THERAPEUTIC EFFICACY OF "INTEGRATIVE, MULTICOMPONENT, GROUP-BASED COGNITIVE BEHAVIORAL THERAPY" FOR CAREGIVERS OF CHILDREN AND ADOLESCENTS WITH AUTISM SPECTRUM DISORDER



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A thesis submitted in fulfillment of the requirements for the award of the degree of Masters of Science (Clinical Psychology)

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To my beloved parents, brother and sister

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ABSTRACT

The present study was focused on investigating the therapeutic efficacy of integrative, multicomponent, group-based cognitive behavioral therapy (CBT) for caregiver burden, coping strategies, and quality of life among caregivers of children and adolescents with autism spectrum disorder (ASD). The study included two phases: phase 1 involved the screening of participants, whereas phase 2 was an outcome study. In phase 1, N=52 caregivers, n=6 fathers, and n=46 mothers, aged 26-60 years old of children and adolescents under 18 years with ASD were screened. The sample was recruited from public and private autism centers, hospitals, and special education institutes of Islamabad. Nonprobability purposive sampling technique was used in the study. A demographic information sheet, Caregiver Burden Inventory (CBI), Coping Strategies Scale for Primary Informal Caregivers (CSSPIC), and WHO Quality of Life Scale-Brief (WHOQOL-Brief) were used to collect data. In phase 2, N=9 mothers aged 31-54 years of children and adolescents with ASD who were screened in phase 1 received the intervention. Pre and post assessments were carried out. The results revealed significant reduction in overall caregiver burden (time dependence, developmental, and emotional burden), the usage of passive coping strategies, and a significant improvement in overall quality of life (social relationships, and environmental quality of life) at post assessment level. Whereas results were nonsignificant for other subdomains. The present study provides evidence that integrative, multicomponent, group-based CBT is an effective intervention for caregivers of children and adolescents with ASD and highlights the importance of incorporating such psychotherapeutic interventions in routine support services to support caregivers in Pakistan and across the globe.

Keywords: Caregiver Burden, Coping Strategies, Quality of Life, Autism Spectrum Disorder

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LIST OF ABBREVIATIONS

APA - American Psychiatric Association

ASD - Autism Spectrum Disorder

CBI - Caregiver Burden Inventory

CBT - Cognitive Behavioral Therapy

CSSPIC - Coping Strategies Scale for Primary Informal Caregivers

QoL - Quality of Life

WHO - World Health Organization

WHOQOL-Brief - WHO Quality of Life Scale-Brief

f - Frequency

k - Number of items

M - Mean

N - Sample Size

p - Level of significance

SD - Standard Deviation

α - Cronbach's Alpha Reliability

% - Percentage

 η^2 - Eta square (effect size)

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Introduction

When it comes to mental health, neurodevelopmental disorders, specifically autism spectrum disorder (ASD) have a global impact, which affects not only the individuals diagnosed, but also their caregivers (Torres et al., 2023). In the past few decades, there has been a notable rise in the prevalence of ASD (McConkey et al., 2019), with a global median prevalence of 100 per 10,000 individuals (Zeidan et al., 2022). ASD is becoming more common throughout Asia, with East Asia having the highest prevalence (0.51% 95% CI: 0.06–4.22%), followed by South Asia (0.31% 95% CI: 0.14–0.65%), where Pakistan is located (Qiu et al., 2020). In 2020, the Pakistan Autism Society estimated that 350,000 children in Pakistan have ASD (Khalid et al., 2021). It is evident from these statistics that a large segment of the population is facing the challenge of providing care to individuals with ASD (Pandey & Sharma, 2018).

The caregiver burden among caregivers of autistic children and adolescents, is significantly increased by autism-related behaviors (Cetinbakis et al., 2020).

Furthermore, a moderate to severe range of caregiver burden is experienced by these caregivers (Pandey & Sharma, 2018). Moreover, in comparison to caregivers of children and adolescents without autism spectrum disorder, caregivers of autistic children and adolescents consistently experience higher psychological distress and caregiver burden (Iovino et al., 2021).

A child's diagnosis of autism not only completely changes the child's life, but it also makes significant changes in the lives of caregivers (Hansen et al., 2018; Mercado et al., 2021). ASD has a wide range of effects on caregiver's life, including

leisure activities, finances, caregiver's physical and mental health, family dynamics, marriage, and relationships with friends, neighbors, and family (Sonido et al., 2022). However, coping with and overcoming the problems that arise when caring for autistic children and adolescents can enrich families and relationships (Abdul-Hameed, 2021).

Due to heightened psychological distress and caregiver burden, the quality of life of caregivers of autistic children and adolescents is negatively impacted (Marsack-Topolewski & Church, 2019). Furthermore, the mental health of caregivers also suffers as a result of the high degree of caregiver burden, leading to depression and anxiety (Pandey & Sharma, 2018).

Existing research highlights the significance of caregiver burden-reduction treatments due to the possible influence of caregiver's well-being on caregiving and the resulting decrease in caregiver burden (Osborne et al., 2008; Giallo et al., 2013; Silaule et al., 2023). Therefore, the current study is focused on investigating the therapeutic efficacy of integrative, multicomponent, group-based cognitive behavioral therapy (CBT) for caregiver burden, coping strategies, and quality of life among caregivers of children and adolescents with autism spectrum disorder.

1.1 Caