (Scheffe) were employed to find any significant difference between the three groups on the dependent variables and are presented in Tables-4 and 5.

Table-4: Showing the Mean, SD, Kurtosis, Skewness of Quality of Life, Depression, Anxiety, Problem focused coping, Emotion focused coping, Avoidance focused coping, and Burden for parents of Autism, ADHD and Normal samples

Groups	Statistics	Quality of Life	Depression	Anxiety	Problem Focus	Emotion Focus	Avoidance Focus	Burden
Autistic parents	Mean	71.20	16.77	32.27	14.42	16.68	17.44	21.75
	SD	4.26	3.29	6.84	3.93	4.42	4.55	4.79
	Kurtosis	0.61	0.95	0.74	0.78	0.55	0.61	0.63
	Skewness	0.16	0.69	-0.64	0.52	0.40	0.534	0.58
ADHD parents	Mean	77.10	13.52	34.26	16.46	18.32	15.42	18.50
	SD	5.01	3.90	6.60	3.13	3.93	3.17	4.84
	Kurtosis	0.86	0.69	0.56	0.83	0.86	0.86	3.94
	Skewness	0.51	0.53	0.97	0.68	0.53	0.89	0.75
Normal Mental parents	Mean	83.30	10.25	21.97	18.30	14.32	13.46	13.05
	SD	4.99	2.31	4.11	4.34	4.42	4.88	3.75
	Kurtosis	0.84	0.41	0.49	0.75	0.61	0.82	0.98
	Skewness	0.67	0.67	0.79	0.63	0.50	0.66	0.63
Total samples	Mean	20.24	13.52	29.50	16.39	16.44	15.44	17.76
	SD	5.09	3.50	5.85	3.80	4.26	4.20	4.46
	Kurtosis	0.77	0.68	0.60	0.79	0.67	0.76	0.85
	Skewness	0.65	0.63	0.80	0.61	4.82	0.73	0.65

Comparison between the three groups on the dependent variables

Table 4 shows the Mean, SD, Kurtosis, skewness comparisons of the three groups on the dependent variables and Table 5 shows the one-way ANOVA between the groups. The following results were obtained:

On Quality of Life: Results revealed that parent of Normal children had a highest Quality of Life than Parent of ADHD ($M=83.30$; 77.10 ; $t= -5.10$; $p < .01$) and Autistic parents ($M=83.30$, 71.20 ; $t= -6.20$; $p < .01$). Thus, autistic parents had a lower Quality of Life than ADHD parents ($M=77.10$, 71.20 ; $t= -4.90$; $p < .01$) and their difference is significant at the .01 level and presented in tables 4 and 5. The hypothesis regarding these variables was accepted.

Many parents of children with ADHD reported to have diminished quality of life (Cappe et. al., 2016). According to earlier research, parents of children with ASD deal with a variety of difficulties that increase their risk of experiencing a poor quality of life (Calonge-Torres et. al., 2017). Parents who have children with disabilities often reported to have physical as well as psychological distress related to caring for their children, which affect their quality of life (Leung & Li-Tsang, 2003). These studies may explain why parents of children with ADHD and Autistic score a lower quality of life than parents with normal mentally healthy children in the study. In the study ADHD carer had higher quality of life than Autistic carer. This may be due to availability of support. ADHD is widely recognized and often has more structured intervention. But autism has severe challenges in communication issue which limit access to effective therapies. Communication difficulties can be stressful for parents of ASD who find it difficult to comprehend their child's needs and desires. This may largely influence the parents' quality of life.

Objective 2: To assess the level of depression in the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.

On Depression: Results revealed that Normal children's parents had a lower level of Depression than ADHD parents ($M =10.25$; 13.52 ; $t = 3.250$; $p < .01$) and Autistic mental health parents ($M=10.25$, 16.77 ; $t = 5.52$; $p < .01$). Autistic parents had

a higher level of depression than ADHD mental health parents ($M=16.77, 13.52; t = -3.25; p < .01$) which is significant at the .01 level as presented in Tables-4 and 5.

The hypothesis regarding these variables was accepted. Previous studies found that caregivers of children with mental and behavioural disorders had a higher prevalence of depression and lower quality of life when compared with controls. There is a higher prevalence of depression or anxiety, and lower Quality of Life scores that comes with lower socioeconomic status, lower education, and being unemployed or financial problems among caregivers of individuals with mental and non-mental illness (Grover et. al., 2017; Geng et. al., 2018; Ribe et. al., 2018). It has been repeatedly observed that parents of children with ASD experience higher levels of anxiety, stress, and depression (Baker et. al., 2011). The research is consistent with previous findings. Caregivers of autistic children have higher level of depression than caregivers of ADHD (Gabra & Hashem, 2021). Numerous findings from earlier studies indicate that carers of children with ASD frequently and severely face affiliate and associative stigma (Wang, 1993). Rearing a child with ASD can be problematic for parents and parents with ASD and they may face more challenging problems than parents with ADHD.

Objective 3 was to assess the level of anxiety in the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.

On Anxiety: Results revealed that ADHD parents had a higher level of Anxiety than Autistic parents ($M=34.26; 32.27; t= 3.30; p < .01$ level) and Normal mental health parents ($M=34.26, 21.97; t= -4.875; p < .01$ level). Autistic parents had a higher level of anxiety than Normal mental health parents ($M= 32.27; 21.97; t= -5.175; p < .01$ level) significant at .01 level which were portrayed in as presented in Tables-4 and 5, and hypothesis 3 was accepted.

Studies have reported that parents who have a disabled child are under more stress, have higher levels of anxiety and have lower levels of self-confidence, higher stigma, and lower self-esteem and harmony in marriage than parents who do not have any disabled children (Cantwell, Muldoon & Gallegher 2015; Ali & Hassiotis, 2012;

Uguz & Toros, 2004; Glidden & Schoolcraft, 2003; With & Coiro, 2003). Romany and Doaa (2021) found that Caregivers of ASD and ADHD have a higher score of stigmas, burden, depression, anxiety, and a poorer Quality of Life than normal; all these variables are worse in ASD caregivers than ADHD caregivers. Another study found that mothers of children with ADHD experienced higher levels of anxiety than mothers of children with ASD and ID (Alrahili, 2023).

Objective 4 was to assess the level of burden in the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.

On Burden: Results revealed that ADHD parents had a lower level of Burden than Autistic parents ($M=25.500, 28.750$; $t= 3.25$; $p < .01$ level) and Normal mental health parents ($M=21.75, 13.05$; $t= 4.700$; $p < .01$ level). Autistic carer had a higher level of burden than Normal mental health parents ($M= 28.750, 21.050$; $t= 5.450$; $p < .01$ level) which is significant at the .01 level which was displayed in Tables 4 and 5. Therefore, the hypothesis for these variables is accepted.

Study had shown that caregivers of children with autism experience higher levels of burden and lower levels of quality of life on all the four domains of quality of life as compared to the caregivers of children without disability and findings indicate different effect as a consequence of different childhood conditions and also the need to provide adequate parental support when providing interventions to their children with disabilities (Geetanshi, 2021).

Objective 5 was to examine the relationship between burden, quality of life, depression, anxiety and coping strategies among three groups - the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.

On Problem focused coping: Results revealed that parents of Normal used higher problem focus coping than ADHD parents ($M = 18.30, 16.46$; $t= 3.90$; $p < .01$ level) and Autistic parents ($M = 18.30, 14.42$; $t= 4.12$; $p < .01$ level) ; and Autistic's parents scored higher on problem focused coping compared to ADHD parents

($M=16.46, 14.42$; $t= 2.775$; $p < .01$ level) and presented in tables 4 and 5. The hypothesis regarding these variables is again accepted.

Parents with disabled children often engage more in problem-focused coping (Twouy et. al. 2007). This may be often due to the increased demand of caregiving and the need to actively manage different stressors associated with their child's condition. Problem-focused coping comes with more positive mental health outcomes, there is possibility of a degree of mitigated risk for psychological maladjustment among Asian parents of children with ASD as compared to western European parents (Taylor and Stanton, 2007; Uchino 2006; Kawachi and Berkman 2001). There is not much literature that show why ADHD parents may have higher level of problem-focused coping than Autistic parents. Autism presents a broader and often more complex set of challenges, such as communication deficits, sensory sensitivities, and social interaction difficulties, which may feel less modifiable through direct intervention.

On Emotion focused coping: Results revealed that ADHD parents had a lower level of emotion focused coping than Autistic parents ($M = 16.68, 18.32$; $t= 3.80$; $p < .05$ level) but higher than Normal mental health parents ($M = 16.68, 14.32$; $t= 4.45$; $p < .05$ level). Autistic parents had a higher level of emotion focused coping than Normal mental health parents ($M= 34.32, 16.32$; $t= 5.65$; $p < .05$ level) significant at .05 level. The hypothesis regarding these variables is thus, partially accepted. Emotion-focused coping is usually adopted by parents of neurodivergent to deal with their feelings of sadness or frustration. They may face societal misunderstanding and judgment about their child's condition which can lead to focus on emotion focused-coping mechanism to navigate feelings of shame or isolation. Twouy and colleagues (2007) found that parents of children with ASD depend largely on emotion-focused coping due to the high levels of stress and unpredictability associated with autism. This may lead to the use of more emotion-focused coping by parents of ASD as compared to parents of ADHD.

On Avoidance focused coping: Results revealed that ADHD parents had a lower level of avoidance focused coping than Autistic parents ($M=15.42, 17.44$; $t= 3.00$; p

< .01 level) but higher than Normal mental health parents (M=15.42, 13.46; t= 4.67; p < .05 level). Autistic parents had a higher level of avoidance focused coping than Normal mental health parents (M= 15.42, 13.46; t= 3.675; p < .01 level) and their difference is significant at the .05 level. The hypothesis regarding these variables is partially accepted. When dealing with children with disability, parents often adopt avoidance coping strategy (Lam et. al., 2002). Avoidance strategies like denial can help parents temporarily relieve them from being excessive concerned about their child's problem when immediate solutions are not met. This finding may explain why the level of avoidance is higher among ADHD and Autistic carer than normal mentally healthy children carer in the study. Smith and associates (2008) reported that parents of children with ASD frequently use avoidance coping strategy to manage chronic stress associated with caregiving, particularly in the absence of effective interventions.

Table-5: Showing significant mean (t-test) between the groups on the Quality of Life, Depression, Anxiety, Problem focused coping, Emotion focused coping, Avoidance focused coping, and Burden among the samples

Dependent variable	Groups	Autistic	Normal	Dependent variable	Groups	Autistic	Normal
Quality of Life	ADHD	-4.90*	-5.100*	Problem focus Avoidance	ADHD	2.775*	3.900*
	Autistic	-	-6.200*		Autistic	-	4.125*
Dependent variable	Groups	Autistic	Normal	Dependent variable	Groups	Autistic	Normal
Depression	ADHD	3.250*	4.525*	Emotion	ADHD	3.800*	4.450*
	Autistic	-	5.525*		Autistic	-	5.650*
Dependent variable	Groups	Autistic	Normal	Dependent variable	Groups	Autistic	Normal
Anxiety	ADHD	3.300*	-4.875*	Avoidance	ADHD	3.000*	3.675*
	Autistic	-	-5.175*		Autistic	-	4.675*
Dependent variable	Groups	Autistic	Normal	*. The mean difference is significant at the 0.01 level.			
Burden	ADHD	3.250*	4.700*				
	Autistic	-	5.450*				

Figure -6: Showing the mean difference in *Quality of Life* among the parents of Autism, ADHD, Normal children and total samples (N=200)

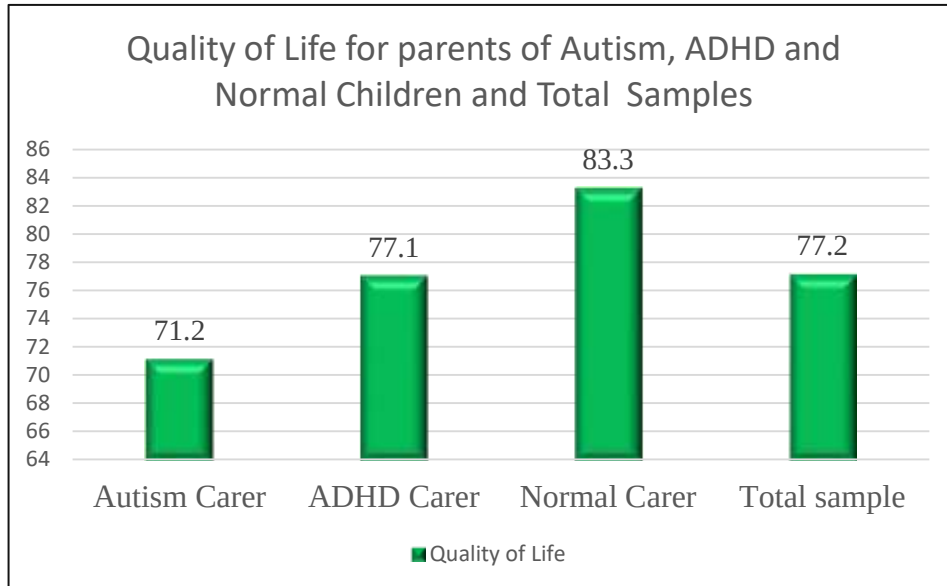


Figure - 7: Showing the mean difference in *Depression* among the Caregivers of Autism, ADHD, Normal children and total samples (N=200).

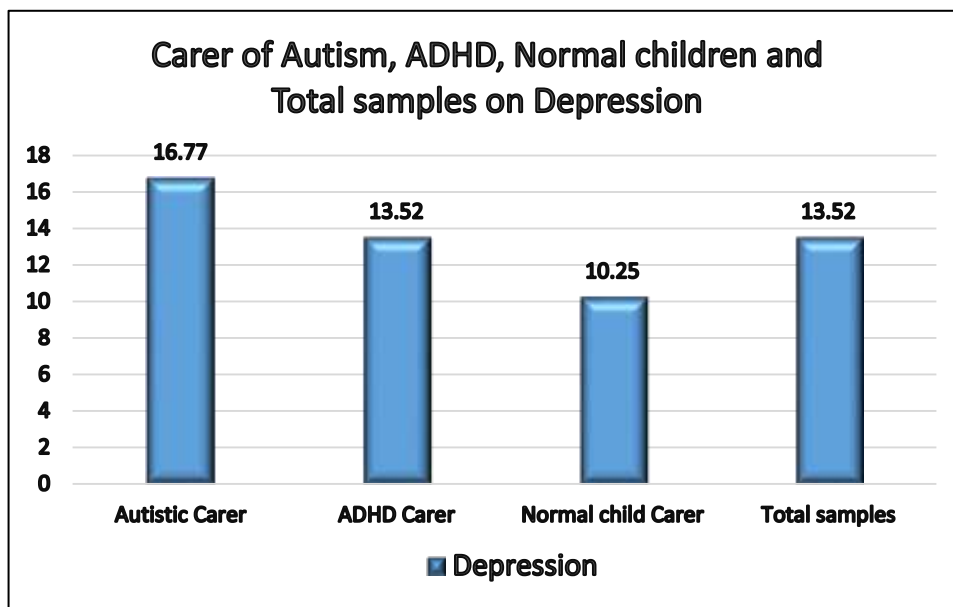


Figure -8: Showing the mean difference in *Anxiety* among the parents of Autism, ADHD, Normal and total samples (N=200).

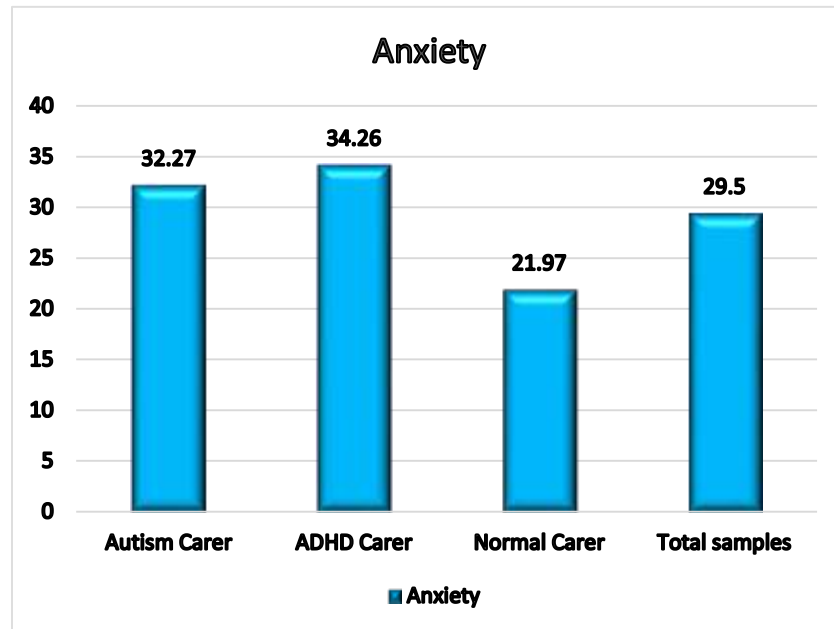


Figure -9: Showing the mean difference in *Problem Focused Coping* among the parents of Autism, ADHD, Normal children and total samples (N=200).

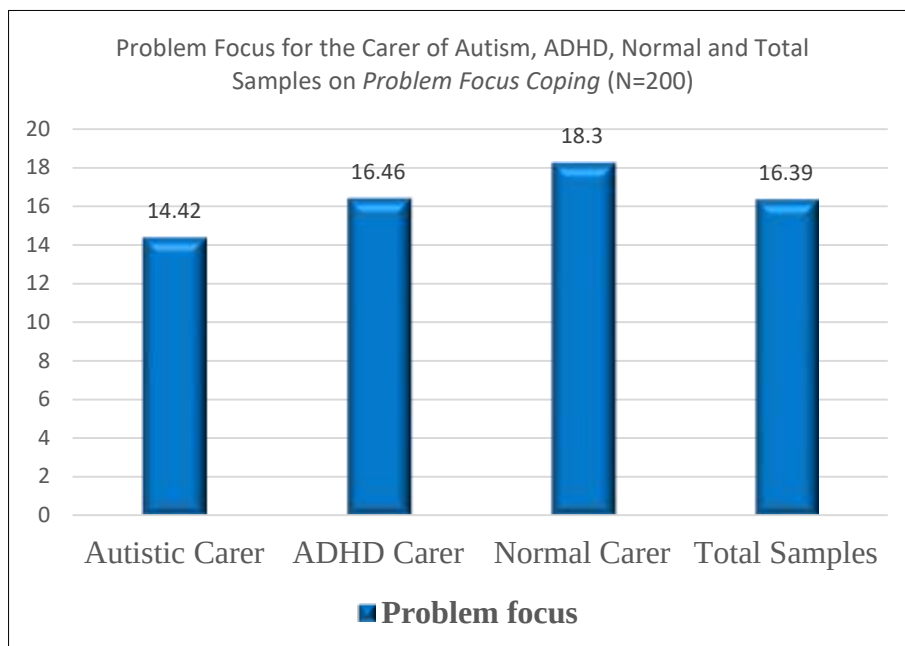


Figure -10: Showing the mean difference among the parents of Autism, ADHD, Normal children and Total sample on *Emotion Focused Coping* (N=200)

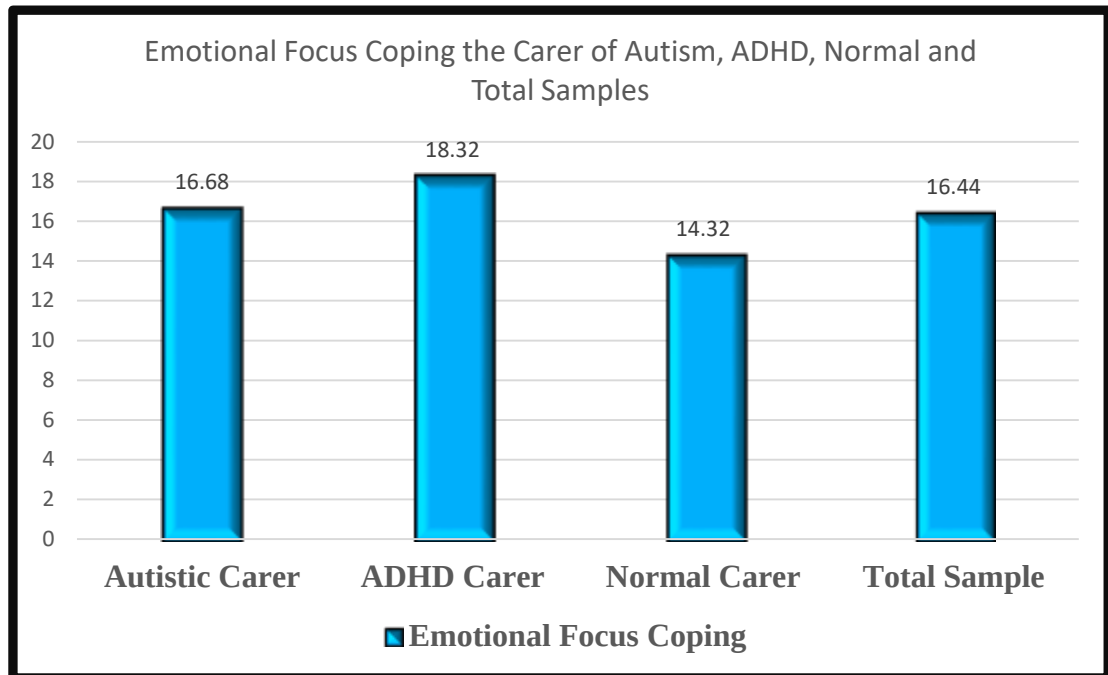


Figure -11: Showing mean difference among the parents of Autism, ADHD, Normal and Total Samples on *Avoidance Coping* (N=200).

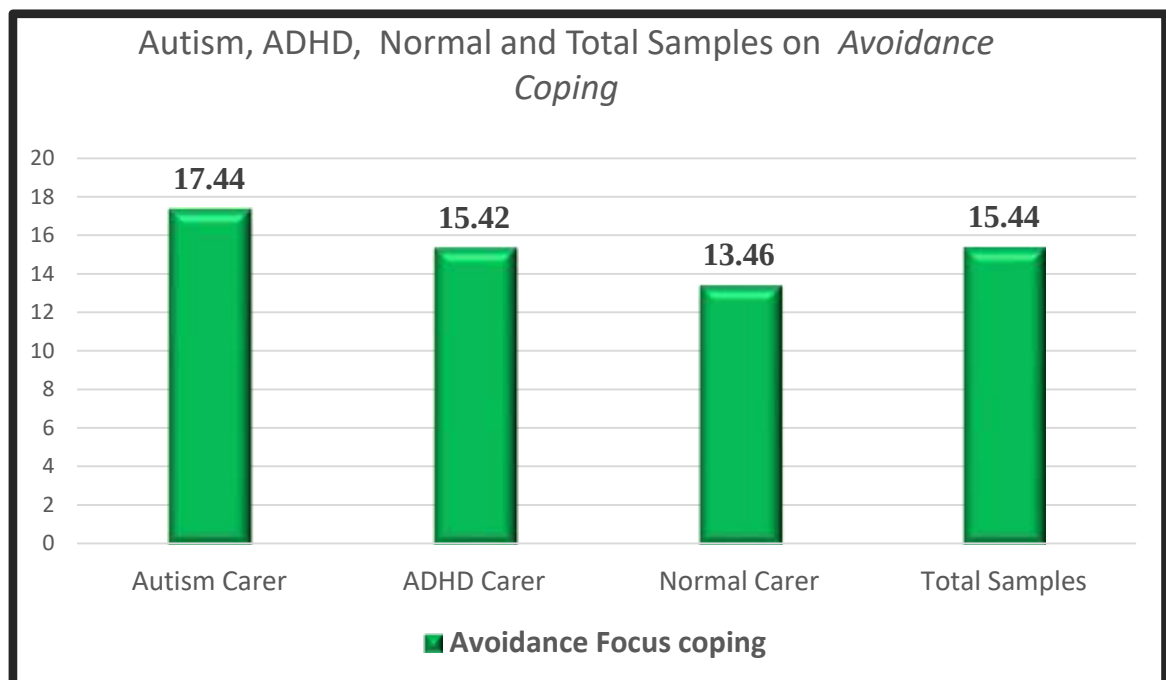
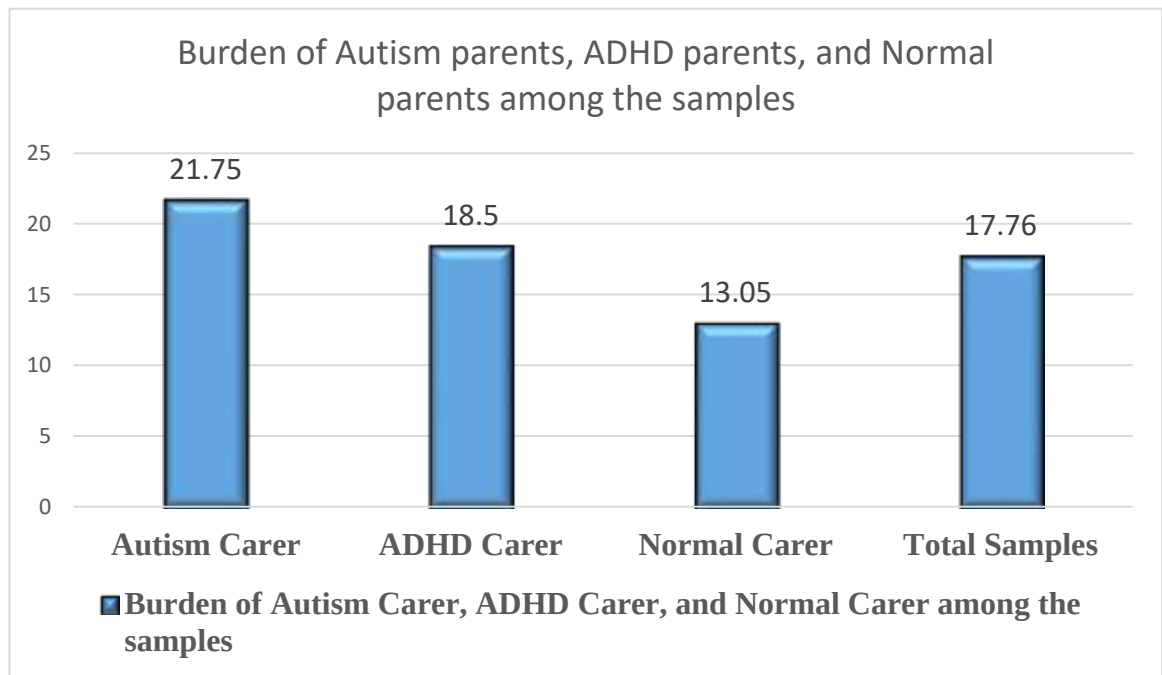


Figure -12: Showing the mean difference in caregiver burden among the parents of Autism, ADHD, Normal and Total samples (N=200) .



Objective 6 : was to examine the relationship between burden, quality of life, depression, anxiety and coping strategies among three groups - the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.

The Pearson's correlation was employed to examine the significant relationship between the Quality of Life, Depression, Anxiety, Problem Focused Coping, Emotion Focused Coping, Avoidance Focused Coping, and Burden, and the results were presented Table 6..

(1) Quality of Life in relation to Depression, Anxiety, Problem Focused Coping, Emotion Focused Coping, Avoidance Focused Coping and Burden. The quality of life had a negative significant relation with depression ($r = -.430^{***}$; $p < .01$), anxiety ($r = -.435^{**}$; $p < .01$), Emotion focused coping ($r = -.453^{**}$; $p < .01$), Avoidance

focused coping ($r=-.417^{**}$; $p < .01$) and Burden ($r=-.675^{**}$; $p < .01$) but positive relation with problem focused coping ($r=.424$; $p < .01$).

(a) Quality of Life in relation to Depression: The quality of life had a negative significant relation with depression ($r=-.430^{***}$; $p < .01$). Therefore, the hypothesis is accepted. The finding is in line with the previous literature. According to Nanayakkara & Singharathana (2022), Quality of life and Depression had a significant negative relationship and caregivers of children with Autism had a higher prevalence of Depression and lower Quality of life when compared with controls. Another study depicted that the low level of QOL and depressive symptoms in more than two thirds of parents of autistic children, psychological empowerment of this group is recommended. A study also found a high and negative correlation between the quality of life and high levels of depressive symptoms and a moderate correlation between environment and income. Depressive symptoms are prevalent among parents of children with Autism (Chen, 2024) Parents with ADHD report higher levels of depression (Ghanizadeh et. al., 2008). This feeling of depression can influence parents' quality of life and vice versa.

(b) Quality of Life in Relation to Anxiety: The quality of life had a negative significant relation with anxiety ($r= -.435^{**}$; $p < .01$). Previous study indicates that caregivers of ASD and ADHD have a higher score of stigmas, burden, depression, anxiety, and a poorer Quality of Life than normal; all these variables are worse in ASD caregivers than ADHD caregivers (Romany and Doaa, 2021). Parents of children with neurodevelopmental disorders reported higher levels of anxiety in their day-to-day life (Alrahili, 2023). For parents, the constant demands of caregiving, uncertainty about child's future, and difficulty in managing challenging behaviors can all contribute to anxiety and may in turn reduce their quality of life.

(c) Quality of Life in Relation to Problem Focused Coping: The quality of life had a negative significant relation with Problem focused coping ($r=.424^{**}$; $p < .01$). Mothers of children with Autism use more problem-focused coping strategies (Smith et. al., 2017). Some also found that mothers use more emotion-focused coping than fathers (Hastings et. al., 2005). Not much literature has been found that is consistent

with the current findings. There is no or little research that studies the coping strategies adopted by parents in Mizo context. Problem-focused coping aims to tackle the root cause of stressors rather than managing emotional responses. Problem-focused coping like finding stressors, taking steps to resolve the stressor may not work well among both fathers and mothers of the samples or may not be utilized well enough and this strategy can in turn unexpectedly lower their quality of life. Use of problem-focused coping alone may not be enough to deal with the children ongoing behavioral problems.

(d) Quality of Life in Relation to Emotion Focused Coping: The quality of life had a negative significant relation with Emotion focused coping ($r = -.453^{**}$; $p < .01$). Vernhet and others (2019), in their research paper, showed that emotion focused coping is a risk factor parental stress and quality of life. Caregiver well-being was lower when emotion-focused strategies were used (Colman et. al., 2019). Emotion-focused coping works on managing emotional distress without changing the situation or the root causes and this can perpetuate challenges rather than resolving them. The perpetuating effect of unresolved issues can diminish one's overall quality of life. This may explain why there is a significant negative relationship between quality of life and emotion-oriented coping among the samples.

(e) Quality of Life in Relation to Avoidance Focused Coping: The quality of life had a negative significant relation with Avoidance focused coping ($r = -.417^{**}$; $p < .01$). Avoidance focused coping tends to be associated with poorer physical and mental health outcomes (Carver et. al., 1989) and reduced QoL (McCabe, 2006). Behavioural and cognitive attempts that are focused on denying, disregarding, or avoiding directly dealing with stressful demands is closely linked to depression (Penley et. al., 2002). These studies may explain why there is a negative relationship between quality of life and avoidance-oriented coping among the samples.

(f) Quality of Life in Relation to Burden: The quality of life had a positive significant relation with Burden ($r = -.475$; $p < .01$). The finding is not consistent with many studies on these variables. Some research shows that the burden of caregiving lowers physical and social aspects of the quality of life (Arasu & Shanbhag, 2021).

Some show negative correlation between caregiver burden and health related quality of life (Agyemang et. al., 2024). The findings may be explained through various factors. In a collective culture like Mizo, Social support and religiosity are quite relevant. Social support can improve the quality of life (Wielewska et. al., 2022). Spirituality/religiousness impact quality of life (Borges et. al., 2021). In a culture like Mizo, caregivers often receive social/religious support from family, friends, or community organizations. This support can buffer the stress associated with caregiving burdens and may contribute positively to parent's quality of life. This may be attributable to the current finding that reveals why there is a positive significant relationship between quality of life and burden.

(2) Depression relation to Anxiety, Problem Focused Coping, Emotion Focused Coping, Avoidance Focused Coping, and Burden: Depression had a significant positive relation with Anxiety ($r=.250^{**}$; $p < .01$), Problem focused coping ($r=.712^{**}$; $p < .01$), Emotion focused coping ($r=.992^{**}$; $p < .01$), Avoidance focused coping ($r=.976^{**}$; $p < .01$) but a negative relation with Burden ($r=-.940^{**}$; $p < .01$).

(a) Depression in Relation to Anxiety: Depression had a significant positive relation with Anxiety ($r=.250^{**}$ $p < .01$). One symptom of depression i.e. hopelessness is significantly related with caregiver's anxiety (Liu et. al., 2023). A study in the *Journal of Autism and Developmental Disorders* (2020) found that high levels of anxiety were predictive of depressive symptoms in parents of children with ASD, suggesting that anxiety often precedes and exacerbates depression.

(b) Depression in Relation to Problem Focused Coping: Depression had a significant negative relation with Problem focused coping ($r=-.312^{**}$ $p < .01$). The finding is not consistent with previous research. Parents who adopt this coping strategy may face repeated failures when dealing with child's need or they can have excessively reliance on this strategy neglecting other strategies which can lead to have feelings of inadequacy or depression.

(c) Depression in Relation to Emotion Focused Coping: Depression had a significant positive relation with Emotion focused coping ($r=.492^{**}$ $p < .01$). Parents

who employ more emotion-focused techniques—like withdrawing, leaving, or separating themselves, report higher levels of depressive symptoms, social isolation, and have more issues with their child (Abbeduto et. al., 2004) The use of emotionally-focused coping strategies increases stress (Cappe et. al., 2011). Emotion focused coping like venting and ruminating focuses on controlling emotions over finding a solution. This can cause one to focus on unpleasant feelings, which can exacerbate feelings of depression.

(d) Depression in Relation to Avoidance Focus Coping: Depression had a significant positive relation with Avoidance focused coping ($r = .476^{**}$; $p < .01$). Parents of ASD often adopt maladaptive coping strategies like Avoidance focused coping (Vernhet et. al., 2019; Lai & Oei, 2014). Avoidance focused coping involves ignoring or distancing oneself from stressors rather than addressing them directly. This may temporarily reduce stress but leaves the root problems unresolved which can have impact on depression.

(e) Depression in Relation to Burden: Depression had a significant positive relation with Burden ($r = .440^{**}$; $p < .01$). Attention-deficit/hyperactivity disorder (ADHD) and autism spectrum disorders (ASD) are linked to substantial emotional and mental burden on caregivers (Cadman et. al., 2015). Stressors associated with raising a child with autism and ADHD include the child's communication difficulties, unstable and aggressive behaviours, self-care limitations, and lack of respite due to the difficulty in finding acceptable substitute caregivers (Gabra & Hashem, 2021).

(3) Anxiety in relation to Problem Focused Coping, Emotion Focused Coping, Avoidance Focused Coping, and Burden: Anxiety had a significant negative relation with Problem focused Coping ($r = -.513^{**}$; $p < .01$) but positive relation with Emotion focused coping ($r = .250^{**}$; $p < .01$), Avoidance focused coping ($r = .272^{**}$; $p < .01$) and Burden ($r = .314^{**}$; $p < .01$).

(a) Anxiety in Relation to Problem Focused Coping: Anxiety had a significant negative relation with Problem focused Coping ($r = -.513^{**}$; $p < .01$). Although

problem focused coping strategy lowers stress levels (Cappe et. al., 2011), the caregiving demands of children with ASD and ADHD are ongoing and unpredictable, which can sustain high anxiety levels. Even parents engaging in problem-solving may feel overwhelmed by the complexity of managing their child's needs. This may be attributed to the significant positive relationship between anxiety and problem-focused coping strategy.

(b) Anxiety in Relation to Emotion Focused Coping: Anxiety had a significant positive relation with Emotion focused coping ($r=.250^{**}$; $p < .01$). Li and associates (2021) found that unsuitable emotion focused coping strategies can be a source of anxiety and depression among primary caregivers. Emotion focused coping strategies increases stress (Cappe et. al., 2011). Maladaptive emotion focused strategies, such as excessive worry or rumination, can trap parents in cycles of negative thinking without leading to solutions. This can reinforce feelings of anxiety.

(c) Anxiety in Relation to Avoidance Focused Coping: Anxiety had a significant positive relation with Avoidance focused coping ($r=.272^{**}$, $p < .01$). Parents using avoidance focused coping may withdraw from social networks or avoid seeking professional help, which can limit access to emotional and practical support. They may miss opportunities for advice, help and validation. This can increase anxiety level among them.

(d) Anxiety in Relation to Burden: Anxiety had a significant positive relation with Burden ($r=.314^{**}$ $p < .01$). The finding inconsistent with past literature. Parental stress and anxiety are higher among caregivers of children with disabilities (Barlow & Ellard, 2006). Compared to fathers, mothers reported more symptoms of stress and anxiety (Demšar & Bakracevic, 2023). Confounding/moderating variables like mother and father's religiousness can also affect the relationship between anxiety and burden.

(4) Problem Focused Coping in Relation to Emotion Focused Coping, Avoidance Focused Coping, and Burden: Problem focused coping had a significant negative relation with Emotion focused coping ($r = -.328^{**}$; $p < .01$) and Avoidance focused coping ($r = -.373^{**}$; $p < .01$) but significant positive relation with Burden ($r = .375^{**}$; $p < .01$).

(a) Problem Focused Coping in Relation to Emotion Focused Coping: Problem focused coping had a significant negative relation with Emotion focused coping ($r = -.328^{**}$; $p < .01$). Parents of children with ASD and ADHD face complex, multifaceted stressors that require both problems focused (practical) and emotion focused (emotional regulation) coping strategies. A parent may actively seek therapies or support for their child (problem-focused coping) while also managing feelings of frustration or grief (emotion- focused coping).

(b) Problem Focused Coping in Relation to Avoidance Focused Coping: Problem focused coping had a significant positive relation with Avoidance focused coping ($r = .373^{**}$; $p < .01$). According to Journal of Autism and Developmental Disorders (2024), parents often combine coping styles to address the multifaceted nature of caregiving stressors. Parenting a child with ASD or ADHD involves a combination of highly stressful situations, some of which may feel controllable (prompting problem-focused coping) and others uncontrollable (prompting avoidance). Parents might use both strategies simultaneously to handle different aspects of their stress.

(c) Problem Focused Coping in Relation to Burden: Problem focused coping had a significant negative relation with Burden ($r = -.375^{**}$; $p < .01$). The increased use of problem-focused strategy reduces the level of stress (Cappe et. al., 2011). Problem-oriented or social support strategies are more effective in lowering the negative effects of stress (Dunn et. al., 2001). The stress that may arise from the burden of caregiving may be controlled to some extent using problem-focused coping. These findings may explain why there is a significant negative correlation between problem-focused coping and burden.

(5) Emotion Focused Coping in relation to Avoidance Focused Coping, and Burden: Emotion focused coping had a significant negative relation with Avoidance focused coping ($r = -.474^{**}$; $p < .01$) but significant positive relation with Burden ($r = .434^{**}$; $p < .01$).

(a) Emotion Focused Coping in Relation to Avoidance Focused Coping: Emotion focused coping had a significant negative relation with Avoidance focused coping ($r = -.474^{**}$; $p < .01$). Emotion focused coping and avoidance focused coping are often adopted by parents with neurodevelopmental disorders. The intense emotional burden of raising a child with ASD or ADHD can lead parents to adopt avoidance strategies to escape overwhelming feelings. Emotion-focused coping, such as venting or self-soothing, may coexist with avoidance to alleviate emotional distress. This coexistence may strengthen the relationship between emotion-focused coping and avoidance-oriented coping in positive way.

(b) Emotion Focused Coping in Relation to Burden: Emotion focused coping had a significant positive relation with Burden ($r = .434^{**}$; $p < .01$). Parents who use more-emotion-focused coping reported higher depressive symptoms, feel more socially isolated, and face more problems with their child (Abbeduto et. al., 2004; Dunn et. al., 2001). The emotion-focused coping may seem to predispose the caregiver to an increase burden and distress.

(6) Avoidance Focused Coping in Relation to Burden.

(a) Avoidance Focused Coping in Relation to Burden: Avoidance focused coping had a significant positive relation with Burden ($r = .435^{**}$; $p < .01$). Avoidance focused coping allows parents to disengage from stressors temporarily, reducing their perception of burden. By avoiding problems or emotionally distancing themselves from children, they may experience short-term relief from caregiving demands.

Table-6: Showing the correlation between the Quality of Life, Depression, Anxiety, Problem focused coping, Emotion focused coping, Avoidance focused coping, and Burden for the whole sample

	Quality of Life	Depression	Anxiety	Problem Focused	Emotion Focused	Avoidance Focused	Burden
Quality of Life	1	-.430**	-.435**	.424**	-.453**	-.417**	-.475**
Depression		1	.250**	-.312**	.492**	.476**	.440**
Anxiety			1	-.513**	.250**	.272**	.314**
Problem Focused				1	-.328**	-.373**	.375**
Emotion Focused					1	-.474**	.434**
Avoidance Focused						1	.435**
Burden							1
** . Correlation is significant at the 0.01 level (2-tailed).							

To investigate the distress of the parents of neurological disorder children, the mental illness effect on quality of life, depression, anxiety, coping styles and burden was done among the parent of ASD, ADHD and Normal children.

To find out the effect of ‘mental illness’ on quality of life, depression, anxiety, problem focused coping, emotion focused coping, avoidance focused coping and burden, a one-way ANOVA was employed as presented in Table-7. The results displayed the higher level of distress in parents of neurological disorder parents for both ASD and ADHD than Normal children’s parents on observed dependent variables as follow,

(i) ***Caring of Mental illness effect on Quality of Life:*** Results revealed that mental illness affects the quality of life by 36% ($F=185.347$; $\eta^2=0.360$). Therefore, the

hypothesis is accepted. Caring for children with mental illnesses such as Autism Spectrum Disorder (ASD) and Attention-Deficit/Hyperactivity Disorder (ADHD) can significantly impact parents' quality of life (QoL). Caregivers of children with Autism had a higher prevalence of Depression and lower Quality of life (Nanayakkara & Singharathana, 2022). Depressive symptoms are prevalent among parents of children with Autism (Chen, 2024) Parents with ADHD report higher levels of depression (Ghanizadeh et. al., 2008). Parents with children who have ADHD and ASD are more likely to struggle to solve problems as a family and make decisions collectively. Children with ADHD exhibit demanding, moody, and uncooperative behaviour, which can be difficult for parents to manage and have an impact on parents' behaviour and adjustment. All these factors can have an effect on quality of life among parents with ASD and ADHD.

(ii) ***Caring of Mental illness effect on Depression:*** Results revealed that mental illness has a 44% effect on depression ($F=302.911$; $\eta^2= 0.438$). Therefore, the hypothesis is accepted. Parents and other family members of autistic individuals exhibited a higher rate of depression than parents of normal children (Attwood & Garnett, 2024). From the moment of diagnosis, caring for a child with a neurodevelopmental disorder elicits a wide range of negative emotions, including guilt, worthlessness, denial, and disappointment (Sharpley et. al., 1997). For mother, the discrepancy between their children's normal look and the severity of their emotional and behavioural issues, the mothers of autistic children are more like to perceive themselves as stigmatised (Tumurbaatar & Chuluunbaatar, 2020). Parents of children with autism may have a higher lifetime prevalence of major depressive disorder than parents of children with Down syndrome (Piven et. al., 1991). The level of depression in parents with ASD and ADHD can be affected by all these factors.

(iii) ***Caring of Mental illness effect on Anxiety:*** Results revealed that mental illness affect anxiety by 33% ($F=279.183$; $\eta^2= 0.327$). Therefore, the hypothesis is accepted. The prevalence of anxiety and self-stigmatization were higher among mothers of autistic children (Alshaigi, 2020). Compared to parents of children without ADHD,

parents of children with ADHD report higher levels of anxiety and depression symptoms (Ghanizadeh et. al., 2008). Parents of ADHD exhibit higher rates of depression and anxiety, less warmth and lower scores in social and environmental domains of Quality of life (Andrade et. al., 2016). Parents may often remain on alert about their child's safety, security, long-term outcomes like independence, career aspects or handle impulsive behaviour. This state of condition may affect parents which can lead them to develop stress and anxiety.

(iv) ***Caring of Mental illness effect on Problem Focused Coping:*** Results revealed that mental illness affect Problem focused coping by 41% ($F=253.934$; $\eta^2=0.413$). Therefore, the hypothesis was accepted. The efficiency and quantity of coping mechanisms a parent uses to manage the demands of stressors associated with children with ASD determines their ability to handle high levels of stress (Zablotsky et. al., 2013). Mothers of children with ASD reported the highest results in the use of planning, active coping, and reframing as problem-focused coping (Smith et. al., 2008). The increased use of problem-focused strategy decreases stress levels (Cappe et. al., 2011) and caregiver burden (Manor-Binyamini, 2011). Parents of children living with ADHD use problem-focused coping strategy as they employ practical solution in dealing with their child's school meeting demands (Wong & Wong, 2021). Caregivers who employ problem-focused strategies experience more favourable outcomes and less carer pressure (Manor-Binyamini, 2011). Adopting problem-focused strategy may help the parents in dealing with challenges caused by their child's behavioural problem.

(v) ***Caring of Mental illness effect on Emotion Focused Coping:*** Results revealed that mental illness has a 36% effect on Emotion focused coping ($F=351.206$; $\eta^2=0.357$). Therefore, the hypothesis is accepted. Some studies found that emotion-focused coping was more frequently used by mothers of children with ASD (Salas et. al., 2017; Hastings et. al., 2005). Parents of ASD used religious behaviours as emotion-focused coping strategy (Gona et. al., 2016). Emotion-focused coping strategy including social support, finding help from supernatural power are common coping strategies among Chinese parents (Lam & Mackenzie, 2002). Mothers of

children with developmental disorder use emotion-focused strategies more often than fathers (Manor-Binyamini, 2011). Parents of ASD and ADHD may use emotion-focusing coping strategy to manage the intense emotional challenges associated with caregiving.

(vi) ***Caring of Mental illness effect on Avoidance Focused Coping:*** Results revealed that mental illness has a 39% effect on Avoidance focused coping ($F=222.539$; $\eta^2=0.392$). Therefore, the hypothesis is accepted. The most common strategy adopted by parents with ADHD seems to be avoidance-oriented coping (Craig et. al., 2020). Some studies have also claimed that parents of children with ASD used avoidance strategies more than that of parents with neurotypical children (Vernhet et. al., 2019). Parents of children with ASD used more escape-avoidance strategies than those in the control group (Pisula & Domasiewicz, 2010). Avoidance coping strategy may help parents with ASD and ADHD to deal with the caregiving burden by distancing themselves from different stressors.

(vii) ***Caring of Mental illness effect on Burden:*** Results revealed that mental illness affect Burden by 46% ($F=185.297$; $\eta^2=0.460$). Therefore, the hypothesis was accepted. The burden experienced by carers of children with ASD and ADHD is quite severe and often goes unnoticed (Murphy et. al., 2018). Parenting a child with autism and ADHD involves stressors like child's communication difficulties, unpredictable and aggressive behaviours, self-care limits, and lack of respite due to the difficulty in finding suitable substitute caregivers (Gabra & Hashem, 2021). According to a study on parents of recently diagnosed children with autism spectrum disorders (ASD), social relatedness deficiencies might be a major burden for parents (Davis & Carter, 2008). Parents with ASD and ADHD are more likely to experience psychological, social, and physical issues than parents of asymptomatic children (Lee et. al., 2013).

Table -7: Showing the effect of mental illness (one-way ANOVA) on the Quality of Life, Depression, Anxiety, Problem focused coping, Emotion focused coping, Avoidance focused coping, and Burden among the samples

Dependent variables	Sum of Squares	Df	Mean Square	F-ratio	Sig.	Eta Squared
Quality of Life	2928.800	1/199	1464.400	185.347	0.000	0.360
Depression	851.517	1/199	425.758	302.911	0.000	0.438
Anxiety	763.817	1/199	381.908	279.183	0.000	0.327
Problem	697.017	1/199	348.508	253.934	0.000	0.413
Emotion	1110.200	1/199	555.100	351.206	0.000	0.357
Avoidance	894.150	1/199	447.075	222.539	0.000	0.392
Burden	1195.400	1/199	597.700	185.297	0.000	0.420

CHAPTER-VI

SUMMARY AND CONCLUSION

SUMMARY AND CONCLUSION

The present study entitled “Quality of Life, Psychological Distress and Coping Strategies of Parents of Children with Neurodevelopmental Disorder” aimed to study the impact of neurodevelopmental disorders such as ADHD and Autism on caregivers, primarily parents by comparing them across several psychological scales such as (i) Mini-Mental Status Examination (MMSE; Kurlowicz, L., & Wallace, M. (1999), (ii) The Zarit Burden Interview (Zarit, Reever & Bach-Peterson, 1980), (iii) The World Health Organization-Five Well-Being Index (WHO-5; WHO. 2024), (iv) Beck Depression Inventory (BDI; Beck, Steel & Brown, 1996), (v) Beck Anxiety Inventory (BAI; Beck et. al., 1988, and (vi) Coping Inventory for Stressful Situations (CISS-21; Endler & Parker (1990). Moreover, the correlation between the dependent variables is also estimated to understand the extent of the relationship between these variables.

Based on the available literature and theory, it was expected that the level of burden and level of depression would be highest among parents of children with Autism, followed by the parents of ADHD but high in Anxiety while the parents of normal children were lowest in burden, depression and anxiety. Quality of Life was expected to be the highest among parents of children with normal mental health. It was also expected that burden, depression, anxiety, avoidance coping and emotional coping will have a positive relationship with each other whereas the quality of life, and task-oriented coping strategy will also have a positive relationship with each other.

The present study employed 120 samples, comprising 40 parents of autism, 40 parents of ADHD, and 40 parents of normal mental health who served as a control group. The samples were selected through a random sampling procedure. The researcher also prepared inclusion and exclusion criteria using ICD-11 and the Mini-International Neuropsychiatric Interview (M.I.N.I.).

Sample characteristics: The sample characteristics include gender, psychiatric illness, age, socio-economic status, number of offspring, marital status, and expert

professionals which were recorded with the help of socio-demographic profiles constructed by the researcher (Lalawmpuia, 2021). Equal representation of illness (ADHD, Autism, Normal), and gender (female and male) were ensured. The distribution of the socio- demographic profiles of the samples including age, socio-economic status, number of offspring, educational

The psychological tests used in the present study were verified their authenticity of the test for the target population.

The data has met the assumptions of parametric statistics (Normality, reliability and homogeneity) which suggested that parametric statistics may be used for further analysis (Table-2-4). The results of the study were displayed following the objectives of the study sequentially as follows:

Objective-1 : To assess the level of quality of life of the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.

. The post-Hoc mean comparison (Scheffe) were employed to find any significant difference between the three groups on the dependent variables and are presented in Tables-4 and 5. Results revealed that parent of Normal children had a highest Quality of Life than Parent of ADHD and Autistic parents. Thus, autistic parents had a lower Quality of Life than ADHD parents and their difference was significant, and the hypothesis 1 was accepted.

Objective 2 was to assess the level of depression in the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.

On Depression: Results revealed that Normal children's parents had a lower level of Depression than ADHD parents and Autistic mental health parents. Autistic parents had a higher level of depression than ADHD mental health parents which is significant at the .01 level as presented in Tables-4 and 5. The hypothesis 2 was accepted.

Objective 3 was to assess the level of anxiety in the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.

On Anxiety: Results revealed that ADHD parents had a higher level of Anxiety than Autistic parents and Normal mental health parents. Autistic parents had a higher level of anxiety than Normal mental health parents significant at .01 level which were portrayed in as presented in Tables-4 and 5, and hypothesis 3 was accepted.

Objective 4 was to assess the level of **burden** in the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.

On Burden: Results revealed that ADHD parents had a lower level of Burden than Autistic parents and Normal mental health parents. Autistic carer had a higher level of burden than Normal mental health parents which is significant at the .01 level which was displayed in Tables 4 and 5. Therefore, our hypothesis for these variables is accepted.

Objective 5 was to examine the relationship between burden, quality of life, depression, anxiety and coping strategies among three groups - the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.

On Problem focused coping: Results revealed that parents of Normal used higher problem focus coping than ADHD parents and Autistic parents and Autistic's parents scored higher on problem focused coping compared to ADHD parents and presented in tables 4 and 5. The hypothesis 5 was again accepted.

On Emotion focused coping: Results revealed that ADHD parents had a lower level of emotion focused coping than Autistic parents but higher than Normal mental health parents. Autistic parents had a higher level of emotion focused coping than Normal mental health parents significant at .01 level. The hypothesis regarding these variables was accepted. **On Avoidance focused coping:** Results revealed that ADHD parents had a lower level of avoidance focused coping than Autistic parents but

higher than Normal mental health parents. Autistic parents had a higher level of avoidance focused coping than Normal mental health parents and their difference is significant at the .01 level. The hypothesis regarding these variables was accepted.

Objective 6 : was to examine the relationship between burden, quality of life, depression, anxiety and coping strategies among three groups - the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.

The Pearson's correlation was employed to examine the significant relationship between the Quality of Life, Depression, Anxiety, Problem Focused Coping, Emotion Focused Coping, Avoidance Focused Coping, and Burden, and the results were presented Table 6..

(1) Quality of Life in relation to Depression, Anxiety, Problem Focused Coping, Emotion Focused Coping, Avoidance Focused Coping and Burden. The quality of life had a negative significant relation with depression, anxiety, Emotion focused, Avoidance focused coping (and Burden but positive relation with problem focused coping

(2) Depression relation to Anxiety, Problem Focused Coping, Emotion Focused Coping, Avoidance Focused Coping, and Burden: Depression had a significant positive relation with Anxiety, Problem focused coping, Emotion focused coping, Avoidance focused coping but a negative relation with Burden.

(3) Anxiety in relation to Problem Focused Coping, Emotion Focused Coping, Avoidance Focused Coping, and Burden: Anxiety had a significant negative relation with Problem focused Coping but positive relation with Emotion focused coping, Avoidance focused coping and Burden.

(4) Problem Focused Coping in Relation to Emotion Focused Coping, Avoidance Focused Coping, and Burden: Problem focused coping had a significant negative relation with Emotion focused coping and Avoidance focused coping (but significant positive relation with Burden.

(5) Emotion Focused Coping in relation to Avoidance Focused Coping, and Burden: Emotion focused coping had a significant negative relation with Avoidance focused coping but significant positive relation with Burden.

(6) Avoidance Focused Coping in Relation to Burden.

Avoidance focused coping had a significant positive relation with Burden. Avoidance focused coping allows parents to disengage from stressors temporarily, reducing their perception of burden. By avoiding problems or emotionally distancing themselves from children, they may experience short-term relief from caregiving demands.

Independent effect of mental illness on dependent variables

To investigate the distress of the parents of neurological disorder children, the mental illness effect on quality of life, depression, anxiety, coping styles and burden was done among the parent of ASD, ADHD and Normal children.

To find out the effect of ‘mental illness’ on quality of life, depression, anxiety, problem focused coping, emotion focused coping, avoidance focused coping and burden, a one-way ANOVA was employed as presented in Table-7.

Results revealed that mental illness effects on quality of life by 36%; also 44% effect on depression on anxiety by 33%, problem focused coping by 41%, Emotion focused coping by 35%, Avoidance focused coping by 39% and on Burden by 46% .

CONCLUSION

In brief, the present study clearly highlighted the Quality of life of the parents of children with neurodevelopment disorder as they had showed lower quality of life when compare with parent of parents of normal children. Parents of children with neurodevelopment disorder were also assessed on their distress (depression, anxiety and burden) which confirmed higher psychological distress comparing with parent of normal children. For further, confirmation of their distress level by assessing their coping strategies. Results revealed parent of neurological disorders (both parents of ASD and ADHD) employed avoidance and emotional focus coping which portrait their distress situation when compare with parent of normal children. The results of the study highlighted the distress of the parents of neurological disorders, and their need of psychological cares, support and intervention which rarely gor attention of researchers.

LIMITATIONS OF THE STUDY

The present study acknowledges several limitations which need to be addressed but are not able to be included in this study due to time constraints. The sample size used in the study was not large enough to effectively represent the targeted population which may, in other words, be specified as not big enough to generalize to the whole targeted population.

Another limitation of the study is that a more systematic and comprehensive empirical cross-examination of parents of children with other neurodevelopmental disorder responses such as conducting qualitative interviews, longitudinal studies, or employing mixed-methods approaches to gain a more in-depth understanding of the issue. Parents expect their child to be born healthy but the diagnosis of a child as disabled during infancy or in later stages takes a heavy toll on his/her happiness and well-being. Diagnosis can precipitate a range of psychological responses in parents, thereby, constituting a crisis for mothers and demanding extraordinary psychological adjustment. In India, the majority of such persons have traditionally been cared for by their families. In today's modern society, this home-based care has resulted in

many adverse consequences. Factors such as changes in the social system (e.g. breaking up of joint families) and the economic system (e.g. unemployment, inflation etc.) have contributed to psychological distress that parents of special children experience. Parents of children with ADHD and Autism may find themselves burdened with a lifelong responsibility of caring for their children and diminished attention to their own health. Other than this, lack of knowledge about disorder, lack of treatment, and sometimes even though treatment is available, it is unaffordable, thus, aggravating the stress levels. This leads to deterioration of quality of life of parents in different domains such as economic, social, educational, and psychological.

Collecting data from parents can indeed present several challenges. They were reluctant to share information or participate in data collection activities due to low acceptance of their disability. Family care and various expected tasks from the caregivers for these children in managing their disorder is of great importance. Also, many researchers had some personal experiences in dealing with the needs of family caregivers of children with ADHD and Autism. The families always have questions about their child's problem, the course and symptoms of the disease, drugs and the general method of caring for these children. So far, no studies have assessed the needs of caregivers for these children in Mizoram and evaluating the needs of caregivers.

SUGGESTIONS FOR FURTHER STUDIES

Many children are born with a disability because of genetic, environmental or unexplained reasons. Families who have a child with disability face emotional and economic hardships. Parents and siblings need to express their disappointment, anger and frustrations and learn to accept and respect the child for his/her own character. Communities can help to provide access to transportation, jobs and social activities and learn to know the child by his character, personality and skills.

The sample size can be increased for generalizing the results. Bigger samples and a wider range of participants covering other neurodevelopmental disorder to have more information for understanding their issues in Mizoram.

This research focused on parents of children with Autism and ADHD. Further studies may include others groups of disability to strengthen the findings.

Only indigenous Mizos were selected for the present study, it does not include mixed parents which could reveal a better understanding of the real situation.

There is a need for more research on the psychosocial well-being of the parents/caregiver of children with disability. It will help to capture the diversity of experiences and challenges faced by caregivers and their specific needs.

SIGNIFICANCE OF THE STUDY:

Many studies have been conducted to determine the quality of life and burden of caregivers but there is a paucity of studies providing the socio-demographic predictors of quality of life of principal caregivers of ADHD and Autism. There is no significant research towards caregiver burden among caregivers of special needs children in Mizoram. The main intention for conducting this research is to understand the in-depth reality of caregiver issues, mental health and quality of life among caregivers.

Understanding the parent's emotional condition is of utmost importance for the management of a child with disability as well as improving for psychological wellbeing. Providing adequate support to parents of disabled children will minimize the potential risks of developing psychological disorders and improve their wellbeing and self-efficacy which is a critical component to enhance the care provided to disabled children and to ensure a better quality of life.

This study focuses the need of intervention, psycho-education, psychotherapies and psychiatric treatment to reduce depression and anxiety, to enhance the quality of life and the coping strategies in the parents of disabled children.

The data from these studies can be used for diagnosis and treatment of specific programs to reduce psychiatric co-morbidity in the parents of disabled children.

The present findings are relevant to the Clinical and Counselling Psychology Professionals, Psychiatrist, Paediatrician, Psychiatric Social Worker, Special Educator, Occupational Therapist, Speech and Language Pathologist, Sign Language Teacher and School Teacher effectively address various issues faced by parents.

Establishing collaborative group as Physicians, Nursing Staff and other professionals is very important to play important role with caregiver and pay more attention for those children and their family caregiver.

APPENDIX

INFORMED CONSENT FORM (Lalawmpuia Ralte, 2022)

Information given to the participant:

- a) **Title of Study:** Quality of Life, Psychological Distress and Coping Strategies of Parent of Children with Neurodevelopmental Disorders.
- b) **Researcher:** Lalawmpuia Ralte, Mizoram University
- c) **Purpose of Study:** Partial fulfillment of the requirements Doctor of Philosophy in Clinical Psychology
- d) **Confidentiality:** Your responses to this study will be anonymous. Every effort will be made by the researcher to preserve confidentiality.
- e) **Voluntary participation:** Your participation in this study is voluntary. It is up to you to decide whether or not to take part in this study. If you decide to take part in this study, you will be asked to sign a consent form. After you sign the consent form, you are still free to withdraw at any time and without giving a reason.

Consent: I have read and I understand the provided information and have had the opportunity to ask questions. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason. I understand that I will be given a copy of this consent form. I voluntarily agree to take part in this study.

Participant's signature _____ **Date** _____

Investigator's signature _____ **Date** _____

APPENDIX - II

SOCIO DEMOGRAPHIC DATA SHEET (Lalawmpuia Ralte, 2022)

Name :

Age :

Sex : Male/Female

No. of siblings : Brother____ Sister____

Birth order in family :

Place of Birth : a)Home b)Hospital

Nature of Delivery : a)Caesarian b)Normal c)Others

Diagnosed as : a)Autism b)ADHD

Diagnosed by : a)Psychiatrist b)Clinical psychologist c)Paediatrician
e)Physician

Socio demographic detail of Parents:

Name :

Age :

Educational qualification :

Occupation :

Monthly Income :

No. of children : Autistic____ Normal____ ADHD____

Any physical or psychological problem that is concerning you :

Any family history of psychiatric illness :

APPENDIX - III

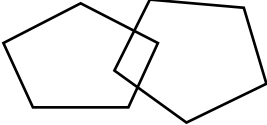
MINI-MENTAL STATE EXAMINATION (MMSE)

Patient's Name: _____

Date: _____

Instructions: Ask the questions in the order listed. Score one point for each correct response within each question or activity.

Maximum Score	Patient's Score	Questions
5		“What is the year? Season? Date? Day of the week? Month?”
5		“Where are we now: State? County? Town/city? Hospital? Floor?”
3		The examiner names three unrelated objects clearly and slowly, then asks the patient to name all three of them. The patient's response is used for scoring. The examiner repeats them until patient learns all of them, if possible. Number of trials: _____
5		“I would like you to count backward from 100 by sevens.” (93, 86, 79, 72, 65, ...) Stop after five answers. Alternative: “Spell WORLD backwards.” (D-L-R-O-W)
3		“Earlier I told you the names of three things. Can you tell me what those were?”
2		Show the patient two simple objects, such as a wristwatch and a pencil, and ask the patient to name them.
1		“Repeat the phrase: ‘No ifs, ands, or buts.’”
3		“Take the paper in your right hand, fold it in half, and put it on the floor.” (The examiner gives the patient a piece of blank paper.)

1		“Please read this and do what it says.” (Written instruction is “Close your eyes.”)
1		“Make up and write a sentence about anything.” (This sentence must contain a noun and a verb.)
1		“Please copy this picture.” (The examiner gives the patient a blank piece of paper and asks him/her to draw the symbol below. All 10 angles must be present and two must intersect.) 
30		TOTAL

APPENDIX –IV

WHO QUALITY OF LIFE-BREF

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks.

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither poor nor good	Good	Very good
1(G1)	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2 (G4)	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3 (F1.4)	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4(F11.3)	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5(F4.1)	How much do you enjoy life?	1	2	3	4	5
6(F24.2)	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7(F5.3)	How well are you able to concentrate?	1	2	3	4	5
8 (F16.1)	How safe do you feel in your daily life?	1	2	3	4	5
9 (F22.1)	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderate ly	Mostly	Completely
10 (F2.1)	Do you have enough energy for everyday life?	1	2	3	4	5
11 (F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5
12 (F18.1)	Have you enough money to meet your needs?	1	2	3	4	5
13 (F20.1)	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14 (F21.1)	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15 (F9.1)	How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how **good or satisfied** you have felt about various aspects of your life over the last two weeks.

		Very dissatisfi ed	Dissa tis- fied	Neither satisfie d nor dissatisf ied	Satisfie d	Ver y satisfi ed
16 (F3.3)	How satisfied are you with your sleep?	1	2	3	4	5
17 (F10.3)	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18(F12.4)	How satisfied are you with your capacity for work?	1	2	3	4	5
19 (F6.3)	How satisfied are you with yourself?	1	2	3	4	5
20(F13.3)	How satisfied are you with your personal relationships?	1	2	3	4	5
21(F15.3)	How satisfied are you with your sex life?	1	2	3	4	5
22(F14.4)	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23(F17.3)	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24(F19.3)	How satisfied are you with your access to health services?	1	2	3	4	5
25(F23.3)	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
26 (F8.1)	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

APPENDIX – V

BECK'S DEPRESSION INVENTORY - II (BDI)

This depression inventory can be self-scored. The scoring scale is at the end of the questionnaire.

1.

- 0 I do not feel sad.
- 1 I feel sad
- 2 I am sad all the time and I can't snap out of it.
- 3 I am so sad and unhappy that I can't stand it.

2.

- 0 I am not particularly discouraged about the future.
- 1 I feel discouraged about the future.
- 2 I feel I have nothing to look forward to.
- 3 I feel the future is hopeless and that things cannot improve.

3.

- 0 I do not feel like a failure.
- 1 I feel I have failed more than the average person.
- 2 As I look back on my life, all I can see is a lot of failures.
- 3 I feel I am a complete failure as a person.

4.

- 0 I get as much satisfaction out of things as I used to.
- 1 I don't enjoy things the way I used to.
- 2 I don't get real satisfaction out of anything anymore.
- 3 I am dissatisfied or bored with everything.

5.

- 0 I don't feel particularly guilty
- 1 I feel guilty a good part of the time.
- 2 I feel quite guilty most of the time.
- 3 I feel guilty all of the time.

6.

- 0 I don't feel I am being punished.
- 1 I feel I may be punished.
- 2 I expect to be punished.
- 3 I feel I am being punished.

7.

- 0 I don't feel disappointed in myself.
- 1 I am disappointed in myself.
- 2 I am disgusted with myself.
- 3 I hate myself.

8.

- 0 I don't feel I am any worse than anybody else.
- 1 I am critical of myself for my weaknesses or mistakes.
- 2 I blame myself all the time for my faults.
- 3 I blame myself for everything bad that happens.

9.

- 0 I don't have any thoughts of killing myself.
- 1 I have thoughts of killing myself, but I would not carry them out.
- 2 I would like to kill myself.
- 3 I would kill myself if I had the chance.

10.

- 0 I don't cry any more than usual.
- 1 I cry more now than I used to.
- 2 I cry all the time now.
- 3 I used to be able to cry, but now I can't cry even though I want to.

11.

- 0 I am no more irritated by things than I ever was.
- 1 I am slightly more irritated now than usual.
- 2 I am quite annoyed or irritated a good deal of the time.
- 3 I feel irritated all the time.

12.

- 0 I have not lost interest in other people.
- 1 I am less interested in other people than I used to be.
- 2 I have lost most of my interest in other people.
- 3 I have lost all of my interest in other people.

13.

- 0 I make decisions about as well as I ever could.
- 1 I put off making decisions more than I used to.
- 2 I have greater difficulty in making decisions more than I used to.
- 3 I can't make decisions at all anymore.

14.

- 0 I don't feel that I look any worse than I used to.
- 1 I am worried that I am looking old or unattractive.
- 2 I feel there are permanent changes in my appearance that make me look unattractive
- 3 I believe that I look ugly.

15.

- 0 I can work about as well as before.
- 1 It takes an extra effort to get started at doing something.
- 2 I have to push myself very hard to do anything.
- 3 I can't do any work at all.

16.

- 0 I can sleep as well as usual.
- 1 I don't sleep as well as I used to.
- 2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
- 3 I wake up several hours earlier than I used to and cannot get back to sleep.

17.

- 0 I don't get more tired than usual.
- 1 I get tired more easily than I used to.
- 2 I get tired from doing almost anything.
- 3 I am too tired to do anything.

18.

- 0 My appetite is no worse than usual.
- 1 My appetite is not as good as it used to be.
- 2 My appetite is much worse now.
- 3 I have no appetite at all anymore.

19.

- 0 I haven't lost much weight, if any, lately.
- 1 I have lost more than five pounds.
- 2 I have lost more than ten pounds.
- 3 I have lost more than fifteen pounds.

20.

- 0 I am no more worried about my health than usual.
- 1 I am worried about physical problems like aches, pains, upset stomach, or constipation.
- 2 I am very worried about physical problems and it's hard to think of much else.
- 3 I am so worried about my physical problems that I cannot think of anything else.

21.

- 0 I have not noticed any recent change in my interest in sex.
- 1 I am less interested in sex than I used to be.
- 2 I have almost no interest in sex.
- 3 I have lost interest in sex completely.

APPENDIX - VI

STATE-TRAIT ANXIETY INVENTORY (STAI)

Name.....Date.....Age..... Sex: Male

S.No.	Not at all	Some What	Moderately so	Very much so
1. I feel calm	1	2	3	4
2. I feel secure	1	2	3	4
3. I am tense	1	2	3	4
4. I feel Strained	1	2	3	4
5. I feel at ease	1	2	3	4
6. I feel upset	1	2	3	4
7. I am presently worrying over possible misfortunes	1	2	3	4
8. I feel satisfied	1	2	3	4
9. I feel frightened	1	2	3	4
10. I feel comfortable	1	2	3	4
11. I feel self confident	1	2	3	4
12. I feel nervous	1	2	3	4

13. I am Jittery	1	2	3	4
14. I feel indecisive	1	2	3	4
15. I am relaxed	1	2	3	4
16. I feel content	1	2	3	4
17. I am worried	1	2	3	4
18. I feel confused	1	2	3	4
19. I feel steady	1	2	3	4
20. I feel pleasant	1	2	3	4

APPENDIX - VII

ZARIT BURDEN SCALE

The following is a list of statements that reflect how people sometimes feel when taking care of another person. After reading each statement, indicate how often you experience the feelings listed by circling the number that best corresponds to the frequency of these feelings.

	Never	Rarely	Sometimes	Frequently	Nearly Always
1) Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
2) Do you feel embarrassed you're your relative's behavior?	0	1	2	3	4
3) Do you feel angry when you are around your relative?	0	1	2	3	4
4) Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	0	1	2	3	4
5) Are you afraid what the future holds for your relative?	0	1	2	3	4
6) Do you feel strained when you are around your relative?	0	1	2	3	4
7) Do you feel that you do not have as much privacy as you would like because of your relative?	0	1	2	3	4
8) Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
9) Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4

10) Do you feel that you have lost control of your life since your relative's illness?	0	1	2	3	4
11) Do you wish you could just leave the care of your relative to someone else?	0	1	2	3	4
12) Do you feel uncertain about what to do about your relative?	0	1	2	3	4
13) Do you feel that you should be doing more for your relative?	0	1	2	3	4
14) Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
15) Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4
16) Do you feel that your relative asks for more help than (s)he needs?	0	1	2	3	4
17) Do you feel that because of the time you spend with your relative that you do not have enough time for yourself?	0	1	2	3	4
18) Do you feel your relative is dependent upon you?	0	1	2	3	4
19) Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
20) Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4
21) Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
22) Do you feel that you do not have enough money to care for your relative in addition to the rest of your expenses?	0	1	2	3	4

**COPING INVENTORY FOR STRESSFUL SITUATIONS (CISS-
21)**

1. Take some time off and get away from the situation (A)
2. Focus on the problem and see how I can solve it (T)
3. Blame myself for having gotten into this situation (E)
4. Treat myself to a favourite food or snack (A)
5. Feel anxious about not being able to cope (E)
6. Think about how I solved similar problems (T)
7. Visit a friend (A)
8. Determine a course of action and follow it (T)
9. Buy myself something (A)
10. Blame myself for being too emotional about the situation (E)
11. Work to understand the situation (T)
12. Become very upset (E)
13. Take corrective action immediately (T)
14. Blame myself for not knowing what to do (E)
15. Spend time with a special person (A)
16. Think about the event and learn from my mistakes (T)
17. Wish that I could change what had happened or how I felt (E)
18. Go out for a snack or meal (A)
19. Analyse my problem before reacting (T)

20. Focus on my general inadequacies (E)

21. Phone a friend (A)

T = Task-oriented coping

E = Emotion-oriented coping

A = Avoidance coping

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- International Seminar on “Emerging Trends in Psychological Interventions :Future Prospects and Challenges” organized by School of Medical and Paramedical Sciences at Mizoram University 14th Nov – 16th Nov 2023.
- International Seminar on “Multidisciplinary Perspectives on Human Development and Learning: Navigating the Nexus of Education, Psychology, Business, Language and Philosophy organized by Assumption University of Thailand and AsiaPacific School Psychology Association at Assumption University (28th – 30th, November, 2024).

RESEARCH PUBLICATION

- Lalawmpuia, Lalnunpuii & Zokaitlaungi (2023). Quality of Life and Depression among Caregivers of Children with Attention Deficit Hyperactivity Disorder (ADHD). Published at Mizoram Educational Journal (A National Refereed Journal) Vol. IX, Issue 3, September 2023 & Vol. IX, Issue 4, December, 2023.
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Burden and Anxiety among Caregivers of Children with ADHD and Autism

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Abstract

The study investigated the burden and anxiety among the parents of ADHD and Autism who were the main caregivers of their child. 80 Parents of ADHD and 80 parents of Autism, 80 parents of children without any mental illness, age range between 30 to 45 years of age, residing in Aizawl, were selected purposive random sampling to serve as a sample. The study used the Zarit Burden Interview (Zarit & Bach-Peterson, 1980) and State-Trait Anxiety Inventory (Sesti, 2000) for the collection of data. Results revealed that the parents of ADHD showed the highest, Parents of Autism and the lowest from parents of children with no mental illness on both Burden and Anxiety at significant levels; the burden and anxiety had significant positive relations. The results may be interpreted as the high need for psychological care of the parents of ADHD and Autism.

Keywords: Burden, Anxiety, ADHD, Autism, Caregivers, children

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INTRODUCTION

Autism spectrum disorder (ASD) is a neurodevelopmental disorder with increasing morbidity in recent years. Children diagnosed with ASD often have deficits in social functioning, exhibit repetitive, stereotyped, and self-stimulatory behavior and typically show marked delay in the development of verbal language. Attention-deficit/hyperactivity disorder (ADHD) is a neurobehavioral disorder characterized by inattention, impulsivity, and hyperactivity. Both ASD and ADHD have heterogeneous and variable impacts on functioning and daily activities for these children and their caregivers.

Studies have reported that parents who have a disabled child are under more stress, have higher levels of anxiety and have lower levels of self-confidence, higher stigma, lower on self-esteem and harmony in marriage than parents who do not have any disabled children

(Cantwell, Muldoon & Gallegher 2015; Ali & Hassiotis, 2012; Uguz & Toros, 2004; Glidden & Schoolcraft, 2003; With & Coiro, 2003).

Behavioural problems of the child have negative impact or effect on family adaptation including quality of life and psychological well-being. Parents may feel helpless, overwhelmed and frightened by this kind of behaviour and often begin to question their parental ability and will have guilt feelings associated with their inability. Parents are usually the primary provider of this care. Given other responsibilities that parents typically have in relation to maintaining stability for their family, the additional responsibility of providing significant levels of care for their child indefinitely may task parents' ability to maintain balance in their own lives. This may lead to stress for parents which could compromise their ability to effectively care for their child.

REVIEW OF LITERATURE

Romany. H Gabra & Doaa. F Hashem (2021) *Middle East current Psychiatry* 28, Article number 83 (2001) conduct a study on "Comparison of caregivers' characteristics, stigma, and disease burden of children with autism spectrum disorder and attention-deficit disorder in Egypt". The current study is a cross-sectional, analytical one aiming to assess some psychiatric characteristics (depression, anxiety, sensitivity) of the caregivers of children with ASD and ADHD. Also, it aims to assess the level of stigma and disease burden and its impact on the quality of life of those caregivers; also, aimed to compare those data between caregivers of both disorders. The current study includes 72 caregivers of ASD and ADHD children (38 caregivers of autism versus 34 caregivers of ADHD) recruited from Assiut governorate (Assiut University's psychological and educational counseling center, and from child and adolescent outpatient clinic in Neurology and psychiatry department, Assiut University Hospital) caregivers of autistic children were 17 father and 21 mother caregivers, while caregivers of ADHD children were 13 fathers and 21 mothers. The age range of the studied sample was from 24 to 45 years old. The average education years of caregivers of autism were 13.41 years, while the average education years of ADHD caregivers were 12.85 years. This study supports the notion that both ADHD and ASD pose a great challenge to their caregivers. Both caregivers have a higher score of affiliate, associative stigma, and diseases burden. Also, both caregivers have a higher score of depression, anxiety, and sensitivity than normal. Both caregivers have also a significantly lower quality of life. The study also examines the difference of severity of such variable between caregivers of ASD

and ADHD showing that caregivers with ASD have a higher score of stigma, burden, depression, anxiety, and sensitivity than caregivers of ADHD. Also, they have a significantly lower QoL scores than caregivers of ADHD. The current results show that caregivers of ASD and ADHD have a higher score of stigmas, burden, depression, anxiety, and a poorer QoL than normal; all these variables are worse in ASD caregivers than ADHD caregivers. This study supports the notion that both ADHD and ASD pose a great challenge for their caregivers which is higher in ASD than ADHD caregivers.

Hans.K., Hanne.M & Egil Junsbu (2010, *International journal of environmental research and public health* conducted a study on “Psychological Distress among Caregivers of Children with Neurodevelopmental Disorders in Nepal”. The aim of the study was to examine the psychological distress among caregivers having children with NDD in rural Nepal. Sixty-three caregivers were visited in their homes and interviewed by experienced mental health professionals. This study examined demographic information, severity of disability, perceived caregiver burden, and psychological distress, measured by the General Health Questionnaire-12 (GHQ-12). The study found a high level of psychological distress in the caregivers ($M = 5.38$, $SD = 2.8$). A majority (90.5%) scored two or higher, indicating the presence of a common mental disorder (CMD). Almost half (46%) scored six or higher, indicating a high level of distress. A majority of the caregivers reported that caring for their disabled child had a negative effect on the caregiver’s economy (70%), physical health (65%), social life (64%), and dreams and expectations for the future (81%). There was a significant relationship between the caregiver’s psychological distress (GHQ-12) and degree of disability in the child (Gross Motor Function Classification System), degree of caregiver burden, feeding problems, having health workers as a possible source of help, receiving incentive from the government, having somebody to confide in, and caregiver illiteracy. A forward regression analysis entering the significant factors indicated that caregiver burden, having someone to confide in, and having health workers as a possible source of help were significant related to psychological distress. The final step of the model explained 42.4% of the variance in psychological distress among the caregivers. The study indicates a high level of psychological distress and high overall burden in caregivers of children with NDD in rural Nepal. Further implications for research and service development are discussed.

STATEMENT OF THE PROBLEM

Parents of children with autism and ADHD are presented with a unique set of challenges associated with providing care for their children. Depending upon the nature and severity of the disability, the child may require significant personal care and monitoring to ensure his or her wellness and safety. There are a limited studies that focus on caregivers of these children. Most of the current research focuses mainly on autistic disorder with limited studies that considered the caregivers of ADHD children. Moreover, there is almost no previous work comparing the extent of stigma and caregiver burden of caregivers in both disorders. Affiliate stigma in caregivers of ASD and ADHD children can affect caregivers' psychological health. It describes the process of internalizing, and coming to be believe, criticism from others that negatively impacts the mental health of those vulnerable caregivers.

OBJECTIVES: The study set forth objectives based on the literature available as under:

- 1) To examine the applicability of the *Zarit Burden Interview (Zarit & Bach-Peterson, 1980)* and *State-Trait Anxiety Inventory (Sesti, 2000)* to the parents of children with ADHD, autism and normal mental health on Burden and Anxiety.
- 2) To examine whether difference exists among the parents of children with ADHD, autism and normal mental health on Burden and Anxiety.
- 3) To examine the relationship between Burden and Anxiety variables.
- 4) To study the predictability of Anxiety on Burden among the samples.

HYPOTHESIS: In consistency with the objectives of the study the following hypotheses were framed for the present study:

- 1) The *Zarit Burden Interview (Zarit & Bach-Peterson, 1980)* and *State-Trait Anxiety Inventory (Sesti, 2000)* will have applicability to authentically assess the Burden and Anxiety levels of the parents of children with ADHD, Autism, and normal mental health.
- 2) It was expected that there will be significant difference between parents of children with ADHD, Autism and Normal mental health about their Burden and Anxiety.
- 3) There will be a positive significant correlation between Burden and Anxiety variables.
- 4) There will be a significant predictability of Anxiety from Burden among the three groups of parents.

METHODOLOGY

Sample : The sample size was 240 in total, 80 parents of ADHD, 80 parents of Autism and 80 parents of normal children without any mental illness selected from Dept of Psychiatry – Kulikawn hospital, Special schools, Child Guidance Centre, District Early Intervention Centre and Private Clinic of Aizawl-Mizoram as per their inclusion and exclusion criteria for the study through purposive random sampling method.

Tools:

- 1. DEMOGRAPHIC DATA SHEET:** It consists of information about socio demographic variables such as age, sex, religion, education, marital status, residence and occupation of the subjects.
- 2. THE ZARIT BURDEN INTERVIEW (Zarit, Reever & Bach-Peterson, 1980):** The Zarit Burden Interview, a popular caregiver self-report measure used by many aging agencies, originated as a 29-item questionnaire (Zarit, Reever & Bach-Peterson, 1980). The 29-item instrument is included in Zarit et al., 1980. The revised version contains 22 items. Each item on the interview is a statement which the caregiver is asked to endorse using a 5-point scale. Response options range from 0 (Never) to 4 (Nearly Always). For shorter administration, shorter versions, ranging from 1 to 18 items, have been developed. A study by Yu, Yap & Liew (2018) found that the 6-item version was the most optimal short version as it provided similar diagnostic utility to the original 22-item version with the fewest items.
- 3. STATE TRAIT ANXIETY INVENTORY (STAI) (Sesti, 2000):** Anxiety was assessed by the state trait anxiety inventory (STAI-State). This scale contains 20 items on, for instance, feeling at ease or upset (Sesti, 2000). Scale scores range from 20 to 80 with higher scores indicating higher levels of anxiety (Van der Ploeg et al., 1980). A STAI-State score of more than 44 defines an individual as highly anxious (Spielberger and Vagg, 1984; Millar et al, 1995). Applying this cut-off level, we defined men with pre-treatment STAI-State scores equal to or below 44 as low anxiety' and those with scores above 44 as 'high anxiety' whereas the range for the state-anxiety was .16 to .62. This low level of stability for the state-anxiety is expected since responses to the items on this scale are thought to reflect the influence of whatever transient situational factors exist at the time of testing.

Design: The study incorporated a between subject research design to explain the objectives and hypotheses.

Procedures : The samples were randomly selected from Dept of Psychiatry – Kulikawn hospital, Special schools, Child Guidance Centre, Private Hospital/clinic, District early intervention centre and Education department of Aizawl-Mizoram with equal representation of male and female, permission was taken from authorities, informed consent was taken from participant, following the manual and APA code of ethics for research.

RESULTS:

Sample characteristics (Sample distribution based on demographic variables)

1) Distribution of age groups among the samples

Age group	Percentage
Below 25 years	10%
26-30 years	35%
31-35years	26%
36-40 years	15%
41- above	14%

2) Educational qualification distribution among the samples

Class	Percentage
Below class X	37%
Class 12	26%
BA	19%
MA	12%
Above MA	6%

3) Employment distribution of the samples

Employment	Percentage
Self-employed	31%
Group IV	21%
Group B	16%
Group A	12%
Businessmen	20%

Objective-1: To examine the applicability of the *Zarit Burden Interview (Zarit & Bach-Peterson, 1980)* and *State-Trait Anxiety Inventory (Sesti, 2000)* to the parents of children with ADHD, autism and normal mental health on Burden and Anxiety.

Table -1: Showing the Psychometric Properties of the tools used for the targeted population

Independent Variables	Statistics	Dependent Variables	
		Burden	Anxiety
ADHD	Mean	28.75	45.15
	SD	1.79	1.29
	Kurtosis	-0.63	0.24
	Skewness	0.28	-0.36
Autism	Mean	25.50	42.28
	SD	1.84	2.34
	Kurtosis	0.94	-0.74
	Skewness	0.75	-0.34
Normal Mental Health	Mean	21.05	38.98
	SD	1.75	1.31
	Kurtosis	-0.98	-0.12
	Skewness	-0.23	-0.30
Reliability (Alpha)		.80	.84
Test of Homogeneity of Variances		.75	.67

The results provided that skewness values and Kurtosis values were less than 1.0 (+/-) which conveyed that the data of Burden and Anxiety scores approximates normality. Cronbach's alpha was .80 on Zarit Burden Interview and .84 for State-Trait Anxiety Inventory. The homogeneity of variances across the three sample groups was also checked which reveals that the distribution is homogenous for Burden .75 ($p < .05$) and Anxiety .67 ($p < .05$). The overall results showed the applicability of the tests within the target population and also highlights the appropriateness of applying parametric tests. The result lends credence to accepting hypothesis no. 1.

Objective-2: To examine any significant difference among the parents of children with ADHD, autism and normal mental health on Burden and Anxiety.

Parents of	Burden	Anxiety
ADHD	28.75	45.15
AUTISM	25.50	42.28
Normal	21.05	38.98
Total	25.10	42.13
Burden		
	AUTISM	Normal
ADHD	3.25*	7.70*
Autism		4.45*
Anxiety		
	AUTISM	Normal
ADHD	2.87*	6.17*
Autism		3.30*

The result in Table-2 showed that parents of ADHD (M=28.75) scored higher than parents of Autistics (25.50; $F=3.25$; $p<.01$) and normal mental health parents (M=21.05; $F=7.70$; $p>.01$) on burden at significant .01 level. The same trend was found on Anxiety that ADHD scored higher than Autism (M=45.15; 42.28; $F=2.87$; $p>.01$) and normal (M=45.15; 42.15; $F=6.17$; $p>.01$) at significant .01 level. From the result we can accept hypothesis no-2.

Objective-3: To examine any significant relationship between Burden and Anxiety variables.

Table- 3: Showing the significant relationship between the dependent variables among the samples'

Dependent Variables	Anxiety
Burden	.53**

From table-2 it is evident that Burden and Anxiety is positively correlated ($r=.53$) although the magnitude showed moderate strength. Therefore we can accept hypothesis no 4 of the study.

Objective -4: To study any significant prediction of burden on anxiety among the samples.

The simple regression analysis results showed that Burden accounts for 47 % of variation within Anxiety which is also significant at the .01 level, and Durbin Watson was lower than 2.0 indicating that there was no autocorrelation detected in the sample, and the results supports hypothesis no-5.

Predictor	Criterion	R Square	F Change	df	Sig. F Change	Durbin-Watson
Burden	Anxiety	0.47	812.43	1/118.00	0.00	1.28

DISCUSSION & CONCLUSION:

Results revealed that the parents of ADHD showed the highest mean score, followed by Parents of Autism and parents of children with no mental illness on both Burden and Anxiety; the burden and anxiety had significant positive relations and also got a support of findings from earlier findings that caregivers of children with ADHD and Autism continued to report significantly higher levels of psychological distress (burden, anxiety etc) and caregiver burden compared to caregivers of children without Developmental disabilities (Emily & Jacqueline, 2021) and Level of anxiety was found to be significantly associated with burden of caregiving (Shrijana & Chandrakala, 2019). The results may be interpreted as the high need for psychological care of the parents of ADHD and Autism.

LIMITATION –

The present study could not compared single parent, small sample used in the present study limit the generalization of present findings and limited psychological variables.

SIGNIFICANT OF THE STUDY –

The study have contributed about the level of burden and anxiety for caregivers which have never been done, and highlighted the need of psychological intervention for them.

SUGGESTION –

- The sample size can be increased for generalizing the results.
- Others groups of disability can also be focused upon.
- There is a need for more research on the psychosocial well-being of the parents/caregiver of children with disability.

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Quality of Life and Depression among Caregivers of Children with ADHD and Autism

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Abstract

The study investigated the Quality of life and depression among Caregivers of Children with ADHD and Autism among their parents who were the main caregivers of their child. 80 Parents of ADHD and 80 parents of Autism, 80 parents of children without any mental illness, age range between 30 to 45 years of age, residing in Aizawl, were selected purposive random sampling to serve as a sample. The study used the subscale of the Quality of Life (WHO Quality of Life-BREF, 1996) and Beck Depression Inventory (BDI) (Beck, Steel & Brown, 1996) for the collection of data. Results revealed that the parents of ADHD showed the lowest, Parents of Autism and the lowest from parents of children with no mental illness on psychological quality of life but reverse results on depression at significant levels; the psychological quality of life and depression had a significant negative relationship. The results may be interpreted as the high need for psychological care of the parents of ADHD and Autism than parents of normal mental health.

Keywords: Quality of Life, Depression, ADHD, Autism, Caregivers, children

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INTRODUCTION

Autism spectrum disorder (ASD) is a neurodevelopmental disorder with increasing morbidity in recent years. Children diagnosed with ASD often have deficits in social functioning, exhibit repetitive, stereotyped, and self-stimulatory behavior and typically show marked delay in the development of verbal language. Attention-deficit/hyperactivity disorder (ADHD) is a neurobehavioral disorder characterized by inattention, impulsivity, and hyperactivity. Both ASD and ADHD have heterogeneous and variable impacts on functioning and daily activities for these children and their caregivers.

Having a child with developmental disabilities creates a crisis event, how parent respond to the stresses of raising their child with special needs depends on a wide variety of factors influencing their ability to cope, such as their interpretation of the crisis event, the family's sources of support, community resources, and family structure. The personality characteristics of the family members, their financial status, educational level, problem-solving skills, and spirituality all influence a family's ability to cope. Strong marital

relationship and social support also help determine parent adjustment (Thwala, Ntinda & Hlanze, 2015; Emerson, 2003; Fazil, Wallace & Singh, 2004). Parents of children with autism and ADHD are presented with a unique set of challenges associated with providing care for their children. Depending upon the nature and severity of the disability, the child may require significant personal care and monitoring to ensure his or her wellness and safety. Parents are usually the primary provider of this care. Given other responsibilities that parents typically have in relation to maintaining stability for their family, the additional responsibility of providing significant levels of care for their child indefinitely may task parents' ability to maintain balance in their own lives. This may lead to stress for parents which could compromise their ability to effectively care for their child.

REVIEW OF LITERATURE

Hoshang and Siavah (2016) did a research on —Quality of life, depression and associated factors among parents of children with autism in Kermanshah, Iran aimed to investigate health-related quality of life (HRQOL), depression, and associated factors among parents of autistic children in Kermanshah. In this cross sectional study performed in 2015, a total of 97 male and female parents of autistic children completed 3 questionnaires: background/demographic checklist, 36-item short-form health survey (SF-36), and Beck's depression inventory. Data were analysed using SPSS version 18. Analysis of the general physical health domain of HRQOL demonstrated no significant difference between men and women ($p > 0.05$). On the other hand, in all sub domains of mental health, women's scores were higher in comparison with men, and there was a significant difference in the mental health domain. Also, analysis of depression level revealed that 25.8% of the subjects had severe depression. Given the low level of QOL and depressive symptoms in more than two thirds of parents of autistic children, psychological empowerment of this group is recommended.

Elena and Rexana (2013) did a study on - Cognitive coping strategies, emotional distress and quality of life in mothers of children with ASD and ADHD—A comparative study in a Romanian population sample. The Quality of Life (QoL) represents a dimension of the overall status and of the wellbeing that might be influenced by various factors. Mothers' emotional and behavioral reactions, when having a child with diagnosis of mental disorder, are different depending on the emotional distress and cognitive coping strategies used. The aim of this study was to assess the cognitive coping strategies, emotional distress and the

relationship between them and the quality of life in mothers of children with Autism Spectrum Disorder (ASD) compared to mothers of children with Attention Deficit Hyperactive Disorder (ADHD). Data were collected from 114 mothers of children with diagnosis of ASD or ADHD. Different psychological measurements have been used in order to assess the quality of life (Family Quality of Life Survey) cognitive coping strategies (Cognitive-Emotional Regulation Questionnaire) and emotional distress (Profile of Affective Distress) of the parents. For QOL and emotional distress, they didn't find significant differences between the two groups. The coping strategies of the mothers of children with ASD that significantly correlated with the overall assessment of the family quality were: positive refocusing, positive re-evaluation and catastrophizing. The results suggest that the use of adaptive coping strategies correlates with a higher family quality of life, while for the maladaptive ones, the relationship is reversed.

Francesco and Rosa (2020) did a study on - A systematic review of coping strategies in parents of children with attention deficit hyperactivity disorder (ADHD). Parents of children with attention deficit hyperactivity disorder (ADHD) use several coping strategies to deal with ADHD symptoms impacting family life. The aim of this systematic review was to summarize the coping strategies used by parents of children with ADHD, identify which tools are most frequently used to measure coping strategies, and examine factors influencing parental coping. Fourteen empirical studies were identified as relevant to our research. Many different types of tools are used to assess coping strategies. They found that parents of ADHD children used more avoidant-focused coping strategies than parents of typical children. Mothers of ADHD children sought significantly more support and used more indirect means than mothers of typically developing (TD) children. This review underlines the importance of further exploring coping mechanisms of parents of children with ADHD in order to promote positive coping strategies for parents of children with ADHD, and to help such parents to identify people who can support them.

STATEMENT OF THE PROBLEM

Behavioural problems of the child have negative impact or effect on family adaptation including quality of life and psychological well-being. Parents may feel helpless, overwhelmed and frightened by this kind of behaviour and often begin to question their parental ability and will have guilt feelings associated with their inability. Parents of children

with ASD and ADHD are presented with a unique set of challenges associated with providing care for their children.

In Indian context, mothers take the sole responsibility for raising and caring the child with disability. Given other responsibilities that mothers typically have in relation to maintaining stability for their family, the additional responsibility of providing significant levels of care for their child indefinitely may task parents' ability to maintain balance in their own lives. This may lead to stress for parents which could compromise their ability to effectively care for their child. Parents develop different positive and negative coping strategies to combat this psychological stress. Significant differences in coping behaviour have been reported among parents with different marital and socioeconomic status.

OBJECTIVES: The study set forth objectives based on the literature available as under:

- 1) To examine the applicability of the *Quality of Life (the subscale of the WHO Quality of Life-BREF (1996) and the Beck Depression Inventory (BDI) (Beck, Steel & Brown, 1996)* to the parents of children with ADHD, autism and normal mental health.
- 2) To determine if there are any variations throughout parents of children with ADHD, Autism and Normal mental health on Quality of life and Depression.
- 3) To investigate the connection between depression and Quality of Life among parents of children with ADHD and Autism.
- 4) To investigate the prediction of Quality of Life from Depression among parents with ADHD and Autism.

HYPOTHESIS: In consistency with the objectives of the study the following hypotheses were framed for the present study:

- 1) *WHO Quality of Life-BREF (1996) and Beck Depression Inventory (BDI) (Beck, Steel & Brown, 1996)* is expected to be a reliable measure among parents of children with ADHD, Autism, and normal mental health.
- 2) It was expected that the parents of children with ADHD would show the highest score, followed by autism and normal mental health on Quality of life and Depression.

- 3) There will be a positive significant correlation between Quality of life and Depression variables.
- 4) There will be a significant predictability of Depression on Quality of life among parents of children with ADHD and Autism.

METHODOLOGY

Sample: The sample size was 240 in total, 80 parents of ADHD, 80 parents of Autism and 80 parents of normal children without any mental illness selected from the Dept of Psychiatry – Kulikawn hospital, Special schools, Child Guidance Centre, District Early Intervention Centre and Private Clinic of Aizawl-Mizoram as per their inclusion and exclusion criteria for the study through purposive sampling method.

TOOL USED:

1. **DEMOGRAPHIC DATA SHEET:** It consists of information about socio demographic variables such as age, sex, religion, education, marital status, residence and occupation of the subjects.
2. **WHO Quality of Life-BREF (1996):** The WHO quality of life assessment was developed by the WHOQOL group with fifteen international field centres, simultaneously in an attempt to develop a quality of life assessment that would be applicable cross-culturally. WHOQOL-BREF domains are physical health, psychological health, social relationship, environment factors. It contains a total of 26 questions. The WHOQOL-BREF should be self-administered if respondents have sufficient ability. Otherwise interviewer assisted or interview administered forms should be used. The internal consistency coefficient ranged from 0.70 to 0.75 for the domains. The test-retest reliability coefficient ranged from 0.41 to 0.79 at item level.
3. **BECK DEPRESSION INVENTORY (BDI) (Beck, Steel & Brown, 1996):** It was developed to measure severity of depression. It contains 21 items and is a 4 point rating scale. Scoring is done in four categories: 0-16 (low), 17-30 (moderate), 31 and above (severe). An analysis of internal consistency yielded a cronbach's alpha of 0.92 for the out patients and .93 for the students. Validity of the scale was found to be .98 (Beck et al., 1996). Item total correlations were performed on the scores of both samples, yielding significant correlations (at the level) for both groups on all items. The test-retest reliabilities were calculated, and yielding an average correlation of .93.

Design: A between subject research design was incorporated to delineate Quality of Life and Depression. A correlation design was also amalgamated to understand the association between Quality of Life and Depression.

Procedures: The samples were randomly selected from Dept of Psychiatry – Kulikawn hospital, different special schools, Child Guidance Centre, private clinic, district early intervention centre and education department of Aizawl-Mizoram with equal representation of male and female. All necessary permissions were taken from the concerning authorities. Confidentialities were maintained and consents were obtained following the manual and APA code of ethics for research.

Results

Sample character (distribution of demographic profiles)

1) Distribution of age groups among the samples

Age group	Percentage
Below 25 years	12%
26-30 years	35%
31-35years	26%
36-40 years	15%
41- above	12%

2) Educational qualification distribution among the samples

Class	Percentage
Below class X	37%
Class 12	26%
BA	19%
MA	12%
Above MA	6%

3) Employment distribution of the samples

Employment	Percentage
Self-employed	31%
Group IV	21%
Group B	16%
Group A	12%
Businessmen	20%

Objective-1: To examine the applicability of the *psychological quality of life the subscale of the WHO Quality of Life-BREF (1996) and the Beck Depression Inventory (BDI) (Beck, Steel & Brown, 1996)* to the parents of children with ADHD, autism and normal mental health.

Table -1: Showing the Psychometric Properties of the test Scale for the targeted population

Independent Variables	Statistics	Dependent Variables	
		Psychological Quality of life	Depression
ADHD	Mean	13.25	16.78
	SD	1.316	1.29
	Kurtosis	-.97	-0.96
	Skewness	-0.46	0.69
Autism	Mean	16.48	13.53
	SD	0.847	0.91
	Kurtosis	-0.49	-0.70
	Skewness	-0.25	0.33
Normal Mental health	Mean	19.63	10.25
	SD	1.350	1.30
	Kurtosis	-0.99	-0.97
	Skewness	0.40	-0.68
Reliability (Alpha)		.81	.83
Test of Homogeneity of Variances		.74	.69

The results provided that skewness values and Kurtosis values were less than 1.0 (+/-) which conveyed that the data approximates normality. Cronbach's alpha showed high reliability for both tools; Quality of life was .81 and Depression reliability was .83. Tests of homogeneity of variance results showed that Psychological Quality of life .74 and on Depression was .69

which are not significant indicating that variances of the three sample groups are approximately equal. The overall results showed the applicability of the tests in the target population and also highlights the appropriateness of applying parametric tests. The result supports accepting hypothesis no-1.

Objective-2 To determine if there are any variations throughout parents of children with ADHD, Autism and Normal mental health on Psychological Quality of life and Depression.

Parents of	Psychological Quality of life	Depression
ADHD	13.25	16.78
AUTISM	16.48	13.53
Normal	19.63	10.25
Total	16.45	13.52
Psychological Quality of life		
	AUTISM	Normal
ADHD	3.25*	7.70*
Autism		4.45*
Depression		
	AUTISM	Normal
ADHD	2.87*	5.18*
Autism		3.30*

The result in Table-2 displayed that parents of ADHD children scored lower than parents of Autistic children ($M=13.25$; 16.48 ; $F=3.35$; $p<.01$) and parents of children with normal mental health ($M=13.25$; 19.63 ; $F=6.40$; $p<.01$), parents of Autistic children scored lower than normal ($M=16.48$; 19.63 ; $F=4.45$; $p<.01$) on Psychological Quality of life at significant .01 level. The reverse trend was found in Depression where parents of ADHD scored higher than parents of Autistics ($M=16.78$; 13.53 ; $F=2.77$; $p<.01$) and parents of children with normal mental health ($M=16.78$; 13.53 ; $F=5.18$; $p<.01$), autism scored higher than normal ($M=13.53$; 10.25 ; $F=3.30$; $p>.010$ at significant .01 level. The result has accepted hypothesis no-2.

Objective-3: To investigate the connection between depression and Psychological Quality of Life among parents of children with ADHD and Autism.

.Table- 3: Showing the significant relationship between the dependent variables- Psychological Quality of life and depression among the samples.

Dependent Variables	Psychological Quality of life	Depression

Psychological Quality of life	1	-.68**
Depression	-.68**	1
**= significant at the 0.01 level (2 tailed)		

The results showed that the Psychological Quality of Life and Depression had a negative correlation ($r = -.53$) which accepted hypothesis no 4 of the study.

Objective -4: To investigate the prediction of Psychological Quality of Life from Depression among parents with ADHD and Autism.

The simple regression analysis results showed that Depression predicted Psychological Quality of life at 46 %, and Durbin Watson was lower than 2.0 indicating that there was no autocorrelation detected in the sample, and the results suggested accepting the hypothesis no-5.

Predictor	Criterion	R Square	F Change	df	Sig. Change F	Durbin-Watson
Depression	Psychological Quality of life	0.46	102.89	1/118.00	0.00	1.15

DISCUSSION & CONCLUSION:

Results revealed that the parents of ADHD showed the lowest, Parents of Autism and the lowest from parents of children with no mental illness on psychological quality of life but reverse results on depression at significant levels; the psychological quality of life and depression had a significant negative relationship and also from support of findings from earlier findings that Caregivers of children with Autism had a higher prevalence of depression and lower quality of life when compared with controls (Nanayakkara & Singharathana, 2022).

LIMITATION –

The present study could not compared single parent, small sample used in the present study limit the generalization of present findings and limited psychological variables.

SIGNIFICANCE OF THE STUDY –

The study have contributed about the level of burden and anxiety for caregivers which have never been done, and highlighted the need of psychological intervention for them.

SUGGESTION –

- The sample size can be increased for generalizing the results.
- Others groups of disability can also be focused upon.
- There is a need for more research on the psychosocial well-being of the parents/caregiver of children with disability.

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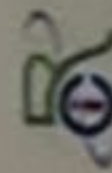
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2024-08 to present | Clinical Psychologist (Clinical Psycholgy)

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ABSTRACT

QUALITY OF LIFE, PSYCHOLOGICAL DISTRESS AND COPING STRATEGIES OF PARENTS OF CHILDREN WITH NEURODEVELOPMENTAL DISORDER

**AN ABSTRACT SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF
PHILOSOPHY**

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**DEPARTMENT OF CLINICAL PSYCHOLOGY
SCHOOL OF MEDICAL & PARAMEDICAL SCIENCES**

JULY, 2025

**QUALITY OF LIFE, PSYCHOLOGICAL DISTRESS AND COPING
STRATEGIES OF PARENTS OF CHILDREN WITH
NEURODEVELOPMENTAL DISORDER**

**BY
LALAWMPUIA
Department of Clinical Psychology**

**Supervised by:
Prof. ZOKAITLUANGI**

**Submitted
In partial fulfillment of the requirement of the Degree of Doctor of
Philosophy in Clinical Psychology of Mizoram University, Aizawl.**

INTRODUCTION

Neurodevelopmental disorders (NDs) are types of disorder which can influence how the brain functions in different ways and it can alter neurological development, the main problems that causing difficulties in social, cognitive, and emotional functioning. The most common Neurodevelopmental disorders are autism spectrum disorder and attention-deficit/hyperactive disorder (May et al., 2019). Neurodevelopmental disorders (NDs) usually onset during the stages of development which makes them most present in toddlers period, children, and adolescents, but it continue to persist into adulthood, or may go undiagnosed until one is an adult (Masuda et al., 2019).

There are many various possible reasons for the onset of Neurodevelopmental disorders. From the research that does exist on the cause of Neurodevelopmental , it is prevalent that both biology and environment play a role. Predispositions like genetics and hormones can be triggered by risk factors such as stress, illness, or trauma (Bale et al., 2010).

Autism spectrum disorder (ASD), attention-deficit hyperactivity disorder (ADHD), epilepsy, intellectual disability, hearing, vision, and motor impairments, including cerebral palsy, are a few examples of neurodevelopmental disorders. Some disorders overlap, for example in children with epilepsy, ASD occurs in 22%, ADHD in 33%, and behavioural/emotional problems in 30–50%. So often individuals with autism spectrum disorder often have intellectual developmental disorder (intellectual disability), and many children with attention-deficit/hyperactivity disorder (ADHD) also have a specific learning disorder (Valerie et al., 2019). The hallmarks of autism spectrum disorder include persistent deficits in social communication and social interaction in a variety of contexts. These deficits can include social reciprocity, nonverbal communicative behaviours used in social interactions, and relationship-building, relationship-maintenance, and relationship-understanding skills (Lach et al., 2009).

ADHD (Attention Deficit Hyperactivity Disorder) is a neurodevelopmental disorder defined by impairing levels of inattention, disorganization, and/or hyperactivity-impulsivity. Inattention and disorganization entail inability to stay on task, seeming not to listen, and losing materials necessary for tasks, at levels that are

inconsistent with age or developmental level. Hyperactivity-impulsivity entails over activity, fidgeting, inability to stay seated, intruding into other people's activities, and inability to wait-symptoms that are excessive for age or developmental level. (APA, 2022). When it comes to conduct disorder and oppositional defiant disorder, two conditions that are commonly referred to as "externalising disorders," ADHD and these conditions often coexist in childhood. ADHD frequently lasts into adulthood, impairing social, intellectual, and professional functioning as a result (Howard, 2022). ADHD first manifests in childhood. The necessity for many symptoms to manifest prior to becoming 12 years old emphasises the significance of a significant clinical presentation in early life (Renate et al.,2020).

Quality of Life

According to the World Health Organization (WHO), 1994 defines "Quality of life is defined as individuals' perceptions of their position in life in the context of culture and value systems in which they live and about their goals, expectations, standards and concerns." Employment, the environment, mental and physical health, education, leisure and recreation, social belonging, religious views, safety, security, and freedom are all considered standard indices of quality of life. Whereas psychological distress can be largely defined as a state of emotional suffering characterized by symptoms of depression (e.g., lost interest; sadness; hopelessness) and anxiety (e.g., restlessness; feeling tense) (Mirowsky & Ross, 2002).

Quality of life has many factors and variables influencing and interacting with its core concepts. Quality of life (QOL) is a philosophically derived concept. Quality of Life is being more frequently used in medicine as the gold standard for diagnosis or therapy. As a result, the idea was also embraced by paediatric psychiatry, where it is applied to both clinical assessments that are tailored to each patient and the evaluation of the efficacy of different medication or psychological therapies.

Caregiver Burden

Caregiver burden is defined as the distress that caregivers feel as a result of providing care. It is specific to the care and varies from anxiety and depression to other emotional and more general responses (Given et al., 2001). Caregiving burden includes physical (Fletcher et al., 2008, Mosher et al., 2013, Osse et al., 2006, Stenberg et al., 2010), psychological (Braun et al., 2007, Deshields et al., 2012, Grunfeld et al., 2004, Mosher et al., 2013, Osse et al., 2006, Song et al., 2011, Stenberg et al., 2010, Williams and McCorkle, 2011), social (Deshields et al., 2012, Goldstein et al., 2004, Song et al., 2011), and financial domains (Deshields et al., 2012, Song et al., 2011, Yun et al., 2005). Physical burden such as sleep disturbance, fatigue and pain were often experienced by caregiver.

A disabled child frequently depends on their family, especially the mother, for help with regard to their physical, social, and emotional requirements (Neely & Dia, 2008). It is extremely difficult for parents to care for a child who is neurodevelopmentally handicapped, and they run a higher risk of developing other psychopathologies such as depression and anxiety (Peter & Monica, 2021). Research has indicated that up to 68% and 52% of these mothers, respectively, suffer from anxiety and despair (Swapnajeet et al., 2013). Due to the pressure of juggling their children's requirements with household duties, mothers are known to have higher rates of depression (Saltanat C et al., 2023).

Depression

Depression influences one's behaviour, cognition, and emotions, and it significantly brings down the quality of care (Tanaka et al., 2015). Depression is caused by the negative evaluation of oneself, which makes it difficult to carry out daily routines as one feels fatigued and loses motivation. It may also lead to physical pain and even suicidal behaviour (Beck, 1986). Hence, it is important to seek solutions to relieve such symptoms and to improve the health of family caregivers of a person with a

disability to protect their mental health and to ensure that they lead a healthy family life.

Caregiving is positively associated with caregiver depression which can have far-reaching consequences for both the caregiver and the patient. Depression adds stress to the living environment and can negatively influence the functioning of the patient (V.T. Root 2007). Depression is a common and serious medical illness that negatively affects how we feel, the way we think and how we act. Depression causes feelings of sadness or a loss of interest in activities once enjoyed. It can lead to a variety of emotional and physical problems and can decrease a person's ability to function at work and home. The symptoms must last at least two weeks for a diagnosis of depression. Depression symptoms can vary from mild to severe and can include: Changes in appetite — weight loss or gain unrelated to dieting, trouble sleeping or sleeping too much, increased fatigue, increase in purposeless physical activity (e.g., hand-wringing or pacing) or slowed movements and speech (actions observable by others), feeling worthless or guilty, difficulty thinking, concentrating or making decisions and thoughts of death or suicide.

Anxiety

Anxiety is an emotion characterized by feelings of tension, worried thoughts and physical changes like increased blood pressure. People with anxiety disorders usually have recurring intrusive thoughts or concerns. They may avoid certain situations out of worry. Studies have shown that a disabled child's needs for care and education, social attitude and judgments relating to disability as well as uncertainty about the child's present and future status are significant sources of stress and anxiety that the families have to face (Ozkan, 2002). Studies have reported that parents who have a disabled child are under more stress, have higher levels of anxiety and have lower levels of self-confidence, higher stigma, and lower self-esteem and harmony in marriage than parents who do not have any disabled children (Cantwell, Muldoon & Gallegher 2015; Ali & Hassiotis, 2012; Uguz & Toros, 2004; Glidden & Schoolcraft, 2003; With & Coiro, 2003,). The presence of a disabled child in the family is an

emotional burden, a stressful life experience and a stressor that requires constant coping reactions from all family members.

Coping

Coping is defined as constantly changing cognitive and behavioural efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person. Under stress, coping is defined as "how people mobilise, guide, manage, energise, and direct behaviour, emotion, and orientation, or how they fail to do so" (Skinner & Wellborn, 1994). The term "conscious volitional efforts to regulate emotion, cognition, behaviour, physiology, and the environment in response to stressful events or circumstances" is a more contemporary definition of coping provided by Compas et al. (2001). Nevertheless, these definitions lack explicit developmental components, despite their greater focus on coping in children and adolescents. These more recent definitions share a number of characteristics and show a growing consensus in the definition of coping. Firstly, these definitions, like the earlier perspectives of Lazarus & Folkman, concentrate on processes that only happen in reaction to acute or chronic stressful events or conditions; that is, coping is the act of enacting processes in response to stress. Secondly, these concepts emphasise laborious reactions to stress. The emphasis on effort suggests that coping is intentional, goal-directed, conscious, and under control. Third, coping has become more and more important as a way to regulate oneself when under stress. Since Lazarus and Folkman's previous research, the focus on regulation has expanded the definition of coping to encompass more than just the "management" of demanding situations.

REVIEW OF LITERATURE

According to a study attention-deficit/hyperactivity disorder and autism spectrum disorder are the most prevalent neurodevelopmental disorders (May et al. 2019). The spectrum of developmental deficiencies or variations ranges from very specific learning or executive function control limits to generalised impairments in social skills or intellectual capacity. Formerly believed to be clearly defined, more modern dimensional ways to measuring the symptoms show a spectrum of intensity,

frequently lacking a very distinct border with usual development (APA, 2022). Researchers found little variation in symptoms across genders for neurodevelopmental disorders, such as autism spectrum disorder, despite the fact that males are more likely to have them. It's still unclear what specifically causes neurodevelopmental disorders (Bale et al., 2010).

ADHD increases family burden and decreases the family functioning of both the children and their parents (Stergiakouli et al., 2017). ADHD impose a significant burden on caregivers, economically as well as socially and emotionally (Dey, 2019) inviting conflicted parent-child interaction patterns, and dysfunctional parenting styles. A lot of research effort has gone into understanding the causes of individual differences in autistic behaviour, with clear evidence for genetic effects. (Le Couteur & Szatmari, 2015). Both ASD and ADHD have heterogeneous and variable impacts on functioning and daily activities for these children and their caregivers (Fealko C et al., 2020).

Caregivers socio demographic factors also play a role in their Quality of Life. However, it is inconclusive as to whether older caregivers have a poorer Quality of Life (Lima et al., 2022). There is a higher prevalence of depression or anxiety and lower Quality of Life scores related to lower socioeconomic status, lower education, and unemployed or financial problems among caregivers of individuals with mental and non-mental illness (Grover et al., 2017 ; Geng et al., 2018; Ribe et al., 2018). Common psychological distress among caregivers includes anxiety and depression (Grover et al., 2017; Stanley et al., 2017). Addressing the quality of life of caregivers of children with neurodevelopmental disorders becomes relevant because it values the perceptions of their health and wellbeing, and identifies the limits and daily challenges in the face of health conditions, disease or treatment of the child under their care (Gislaine et al., 2019).

Quality of Life and Caregivers Burden

Studies exploring the impact of caregiving duration on Quality of Life have reported mix results (Ukpong et al., 2021). Caregivers' own psychological and intrinsic factors, including self-esteem and psychological distress, are also strong

factors associated with Quality of Life (Grover et al., 2017; Stanley et al., 2017). Many research on caregivers has reported on the comprehensive challenges experienced by caregivers, including negative impacts on their physical and emotional well-being, difficulties in relationships with other family members, work challenges and financial constraints because of loss of income (Sherman et al., 2008). Primary caregivers face multiple challenges and experience impairments in their quality of life (Bruder, 2016).

Common psychological distress among caregivers includes anxiety and depression. Caregivers' socio demographic factors also play a role in their Quality of Life. However, it is inconclusive as to whether older caregivers have a poorer Quality of Life (Lima et al., 2022). Female caregivers tend to have poorer Quality of Life due to traditional family roles in different cultures (Hsia et al., 2020; Cohen et al., 2021). When compared to carers of children without disabilities, caregivers of children with autism experience higher levels of burden and lower levels of quality of life across all four domains of quality of life. Research suggests that different childhood conditions have different effects, and that parents must provide their disabled children with adequate parental support when providing intervention (Geetanshi, 2021). Caregivers with ADHD and ASD have very high levels of burden and are significantly higher in the ASD group when compared with acquired brain injury (Higginson et al., 2010).

Quality of Life and Depression

The research evaluated the QoL and depression among 202 primary caregivers of ADHD children by comparing them with a control group and found that parents of ADHD children reported poorer family QoL and higher parental depression and anxiety disorders (Cussen et al., 2012). Akvardar and colleagues compared the QoL scores between patients with psychiatric disorders and the control group, and patients with mental illness reported less satisfaction compared with patients with normal controls (Akvardar et al., 2006). Craig and colleagues (2020) did a study on a systematic review of coping strategies in parents of children with attention deficit hyperactivity disorder (ADHD). The presence of ADHD has a deep

and enormous impact not only on the patients but also on their family members in giving care to them (Harpin, 2005). Caring for a child with ADHD invites family, marital, and parental problems, reduces parenting efficacy, and increases the level of parental stress (Danckaerts et al., 2010); and also accompanied by feelings of guilt which increases vulnerability to depression (Johnston & Mash, 2001) and worse quality of life (Faraone et al., 2005; Desidério et al., 2010).

Caregivers of children with mental and behavioural disorders had a higher prevalence of depression and lower quality of life when compared with controls. There is a higher prevalence of depression or anxiety and lower Quality of Life scores related to lower socioeconomic status, lower education, and unemployed or financial problems among caregivers of individuals with mental and non-mental illness (Grover et al., 2017 ; Geng et al., 2018; Ribe et al., 2018).

Quality of Life and Anxiety

Caregivers of ASD and ADHD have a higher score of stigmas, burden, depression, anxiety, and a poorer Quality of Life than normal; all these variables are worse in ASD caregivers than ADHD caregivers (Romany and Doaa, 2021). Some studies found that not all caregivers of children with ASD experience increased stress levels and elevated depression and anxiety symptoms. Some families display traits of resilience, such as family hardiness, which was inversely associated with depression (Weiss, 2002). Perceived social support (Ekas et al., 2010; Weiss et al., 2013; Zablotzky et al., 2013; Whitehead et al., 2015; Drogomyretska et al., 2020), psychological resilience (Bitsika et al., 2013), religious beliefs (Ilias et al., 2018), effective coping skills (Zablotzky et al., 2013) and participation in parental support groups (Kerr and McIntosh, 2000) may play a role in protecting parental mental health and wellbeing of caregivers of autistic children.

Quality of Life in relation and Coping Strategies

Considering the context-dependent nature of stress coping as conceptualized in Lazarus and Folkman (1985), caution is to be taken when applying general coping constructs across distinct cultural groups such as that between western and Asian parents of children with ASD (Chun et al. 2006; Sawang et al. 2006; Oyserman et al.

2002). Considering theoretical underpinnings of collectivism-individualism, Asian parents of children with ASD who may value group gains could be biased towards collectivistic problem-focused coping methods such as seeking treatments and gathering help from support networks, while western European parents more focused on self-gain may identify better with individualistic, self-focused coping such as passive appraisal and avoidance (Markus and Kitayama 1991; Oyserman et al. 2002; Sawang et al. 2006; Tzoy et al. 2007). These findings suggest that pre-existing cultural worldviews could influence individual approaches towards stress coping (Sawang et al. 2006).

Use of problem-focussed coping is associated with better caregiver adjustment than emotion-focussed coping (Pakenham, 2001). Branscum (2011) suggests that adverse caregiving effects in adults can be lessened with adequate social support and problem-focussed coping.

Caregivers Burden in relation with Depression

Increased caregiver stress or depression has been shown to decrease parenting abilities (Cummings and Davis, 1994), which can in turn negatively impact the child's physical and mental health (Olfson et al., 2003; Lushin and O'Brien, 2016). Researchers found that parenting stress was inversely associated with successful outcomes of early learning processes of autistic children (Osborne et al., 2008) and was strongly directly associated with the development of depressive symptoms and deterioration of the quality of life in parents of children with high-functioning pervasive developmental disorders (Suzumura, 2015).

Caregivers Burden in relation with Anxiety

Studies have shown that a disabled child's needs for care and education, social attitude and judgments relating to disability as well as uncertainty about the child's present and future status are significant sources of stress and anxiety that the families have to face (Ozkan, 2002). Studies have reported that parents who have a disabled child are under more stress, have higher levels of anxiety and have lower levels of self-confidence, higher stigma, and lower self-esteem and harmony in marriage than parents who do not have any disabled children (Cantwell, Muldoon &

Gallegher 2015; Ali & Hassiotis, 2012; Uguz & Toros, 2004; Glidden & Schoolcraft, 2003; With & Coiro, 2003).

Research has consistently shown that informal family caregiving is often a burdensome role with negative consequences on carers' physical and emotional health (Sallim et al., 2015 & Lee et al., 2003).

Caregivers Burden in relation with Coping strategies

There is growing awareness regarding caregiver stigma and burden for families raising children and adolescents with autism spectrum disorders (ASDs) and ADHD. In this issue, (Cadman et al., 2015) focus on the increased recognition that both ASD and attention-deficit/hyperactivity disorder (ADHD) are associated with significant mental and emotional burdens to caregivers. However, the extent of caregiver suffering is clearly different in both disorders (Cadman et al., 2015). A study findings state that there is a significant positive relationship between caregiver burden and problem-focused coping. Correlation analysis also revealed that both emotion-focused coping and avoidant coping positively correlated with caregiver burden. Both types of coping are dysfunctional by nature, and caregivers adopt them as escaping strategies (Monteiro et al., 2018).

The most widely used strategy by parents of ADHD children seems to be problem focused coping and social support-seeking. Thus, in their intervention efforts healthcare professionals need to promote positive coping strategies helping parents identify people who can support them, either within their family or through an association or professionals (Francesco et al., 2020).

Depression in relation with Anxiety

Maternal depression has been shown to affect the child's psychological, intellectual, and psychosocial development, and may increase the risk of malnourishment and physical as well as psychiatric illness in the child . The resources, family support, and overall functioning of the family are important factors for achieving a satisfying life for children with disabilities (Majnemar et., 2007). Caregivers of ADHD and Autism reported higher levels of burden, depression, anxiety, and stress and a greater decrease in their quality of life compared with

caregivers of children with normal development (Pecor et al., 2021). Caregivers of children with ASD and ADHD have a higher score of depression, anxiety, and sensitivity than normal, and also have a significantly lower quality of life; ASD has a higher score of stigma, burden, depression, anxiety, and sensitivity than caregivers of ADHD with a significantly lower QOL score than caregivers of ADHD which demonstrated that ADHD and ASD pose a great challenge for their caregivers (Gabra & Hashem, 2021).

STATEMENT OF THE PROBLEM

Neurodevelopmental disorders (NDDs) represent a group of diseases characterized by an altered development of the Central Nervous System (CNS) that leads to the manifestation of brain dysfunctions later in life and that may be associated with neuropsychiatric problems or impaired motor function, learning, language or non-verbal communication (Dymen et al. 2020). Neurodevelopmental illnesses often affect the day-to-day functioning of the entire family because they disrupt social and economic norms. Activities that promote their own well-being take a backseat as parents focus their time and energy on rectifying misbehaviour. In addition, feelings that surface include annoyance, melancholy, hopelessness, and emotional hypersensitivity. (Gilberg et al., 2019). Mothers of children with mental and neurological impairments report high burden and bad quality of life, according a comprehensive review on the topic. (Reis et al., 2020).

Providing care for individuals with disabilities is associated with a variety of negative experiences (Fazree et al., 2021). Quality of life (QOL) is an important outcome for the monitoring and treatment of neurocognitive developmental disorders and disabilities (NDD), as well as for understanding the experiences and difficulties faced by patients and their families. According to Conway et al. (2020), it is a complex construct that captures how each individual subjectively evaluates their degree of independence, social functioning, psychological well-being, and physical health. Because NDD is marked by impairments or comorbidities in multiple domains of function, it is not surprising that children with neurocognitive

developmental disorders and disabilities (NDD) and their families experience lower quality of life (QOL) than peers (Puka et al., 2020).

Caregivers of children with autism experience higher level of burden and lower level of quality of life on all the four domains of quality of life as compared to the caregivers of children without disability and findings indicate that different effect as a consequence of different childhood conditions and also the need to provide adequate parental support when providing intervention to their children with disabilities (Geetanshi , 2021). Caregivers with ADHD and ASD have very high levels of burden and are significantly higher in the ASD group when compared with acquired brain injury (Higginson et al., 2010). Studies found that the caregiver burden for ADHD (Beecham & Knapp, 1992) caregiving burden is significantly associated with comorbid psychiatric symptoms. The unmet need is significant to endorse the burden of the caregiver which was significantly correlated with the burden for both disorders concerning social contact, major mental health problems, appropriate daytime activities, the safety of self and communication (Akbari et al., 2018).

In India, the majority of such persons have traditionally been cared for by their families. In today's modern society, this home-based care has resulted in many adverse consequences. Factors such as changes in the social system (e.g. breaking up of joint families) and the economic system (e.g. unemployment, inflation etc) have contributed to the stress that parents of special children experience. Parents of children with ADHD and Autism may find themselves burdened with a lifelong responsibility of caring for their children and diminished attention to their own health. Other than this, lack of knowledge about disorder, lack of treatment, and if treatment is available, it is unaffordable, adds on the stress. This leads to deterioration of quality of life of parents in different domains such as economic, social, educational, and psychological (Jain et al., 2019). In the Indian context, mothers take the sole responsibility for raising and caring for a child with a disability. Given other responsibilities that mothers typically have about maintaining stability for their family, the additional responsibility of providing significant levels of care for their child indefinitely may task parents' ability to maintain balance in

their own lives. This may lead to stress for parents which could compromise their ability to effectively care for their child. Hence, Female caregivers tend to have poorer Quality of Life due to traditional family roles in different cultures (Hsia et al., 2020; Cohen et al., 2021). There is a higher prevalence of depression or anxiety and lower Quality of Life scores related to lower socioeconomic status, lower education, and unemployed or financial problems among caregivers of individuals with mental and non-mental illness (Grover et al., 2017 ; Geng et al., 2018; Ribe et al., 2018).

Parents who voiced concerns to healthcare providers felt uneasy, rejected, and shunned because of medical inexperience and a lack of knowledge in handling complex medical and behavioural issues (2019, Abegaz et al.) .

Having a child with developmental disabilities creates a crisis event, how parents respond to the stresses of raising their child with special needs depends on a wide variety of factors influencing their ability to cope, such as their interpretation of the crisis event, the family's sources of support, community resources, and family structure. The personality characteristics of the family members, their financial status, educational level, problem-solving skills, and spirituality all influence a family's ability to cope. Strong marital relationships and social support also help determine parent adjustment (Thwala et al., 2015; Hlanze, 2015; Emerson, 2003; Fazil et al., 2004). For children with developmental and intellectual disabilities, mothers provide the majority of care, including community-based care and coordination of requirements with doctors. Mothers are therefore more vulnerable to stress and burnout (Lafferty et al., 2016). Research has indicated that up to 68% and 52% of these mothers, respectively, suffer from anxiety and despair (Swapnajeet et al., 2013). Due to the pressure of juggling their children's requirements with household duties, mothers are known to have higher rates of depression (Saltanat et al., 2023). It is reported that caregiving for children with ASD is more stressful and challenging than parenting children with typical development and children with other developmental disabilities (Pandey et al., 2018 & Valicenti et al., 2015).

Anxiety and depression among parents of children with intellectual disabilities was the subject of a study that revealed a notably higher percentage of moms (89%) than fathers (77%), who reported having either anxiety or depression

alone. Thirty-three percent of mothers matched the criterion for depression, forty percent for anxiety, and thirty-five percent for both. Fathers who had anxiety had 42%, depression had 31%, and anxiety and depression together had 3%. The parent's gender and the individual mental diagnoses of anxiety, depression, and anxiety and depression combined were significantly correlated (Azeem et al., 2013) discovered a noteworthy correlation between a mother's anxiety and depression, or both.

Behavioural problems of the child have a negative impact or effect on family adaptation including quality of life and psychological well-being. Parents may feel helpless, overwhelmed and frightened by this kind of behaviour and often begin to question their parental ability and will have guilt feelings associated with their inability. Parents of children with ASD and ADHD are presented with a unique set of challenges associated with providing care for their children.

Studies have shown that families of these children will experience more problems compared to the families of healthy children. Their main problems were more stress, conflicted family environment, disciplinary actions along with violence and inappropriate interactions, marital conflicts, parents' distress, more economic burdens, parents' depression, and parents' aggressive and inappropriate behaviours toward other children caused by the burdens imposed on them by their child with ADHD. Also lacking appropriate coping skills and decreased social and familial support, ambiguity in dealing with the child, negative feelings and fear from ADHD-related labels, and consequently, hiding the disease and not pursuing its treatment are some of the other problems of these ADHD families. The mental pressure caused by raising such difficult children may cause losses in couples' relations. Not only children would be facing these problems, but they may also affect the families and the society (Powell et al., 2010; Savundranayagam et al., 2011).

Parents develop different positive and negative coping strategies to combat this psychological stress. Significant differences in coping behaviour have been reported among parents with different marital and socioeconomic status. These coping methods also predict the outcomes of their distress, which may increase or

decrease depending on the ways of coping. To help themselves, parents rely on different sources of support. Strengthening these sources, formal or informal, can help to create a positive impact on their well-being (Lai & Oei, 2014).

In order to handle a patient's disability and the different caregiving responsibilities at hand, carers employ a variety of coping mechanisms. The type of partnership can also influence the caring role. A parent's caregiving responsibilities are different from those of a husband or wife.(Elena, 2021). The nature of the caregiving role can also be influenced by social status and cultural norms. The process of providing care can be seen in terms of the so-called stress-appraisal-coping model, in which appraisal is the primary component (Chakrabarti & Gill 2002). One way to look at caregiving is as a life stressor, and how one handles this stressor depends on their own traits as well as the features of the context in which they provide care. The factors that affect a caregiver's capacity to manage a patient's sickness include the patient's condition, the amount of work they have to do, their own psychological health, and their assessment of the patient's support system. Additional significant correlations have been found between these mediating characteristics and the particular coping strategies used by carers. First, among other things, Chakrabarti & Gill (2002) differentiate between coping strategies that are problem-focused and those that are emotion-focused. Problem-focused techniques usually entail the patient's increased social activity, constructive communication, and the search for more knowledge regarding the illness. Avoidance, compulsion, resignation, cooperation, seeking spiritual assistance, and drug and alcohol usage are examples of emotion-focused tactics. Talking with friends and pursuing one's own hobbies are two more adaptable ways.

Family care and various expected tasks from the caregivers for these patients in managing their disorder is of great importance. Also the researchers had some personal experiences in dealing with the needs of family caregivers of children with ADHD and Autism . The families always have questions about their child's problem, the course and symptoms of the disease, drugs and the general method of caring for these patients. So far no studies have assessed the needs of caregivers for these patients in Mizoram and evaluating the needs of caregivers.

Many studies have been conducted to determine the quality of life and burden of caregivers but there is a paucity of studies providing the socio-demographic predictors of quality of life of principal caregivers of ADHD and Autism. There is no significant research towards caregivers burden of special needs children in Mizoram. The main intention for conducting this research is to understand in-depth reality of caregivers issues, mental health, quality of life and family relations among caregivers.

OBJECTIVES:

- 1) To assess the level of burden of the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.
- 2) To assess the quality of life of the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.
- 3) To assess the level of depression in the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.
- 4) To assess the level of anxiety of the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.
- 5) To assess the coping strategies of the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.
- 6) To examine the relationship between burden, quality of life, depression, anxiety and coping strategies among three groups - the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.

HYPOTHESES

- 1) There will be the highest level of burden on the parents of children with ADHD, followed by parents of children with Autism, and parents of normal mentally healthy children.

- 2) There will be the highest quality of life for the parents of normal mentally healthy children, followed by parents of children with Autism, and parents of children with ADHD.
- 3) There will be the highest level of depression among the parents of children with ADHD, followed by parents of children with Autism, and parents of normal mentally healthy children.
- 4) There will be the highest level of burden on the parents of children with ADHD, followed by parents of children with Autism, and parents of normal mentally healthy children.
- 5) Parents of children with autism, and parents of children with ADHD will use avoidance and emotional coping whereas parents of normal mentally healthy children will use task-oriented coping strategies.
- 6) It is expected that burden, depression, anxiety, avoidance coping and emotional coping will have a positive relationship with each other whereas the quality of life, and task-oriented coping strategy will also have a positive relationship with each other; burden, depression, anxiety, avoidance coping and emotional coping will have a negative relationship with the quality of life and task-oriented coping strategy.

METHODS AND PROCEDURE

Research Design: The study aims to Correlational Design to compare parents of children with Autism, ADHD and normal mentally healthy children on quality of life, depression, anxiety, coping strategies and burden.

Sample: The sample size was be 120 in total, 40 parents of autism, 40 parents of ADHD and 40 parents of normal health to serve as a control group. Sample selection will be done in a multi-stage procedure: (i) samples for 40 children of autism, 40 children of ADHD were selected from Gilead Special Schools, Child Guidance Centre, and Private clinics, District Early Intervention Centres located in Aizawl-Mizoram who were already identified having autism / ADHD by registered professionals; and (ii) parent of selected children samples comprising- 40 parents of autism, 40 parents of ADHD were identified through their children; (iii) sample of

normal children were selected from Aizawl city based on the socio-demographic profile of the selected samples for 40 children of autism, 40 children of ADHD; and (iv) 40 parents of normal mental health children were identified through their children who were already identified. For the final count, 40 parents of autism, 40 parents of ADHD and 40 parents of normal health serve as a control group were used to serve as a sample. The sample selection was follow a purposive sampling procedure, and the age range for the samples was 25-45 years of age.

Tool Used: The following psychological tools were employed for the collection of Data:

1. Socio-demographic data sheet (Lalawmpuia, 2021): A specially designed Performa containing necessary and basic information like name, age, sex, religion, marital status, education, monthly income, etc will be used.

2. Inform Consent form (Lalawmpuia, 2021) : An informed consent form was designed by the researcher, especially for this study in which the participant were be informed about the purpose of the study, and expected contribution/participation from the participant, assurance of keeping personal information as confidential, purely voluntary participation and can leave anytime if he/she is will without any penalty, nothing will be harmful for the participant, inclusion of participant in the research will be purely base on his/her willingness/ consent. After informing all, the participants were asked for consent that he/she is willing to perform in the study and to give in writing on the Inform Consent Form.

3. Mini-Mental Status Examination (Folstein et al., 1975) :

The mini–mental state examination (MMSE) is a 30-point questionnaire that is used extensively in clinical and research settings to measure cognitive impairment. The MMSE's purpose has been not, on its own, to provide a diagnosis for any particular nosological entity. Administration of the test takes between 5 and 10 minutes and examines functions including registration (repeating named prompts), attention and calculation, recall, language, ability to follow simple commands and orientation.

4. The Zarit Burden Interview (Zarit, Reever & Bach-Peterson, 1980): The Zarit Burden Interview, a popular caregiver self-report measure used by many ageing agencies, originated as a 29-item questionnaire (Zarit, Reever & Bach-Peterson, 1980). The 29-item instrument is included in Zarit et al., 1980. The revised version contains 22 items. Each item on the interview is a statement that the caregiver is asked to endorse using a 5-point scale. Response options range from 0 (Never) to 4 (Nearly Always).

5. WHO Quality of Life-BREF (1996): The WHO quality of life assessment was developed by the WHOQOL group with fifteen international field centres, simultaneously in an attempt to develop a quality of life assessment that would be applicable cross-culturally. WHOQOL-BREF domains are physical health, psychological health, social relationship, environment factors. It contains a total of 26 questions. The WHOQOL-BREF should be self-administered if respondents have sufficient ability. Otherwise interviewer assisted or interview administered forms should be used. The internal consistency coefficient ranged from 0.70 to 0.75 for the domains. The test-retest reliability coefficient ranged from 0.41 to 0.79 at item level and 0.76-0.80 domain level all at $p < 0.01$.

6. Beck Depression Inventory (BDI) (Beck, Steel & Brown, 1996): It was developed to measure the severity of depression. It contains 21 items and is a 4-point rating scale. Scoring is done in four categories: 0-16 (low), 17-30 (moderate), and 31 and above (severe). An analysis of internal consistency yielded a Cronbach's alpha of 0.92 for the outpatients and .93 for the students. The validity of the scale was found to be .98 (Beck et al., 1996). Item total correlations were performed on the scores of both samples, yielding significant correlations (at the level) for both groups on all items. The test-retest reliabilities were calculated, yielding an average correlation of .93.

7. State trait anxiety inventory (STAI) (Sesti, 2000): Anxiety was assessed by the state-trait anxiety inventory (STAI-State). This scale contains 20 items on, for instance, feeling at ease or upset (Sesti, 2000). Scale scores range from 20 to 80 with higher scores indicating higher levels of anxiety (Van der Ploeg et al., 1980). An STAI-State score of more than 44 defines an individual as highly anxious

(Spielberger & Vagg, 1984; Millar et al, 1995). Applying this cut-off level, we defined men with pre-treatment STAI-State scores equal to or below 44 as low anxiety and those with scores above 44 as high anxiety' whereas the range for the state anxiety was .16 to .62.

8. The Coping Inventory for Stressful Situations--Short Form (CISS-SF; Endler & Parker, 1999): This scale was modified from the 48 items Coping Inventory for Stressful Situations (CISS; Endler & Parker 1990) to assess three dimensions (task-oriented, emotional and avoidant) of self-reported responses to stressful circumstances. The short form was created by eliminating items from the original CISS that had the lowest item-total correlations, resulting in a 21-items measure with 7 items per subscale. Confirmatory factor analysis and internal consistency were reported. Further research is needed to develop the avoidance subscales of the CISS-SF. Participants rate each question on a 5-point Likert scale. Higher scores indicate more use of coping strategies. It is a sound psychometric instrument with Cronbach's α : task focused=0.78-.87, emotion focused=0.78-.87, and avoidant coping=.70-.80.

Procedure: The conduction of the data collection for the present study was follow stepwise including (1) construction of a Socio-demographic profile, (ii) collection of selected psychological tests, translation if needed, multiplication of the psychological scale/subscales was done, (iii) any required permission/consent for data collection was taken from the authorities of hospital, Centres, Home etc who are taking care of the children, (iv) Inform about the purpose of the study, expected participation, assurance of confidentiality for keeping personal information, ensuring voluntary and personal decision of the participant will be respected, and consent was taken from the participant or the caretakers (ii) Sample selection and identification was done by employing the Socio-demographic profile, and mainly purposive sampling procedure was attempted but random sampling procedure followed as far as possible (iii) administration of the selected psychological scales on the selected samples done as per American Psychological Association (APA) 2014 code of ethics and the prescribed instruction given in the manuals shall be followed, (iv) the researcher taken precaution on unresponsive on each item etc.

RESULTS AND DISCUSSION

The present study entitled “Quality of Life, Psychological Distress and Coping Strategies of Parents of Children with Neurodevelopmental Disorder” aimed to study the impact of neurodevelopmental disorders such as ADHD and Autism on caregivers, primarily parents by comparing them across several psychological scales such as (i) Mini-Mental Status Examination (Folstein et al., 1975) (ii) The Zarit Burden Interview (Zarit, Reever & Bach-Peterson, 1980), (iii) The World Health Organization-Five Well-Being Index (WHO-5; WHO. 2024), (iv) Beck Depression Inventory (BDI; Beck, Steel & Brown, 1996), (v) State trait anxiety inventory (STAI) (Sesti, 2000), and (vi) Coping Inventory for Stressful Situations (CISS-21; Endler & Parker (1990). Moreover, the correlation between the dependent variables is also estimated to understand the extent of the relationship between these variables.

Based on the available literature and theory, it was expected that the level of burden and level of depression would be highest among parents of children with Autism, followed by the parents of ADHD but high in Anxiety while the parents of normal children were lowest in burden, depression and anxiety. Quality of Life was expected to be the highest among parents of children with normal mental health. In coping mechanisms, it was hypothesized that Parents of Autism and ADHD were expected to employ more avoidance and emotional coping while parents of children with normal mental health were expected to use task-oriented coping strategies. It was also expected that burden, depression, anxiety, avoidance coping and emotional coping will have a positive relationship with each other whereas the quality of life, and task-oriented coping strategy will also have a positive relationship with each other.

The present study employed 120 samples, comprising 40 parents of autism, 40 parents of ADHD, and 40 parents of normal mental health who served as a control group. The samples were selected through a random sampling procedure.

Sample characteristics: The sample characteristics include gender, psychiatric illness, age, socio-economic status, number of offspring, marital status, and expert professionals which were recorded with the help of socio-demographic profiles

constructed by the researcher (Lalawmpuia, 2021). Equal representation of illness (ADHD, Autism, Normal), and gender (female and male) were ensured. The distribution of the socio- demographic profiles of the samples including age, socio-economic status, number of offsprings, educational.

The psychological tests used in the present study were originally constructed and standardized based on the population of another culture, and the psychometric test was done to verify the authenticity of the test for the target population.

The data has met the assumptions of parametric statistics (Normality, reliability and homogeneity) which suggested that parametric statistics may be used for further analysis (Table-2-4). The results of the study were displayed following the objectives of the study sequentially as follows:

Objective-1: To assess the level of quality of life of the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.

. To compare the three groups- (i) Parents of Autistics (ii) Parents of ADHD (iii) Parents of normal mental health, the descriptive statistics and post-Hoc mean comparison (Scheffe) were employed to find any significant difference between the three groups on the dependent variables and are presented in Tables-4 and 5.

On Quality of Life: Results revealed that parent of Normal children had a highest Quality of Life than Parent of ADHD ($M=83.30$; 77.10 ; $t= -5.10$; $p < .01$) and Autistic parents ($M=83.30$, 71.20 ; $t= -6.20$; $p < .01$). Thus, autistic parents had a lower Quality of Life than ADHD parents ($M=77.10$, 71.20 ; $t= -4.90$; $p < .01$) and their difference is significant at the .01 level and presented in tables 4 and 5. Our hypothesis regarding these variables is accepted.

Many parents of children with ADHD reported to have diminished quality of life (Cappe et. al., 2016). According to earlier research, parents of children with ASD deal with a variety of difficulties that increase their risk of experiencing a poor quality of life (Calonge-Torres et. al., 2017). Parents who have children with disabilities often reported to have physical as well as psychological distress related to

caring for their children, which affect their quality of life (Leung & Li-Tsang, 2003). These studies may explain why parents of children with ADHD and Autistic score a lower quality of life than parents with normal mentally healthy children in our study. In our study ADHD carer had higher quality of life than Autistic carer. This may be due to availability of support. ADHD is widely recognized and often has more structured intervention. But autism has severe challenges in communication issue which limit access to effective therapies. Communication difficulties can be stressful for parents of ASD who find it difficult to comprehend their child's needs and desires. This may largely influence the parents' quality of life.

Objective 2: To assess the level of depression in the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.

On Depression: Results revealed that Normal children's parents had a lower level of Depression than ADHD parents ($M = 10.25; 13.52; t = 3.250; p < .01$) and Autistic mental health parents ($M = 10.25, 16.77; t = 5.52; p < .01$). Autistic parents had a higher level of depression than ADHD mental health parents ($M = 16.77, 13.52; t = -3.25; p < .01$) which is significant at the .01 level as presented in Tables-4 and 5.

Our hypothesis regarding these variables was accepted. Previous studies found that caregivers of children with mental and behavioural disorders had a higher prevalence of depression and lower quality of life when compared with controls. There is a higher prevalence of depression or anxiety, and lower Quality of Life scores that comes with lower socioeconomic status, lower education, and being unemployed or financial problems among caregivers of individuals with mental and non-mental illness (Grover et. al., 2017) the study was consistent with previous findings. Caregivers of autistic children have higher level of depression than caregivers of ADHD (Gabra & Hashem, 2021). Numerous findings from earlier studies indicate that carers of children with ASD frequently and severely face affiliate and associative stigma (Wang, 1993). Rearing a child with ASD can be problematic for parents and parents with ASD and they may face more challenging problems than parents with ADHD.

Objective 3 was to assess the level of anxiety in the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.

On Anxiety: Results revealed that ADHD parents had a higher level of Anxiety than Autistic parents ($M=34.26$; 32.27 ; $t= 3.30$; $p < .01$ level) and Normal mental health parents ($M=34.26$, 21.97 ; $t= -4.875$; $p < .01$ level). Autistic parents had a higher level of anxiety than Normal mental health parents ($M= 32.27$; 21.97 ; $t= -5.175$; $p < .01$ level) significant at .01 level which were portrayed in as presented in Tables-4 and 5, and hypothesis 3 was accepted.

Studies have reported that parents who have a disabled child are under more stress, have higher levels of anxiety and have lower levels of self-confidence, higher stigma, and lower self-esteem and harmony in marriage than parents who do not have any disabled children (Cantwell, Muldoon & Gallegher 2015).

Objective 4 was to assess the level of burden in the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.

On Burden: Results revealed that ADHD parents had a lower level of Burden than Autistic parents ($M=25.500$, 28.750 ; $t= 3.25$; $p < .01$ level) and Normal mental health parents ($M=21.75$, 13.05 ; $t= 4.700$; $p < .01$ level). Autistic carer had a higher level of burden than Normal mental health parents ($M= 28.750$, 21.050 ; $t= 5.450$; $p < .01$ level) which is significant at the .01 level which was displayed in Tables 4 and 5. Therefore, our hypothesis for these variables is accepted.

Study had shown that caregivers of children with autism experience higher levels of burden and lower levels of quality of life on all the four domains of quality of life as compared to the caregivers of children without disability and findings indicate different effect as a consequence of different childhood conditions and also the need to provide adequate parental support when providing interventions to their children with disabilities (Geetanshi, 2021).

Objective 5 was to examine the relationship between burden, quality of life, depression, anxiety and coping strategies among three groups - the parents of

children with autism, parents of children with ADHD and parents of normal mentally healthy children.

On Problem focused coping: Results revealed that parents of Normal used higher problem focus coping than ADHD parents ($M = 18.30, 16.46; t = 3.90; p < .01$ level) and Autistic parents ($M = 18.30, 14.42; t = 4.12; p < .01$ level) ; and Autistic's parents scored higher on problem focused coping compared to ADHD parents ($M = 16.46, 14.42; t = 2.775; p < .01$ level) and presented in tables 4 and 5. Our hypothesis regarding these variables is again accepted.

Parents with disabled children often engage more in problem-focused coping (Twoy et. al. 2007). This may be often due to the increased demand of caregiving and the need to actively manage different stressors associated with their child's condition. Problem-focused coping comes with more positive mental health outcomes, there is possibility of a degree of mitigated risk for psychological maladjustment among Asian parents of children with ASD as compared to western European parents (Taylor and Stanton, 2007; Uchino 2006; Kawachi and Berkman 2001). There is not much literature that show why ADHD parents may have higher level of problem-focused coping than Autistic parents. Autism presents a broader and often more complex set of challenges, such as communication deficits, sensory sensitivities, and social interaction difficulties, which may feel less modifiable through direct intervention.

On Emotion focused coping: Results revealed that ADHD parents had a lower level of emotion focused coping than Autistic parents ($M = 16.68, 18.32; t = 3.80; p < .05$ level) but higher than Normal mental health parents ($M = 16.68, 14.32; t = 4.45; p < .05$ level). Autistic parents had a higher level of emotion focused coping than Normal mental health parents ($M = 34.32, 16.32; t = 5.65; p < .05$ level) significant at .05 level. The hypothesis regarding these variables is thus, partially accepted. Emotion-focused coping is usually adopted by parents of neurodivergent to deal with their feelings of sadness or frustration. They may face societal misunderstanding and judgment about their child's condition which can lead to focus on emotion focused-

coping mechanism to navigate feelings of shame or isolation. Twoy and colleagues (2007) found that parents of children with ASD depend largely on emotion-focused coping due to the high levels of stress and unpredictability associated with autism. This may lead to the use of more emotion-focused coping by parents of ASD as compared to parents of ADHD. 17.44; 15.42; 13.46

On Avoidance focused coping: Results revealed that ADHD parents had a lower level of avoidance focused coping than Autistic parents ($M=15.42$, 17.44; $t= 3.00$; $p < .01$ level) but higher than Normal mental health parents ($M=15.42$, 13.46; $t= 4.67$; $p < .05$ level). Autistic parents had a higher level of avoidance focused coping than Normal mental health parents ($M= 15.42$, 13.46; $t= 3.675$; $p < .01$ level) and their difference is significant at the .05 level. Our hypothesis regarding these variables is partially accepted. When dealing with children with disability, parents often adopt avoidance coping strategy (Lam et. al., 2002). Avoidance strategies like denial can help parents temporarily relieve them from being excessive concerned about their child's problem when immediate solutions are not met. This finding may explain why the level of avoidance is higher among ADHD and Autistic carer than normal mentally healthy children carer in our study. Smith and associates (2008) reported that parents of children with ASD frequently use avoidance coping strategy to manage chronic stress associated with caregiving, particularly in the absence of effective interventions.

Objective 6 : was to examine the relationship between burden, quality of life, depression, anxiety and coping strategies among three groups - the parents of children with autism, parents of children with ADHD and parents of normal mentally healthy children.

The Pearson's correlation was employed to examine the significant relationship between the Quality of Life, Depression, Anxiety, Problem Focused Coping, Emotion Focused Coping, Avoidance Focused Coping, and Burden, and the results were presented Table 6..

(1) Quality of Life in relation to Depression, Anxiety, Problem Focused Coping, Emotion Focused Coping, Avoidance Focused Coping and Burden. The quality of

life had a negative significant relation with depression ($r=-.430^{****}$; $p < .01$), anxiety ($r=-.435^{**}$; $p < .01$), Emotion focused coping ($r=-.453^{**}$; $p < .01$), Avoidance focused coping ($r=-.417^{**}$; $p < .01$) and Burden ($r=-.675^{**}$; $p < .01$) but positive relation with problem focused coping ($r=.424$; $p < .01$).

(2) Depression relation to Anxiety, Problem Focused Coping, Emotion Focused Coping, Avoidance Focused Coping, and Burden: Depression had a significant positive relation with Anxiety ($r=.250^{**}$; $p < .01$), Problem focused coping ($r=.712^{**}$; $p < .01$), Emotion focused coping ($r=.992^{**}$; $p < .01$), Avoidance focused coping ($r=.976^{**}$; $p < .01$) but a negative relation with Burden ($r=-.940^{**}$; $p < .01$).

(3) Anxiety in relation to Problem Focused Coping, Emotion Focused Coping, Avoidance Focused Coping, and Burden: Anxiety had a significant negative relation with Problem focused Coping ($r=-.513^{**}$; $p < .01$) but positive relation with Emotion focused coping ($r=.250^{**}$; $p < .01$), Avoidance focused coping ($r=.272^{**}$; $p < .01$) and Burden ($r=.314^{**}$; $p < .01$).

(4) Problem Focused Coping in Relation to Emotion Focused Coping, Avoidance Focused Coping, and Burden: Problem focused coping had a significant negative relation with Emotion focused coping ($r=-.328^{**}$; $p < .01$) and Avoidance focused coping ($r=-.373^{**}$; $p < .01$) but significant positive relation with Burden ($r=-.375^{**}$; $p < .01$).

(5) Emotion Focused Coping in relation to Avoidance Focused Coping, and Burden: Emotion focused coping had a significant negative relation with Avoidance focused coping ($r=-.474^{**}$; $p < .01$) but significant positive relation with Burden ($r=.434^{**}$; $p < .01$).

(6) Avoidance Focused Coping in Relation to Burden.

Avoidance focused coping had a significant positive relation with Burden ($r=.435^{**}$; $p < .01$). Avoidance focused coping allows parents to disengage from stressors temporarily, reducing their perception of burden. By avoiding problems or emotionally distancing themselves from children, they may experience short-term relief from caregiving demands.

To investigate the distress of the parents of neurodevelopmental disorder children, the mental illness effect on quality of life, depression, anxiety, coping and burden was done among the parents of ASD, ADHD and Normal children.

To find out the effect of ‘mental illness’ on quality of life, depression, anxiety, problem focused coping, emotion focused coping, avoidance focused coping and burden, a one-way ANOVA was employed as presented in Table-7. The results displayed the higher level of distress in parents of neurodevelopmental disorder parents for both ASD and ADHD than normal children’s parents on observed dependent variables as follow:

(i) Caring of Mental illness effect on Quality of Life: Results revealed that mental illness affects the quality of life by 36% ($F=185.347$; $\eta^2= 0.360$). Caring for children with mental illnesses such as Autism Spectrum Disorder (ASD) and Attention-Deficit/Hyperactivity Disorder (ADHD) can significantly impact parents' quality of life (QoL). Caregivers of children with Autism had a higher prevalence of Depression and lower Quality of life (Nanayakkara & Singharathana, 2022).

(ii) Caring of Mental illness effect on Depression: Results revealed that mental illness has a 44% effect on depression ($F=302.911$; $\eta^2= 0.438$). Parents and other family members of autistic individuals exhibited a higher rate of depression than parents of normal children (Attwood & Garnett, 2024). From the moment of diagnosis, caring for a child with a neurodevelopmental disorder elicits a wide range of negative emotions, including guilt, worthlessness, denial, and disappointment (Sharpley et. al., 1997).

(iii) Caring of Mental illness effect on Anxiety: Results revealed that mental illness affect anxiety by 33% ($F=279.183$; $\eta^2= 0.327$). The prevalence of anxiety and self-stigmatization were higher among mothers of autistic children (Alshaigi, 2020). Compared to parents of children without ADHD, parents of children with ADHD report higher levels of anxiety and depression symptoms (Ghanizadeh et. al., 2008).

Parents may often remain on alert about their child's safety, security, long-term outcomes like independence, career aspects or handle impulsive behaviour. This state of condition may affect parents which can lead them to develop stress and anxiety.

(iv) Caring of Mental illness effect on Problem Focused Coping: Results revealed that mental illness affect Problem focused coping by 41% ($F=253.934$; $\eta^2=0.413$). The efficiency and quantity of coping mechanisms a parent uses to manage the demands of stressors associated with children with ASD determines their ability to handle high levels of stress (Zablotsky et. al., 2013). Mothers of children with ASD reported the highest results in the use of planning, active coping, and reframing as problem-focused coping (Smith et. al., 2008). The increased use of problem-focused strategy decreases stress levels (Cappe et. al., 2011) and caregiver burden (Manor-Binyamini, 2011). Caregivers who employ problem-focused strategies experience more favourable outcomes and less carer pressure (Manor-Binyamini, 2011). Adopting problem-focused strategy may help the parents in dealing with challenges caused by their child's behavioural problem.

(v) Caring of Mental illness effect on Emotion Focused Coping: Results revealed that mental illness has a 36% effect on Emotion focused coping ($F=351.206$; $\eta^2=0.357$). Some studies found that emotion-focused coping was more frequently used by mothers of children with ASD (Salas et. al., 2017; Hastings et. al., 2005). Parents of ASD used religious behaviours as emotion-focused coping strategy (Gona et. al., 2016). Emotion-focused coping strategy including social support, finding help from supernatural power are common coping strategies among Chinese parents (Lam & Mackenzie, 2002).

(vi) Caring of Mental illness effect on Avoidance Focused Coping: Results revealed that mental illness has a 39% effect on Avoidance focused coping ($F=222.539$; $\eta^2=0.392$). The most common strategy adopted by parents with ADHD seems to be avoidance-oriented coping (Craig et. al., 2020). Some studies have also claimed that parents of children with ASD used avoidance strategies more than that of parents with neurotypical children (Vernhet et. al., 2019).

(vii) Caring of Mental illness effect on Burden: Results revealed that mental illness affect Burden by 46% ($F=185.297$; $\eta^2= 0.460$). The burden experienced by carers of children with ASD and ADHD is quite severe and often goes unnoticed (Murphy et. al., 2018). According to a study on parents of recently diagnosed children with autism spectrum disorders (ASD), social relatedness deficiencies might be a major burden for parents (Davis & Carter, 2008). Parents with ASD and ADHD are more likely to experience psychological, social, and physical issues than parents of asymptomatic children (Lee et. al., 2013).

In brief, the present study clearly highlighted the Quality of life of the parents of children with neurodevelopment disorder as they had showed lower quality of life when compare with parent of parents of normal children. Parents of children with neurodevelopment disorder were also assessed on their distress (depression, anxiety and burden) which confirmed higher psychological distress comparing with parent of normal children. For further, confirmation of their distress level by assessing their coping strategies. Results revealed parent of neurological disorders (both parents of ASD and ADHD) employed avoidance and emotional focus coping which portrait their distress situation when compare with parent of normal children. The results of the study highlighted the distress of the parents of neurological disorders, and their need of psychological cares, support and intervention which rarely got attention of researchers.

SUMMARY AND CONCLUSION

The results of the present study can be summarized in accordance with the hypotheses statement as follows:

The first objective of the study examines the significant difference between the groups (parents of ADHD children, parents of Autistic children and parents of normal mentally healthy children) on quality of life, depression, anxiety, problem-focused coping strategy, emotion- focused coping, avoidance-focused coping strategy and burden. Our first hypothesis is partially accepted.

In the quality of life, parents of normal mentally healthy children scored higher than parents of ADHD children and parents of Autistic children. Parents of ADHD children scored higher than Autistic parents. Parents of ADHD and ASD faces many physical, psychological and social challenges in dealing with their child's behavioural problem. Parents with children who have ADHD and ASD are more likely to struggle to solve problems as a family and make decisions collectively. Children with ADHD exhibit demanding, moody, and uncooperative behaviour, which can be difficult for parents to manage and have an impact on parents' behaviour and adjustment. Depressive symptoms are also common among parents of ADHD and ASD. All these factors can lead to lower quality of life as compared to parents of normal mentally healthy children. When comparing ADHD and ASD, ADHD is widely recognized and often has more structured intervention. But autism has severe challenges in communication issue which limit access to effective therapies. Communication difficulties can be stressful for parents of ASD who find it difficult to comprehend their child's needs and desires (Marriott et. al., 2022).

In Depression, parents of autistic children scored higher than parents of ADHD children and normal mentally healthy children's parents. ADHD child caring parents scored higher than carers of normal mentally healthy children. Several findings found that parents of children with ASD frequently and severely face affiliate and associative stigma (Wang, 1993). Rearing a child with ASD and ADHD can be a great problem for parents and parents with ASD children may face more challenging problems than parents with ADHD children.

In Anxiety, parents of children with ADHD experience higher anxiety levels than parents of children with ASD and those of children with normal mentally healthy children. Parents of children with ASD also have higher anxiety than those of normal mentally healthy children. Parenting a child with disabilities, including ASD or ADHD, is linked to increased stress, anxiety, stigma, marital disharmony, and lower self-esteem. While ASD caregivers generally face worse stigma, burden, and quality of life. Some research findings suggests that ADHD caregivers, particularly mothers, report higher anxiety levels than those caring for children with ASD or intellectual disabilities.

In problem-focused coping, parents of children with ADHD exhibit higher levels of problem-focused coping compared to those of children with ASD and normal mentally healthy children. Parents of children with ASD also use more problem-focused coping than those of normal mentally healthy children. Problem-focused coping is commonly employed by parents of children with disabilities due to the demands of caregiving and the need to manage stressors. This coping strategy is associated with better mental health outcomes and potentially mitigates psychological risks among Asian parents compared to Western counterparts. ADHD caregivers may use more problem-focused coping as ADHD-related challenges are perceived as more modifiable than the complex, pervasive issues associated with autism.

In emotion-focused coping, ADHD parents use less emotion-focused coping than autistic parents but more than parents of individuals with normal mental health. Specifically, autistic parents exhibit the highest levels of emotion-focused coping, followed by ADHD parents, and then normal mental health parents. Emotion-focused coping is commonly used by parents of neurodivergent children to manage feelings of sadness, frustration, and societal judgment, helping them navigate the emotional challenges associated with caregiving. Emotion-focused coping, such as seeking emotional/social support from friends or family, can help mitigate the negative emotional impact of challenges caused by their child behavioural problems.

In avoidance-focused coping, ADHD carers exhibited lower levels of avoidance-focused coping than autistic parents but higher levels than parents of individuals with normal mental health. Autistic parents reported the highest levels of avoidance-focused coping, followed by ADHD parents and normal mental health parents. Parents of children with disabilities often adopt avoidance strategies, such as denial, to manage the emotional burden when immediate solutions are unavailable. This may explain the higher levels of avoidance-focused coping observed among ADHD and autistic parents compared to parents of children with typical mental health. Parents of children with ASD frequently use avoidance coping strategies to manage chronic stress associated with caregiving, particularly in the absence of effective interventions.

In burden, ADHD parents experience a lower level of burden than autistic parents but a higher level than parents of children with normal mental health. Autistic parents reported the highest levels of burden, followed by ADHD parents, and then normal mental health parents. Children with ASD often have more diverse and intense needs, including difficulties with communication, social interaction, and repetitive behaviours. They may also have sensory sensitivities or require more extensive assistance with daily activities compared to children with ADHD and normal mentally healthy children.

The second objective of the study examines the correlation between dependent variables (quality of life, depression, anxiety, problem-focused coping, emotion-focused coping, avoidant- focused coping and burden).

Quality of Life has a significant relationship with Depression, Anxiety, Problem Focused Coping, Emotion Focused Coping, Avoidance Focused Coping and Burden. The quality of life had a negative significant relation with depression and anxiety with moderate correlation. The parents/caregivers of ASD and ADHD often face significant challenges related to their child's physical, emotional and social demands. The constant demands of caregiving, uncertainty about child's future, and difficulty in managing challenging behaviors can all increase parent's level of depression and anxiety, and these can lower their quality of life. Quality of life has a significant negative correlation with Problem-focused coping, Emotion-focused coping and Avoidance focused coping. For parents, use of one coping strategy may not be enough to deal with their child everyday behaviour. Quality of life has significant positive correlation with burden. Some moderating variables like social support, religiosity among parents can buffer the stress associated with caregiving burdens and may contribute positively to parent's quality of life.

Depression had a significant positive relationship with Anxiety, Problem focused coping, Emotion focused coping, and Avoidance focused coping but negative relation with Burden. The constant demands of caregiving, uncertainty about a child's future, and difficulty in managing challenging behaviors can all contribute to anxiety. A study in the *Journal of Autism and Developmental Disorders* (2020) found that high levels of anxiety were predictive of depressive symptoms in parents of children with ASD, suggesting that anxiety often precedes and exacerbates depression. Problem-

focused coping is typically associated with positive outcomes, its effectiveness may be limited in cases where challenges (e.g., autism-related behaviours) are less modifiable. Similarly, reliance on emotion-focused and avoidance coping might provide short-term relief but may exacerbate long-term emotional distress, perpetuating depression. Depression has negative significant relationship with burden. Stressors associated with raising a child with autism and ADHD include the child's communication difficulties, unstable and aggressive behaviours, self-care limitations, and lack of respite due to the difficulty in finding acceptable substitute caregivers (Gabra & Hashem, 2021). This may add additional burden to the parents.

Anxiety had a significant positive relation with Problem focused Coping, Emotion focused coping, Avoidance focused coping but negative relation with Burden. Although problem-focused coping strategy lower stress levels (Cappe et. al., 2011), the caregiving demands of children with ASD and ADHD are ongoing and unpredictable, which can sustain high anxiety levels. Maladaptive emotion-focused strategies, such as excessive worry or rumination, can restrict parents in cycles of negative thinking without leading to solutions. This can reinforce feelings of anxiety. Parents using avoidance-oriented coping may withdraw from social networks or avoid seeking professional help, which can limit access to emotional and practical support. They may miss opportunities for advice, help and validation. Majority of the participants in our study has monthly income of 15001-20000. Financial constraints may hinder parents from seeking professional support. All these factors can increase anxiety level among parents. Anxiety has significant negative relation with Burden. Confounding/moderating variables like mother and father's religiousness can also affect the relationship between anxiety and burden.

Problem-focused Coping had a significant positive relation with Emotion focused coping, Avoidance focused coping. Parents of children with ASD and ADHD face complex, multifaceted stressors that require both problem-focused (practical) and emotion-oriented (emotional regulation) coping strategies. A parent may actively seek therapies or support for their child (problem-focused coping) while also managing feelings of frustration or grief (emotion-oriented coping). Some others can be uncontrollable (prompting avoidance). Parents might use all these strategies simultaneously to handle different aspects of their stress. Problem-focused coping

had negative significant relationship with burden. Problem-focused coping involves actively addressing stressors, such as seeking therapies, implementing behavioural interventions, or organizing structured routines for the child. These efforts may help reduce caregiving demands, leading to a lower sense of burden.

Emotion Focused Coping had a significant positive relation with Avoidance focused coping but a significant negative relation with Burden. The intense emotional burden of raising a child with ASD or ADHD can lead parents to adopt avoidance strategies to escape overwhelming feelings. Emotion-focused coping, such as venting or self-soothing, may coexist with avoidance to alleviate emotional distress. This coexistence may strengthen the relationship between emotion-focused coping and avoidance-oriented coping in a positive way. Emotion-Oriented Coping had a significant negative relation with Burden. The emotion-focused coping may seem to predispose the caregiver to an increase burden and distress.

Avoidance Focused Coping had a significant negative relation with Burden. Avoidance focused coping allows parents to disengage from stressors temporarily, reducing their perception of burden. By avoiding problems or emotionally distancing themselves from children, they may experience short-term relief from caregiving demands.

The third objective of the study examine the effect of caring of mental illness on Quality of life, depression, anxiety, problem-focused coping, emotion-focused coping, avoidance-focused coping and burden.

Caring of mental illness had a significant effect on quality of life. Parents with ASD and ADHD are more likely to face challenges related to the physical, emotional, educational and social demands of their child. Children with ADHD exhibit demanding, moody, and uncooperative behaviour, while children with Autism face severe communication issues. This can be difficult for parents to manage and may have an effect on parents' behaviour and adjustment leading to lower quality of life.

Caring of mental illness also had significant effect on Depression and Anxiety. Caring for a child with a neurodevelopmental disorder elicits a wide range of negative emotions, including guilt, worthlessness, denial, and disappointment. Parents may often remain on alert about their child's safety, security, long-term

outcomes like independence, career aspects or handle impulsive behaviour. All these factors may affect their mental health which can lead to depression and anxiety.

Caring of mental illness also had significant effect on problem-focused coping, emotion-focused coping and avoidance coping. Many parents adopt multiple coping strategies, some research has also found mothers to use more emotion-focused oriented type, while avoidance oriented may be more common among parents of ADHD. The use of coping strategy may depend on the child's severity of the symptoms, family, social and religious support. Emotion-focused coping like seeking social help, help from religious people or divine beings may be common especially in Mizo context. Parents may adopt multiple coping strategies in dealing with the diverse and complex nature of children with ASD and ADHD.

Caring of mental illness had a significant effect on Burden. Parenting a child with autism and ADHD involve stressors like child's communication difficulties, unpredictable and aggressive behaviours, self-care limits, and lack of respite due to the difficulty in finding suitable substitute caregivers. All these can be problematic for parents which may lead to increase burden when compared with parents of normal mentally healthy children.

LIMITATIONS OF THE STUDY

The present study acknowledges several limitations which need to be addressed but are not able to be included in this study due to time constraints. The sample size used in the study was not large enough to effectively represent the targeted population which may, in other words, be specified as not big enough to generalize to the whole targeted population.

Another limitation of the study is that a more systematic and comprehensive empirical cross-examination of parents of children with other neurodevelopmental disorder responses such as conducting qualitative interviews, longitudinal studies, or employing mixed-methods approaches to gain a more in-depth understanding of the issue. Parents expect their child to be born healthy but the diagnosis of a child as disabled during infancy or in later stages takes a heavy toll on his/her happiness and well-being. Diagnosis can precipitate a range of psychological responses in parents, thereby, constituting a crisis for mothers and demanding extraordinary psychological

adjustment. In India, the majority of such persons have traditionally been cared for by their families. In today's modern society, this home-based care has resulted in many adverse consequences. Factors such as changes in the social system (e.g. breaking up of joint families) and the economic system (e.g. unemployment, inflation etc.) have contributed to psychological distress that parents of special children experience. Parents of children with ADHD and Autism may find themselves burdened with a lifelong responsibility of caring for their children and diminished attention to their own health. Other than this, lack of knowledge about disorder, lack of treatment, and sometimes even though treatment is available, it is unaffordable, thus, aggravating the stress levels. This leads to deterioration of quality of life of parents in different domains such as economic, social, educational, and psychological.

Collecting data from parents can indeed present several challenges. They were reluctant to share information or participate in data collection activities due to low acceptance of their disability. Family care and various expected tasks from the caregivers for these children in managing their disorder is of great importance. Also, many researchers had some personal experiences in dealing with the needs of family caregivers of children with ADHD and Autism. The families always have questions about their child's problem, the course and symptoms of the disease, drugs and the general method of caring for these children. So far, no studies have assessed the needs of caregivers for these children in Mizoram and evaluating the needs of caregivers.

SUGGESTIONS FOR FURTHER STUDIES

Many children are born with a disability because of genetic, environmental or unexplained reasons. Families who have a child with disability face emotional and economic hardships. Parents and siblings need to express their disappointment, anger and frustrations and learn to accept and respect the child for his/her own character. Communities can help to provide access to transportation, jobs and social activities and learn to know the child by his character, personality and skills.

- The sample size can be increased for generalizing the results. Bigger samples and a wider range of participants covering other neurodevelopmental disorder to have more information for understanding their issues in Mizoram.

- This research focused on parents of children with Autism and ADHD. Further studies may include others groups of disability to strengthen the findings.
- Only indigenous Mizos were selected for the present study, it does not include mixed parents which could reveal a better understanding of the real situation.
- There is a need for more research on the psychosocial well-being of the parents/caregiver of children with disability. It will help to capture the diversity of experiences and challenges faced by caregivers and their specific needs.

Significance of the study:

Many studies have been conducted to determine the quality of life and burden of caregivers but there is a paucity of studies providing the socio-demographic predictors of quality of life of principal caregivers of ADHD and Autism. There is no significant research towards caregiver burden among caregivers of special needs children in Mizoram. The main intention for conducting this research is to understand the in-depth reality of caregiver issues, mental health and quality of life among caregivers.

Understanding the parent's emotional condition is of utmost importance for the management of a child with disability as well as improving for psychological wellbeing. Providing adequate support to parents of disabled children will minimize the potential risks of developing psychological disorders and improve their wellbeing and self-efficacy which is a critical component to enhance the care provided to disabled children and to ensure a better quality of life.

This study focuses the need of intervention, psycho-education, psychotherapies and psychiatric treatment to reduce depression and anxiety, to enhance the quality of life and the coping strategies in the parents of disabled children.

The data from these studies can be used for diagnosis and treatment of specific programs to reduce psychiatric co-morbidity in the parents of disabled children.

The present findings are relevant to the Clinical and Counselling Psychology Professionals, Psychiatrist, Paediatrician, Psychiatric Social Worker, Special

Educator, Occupational Therapist, Speech and Language Pathologist, Sign Language Teacher and School Teacher effectively address various issues faced by parents.

Establishing collaborative group as Physicians, Nursing Staff and other professionals is very important to play important role with caregiver and pay more attention for those children and their family caregiver.

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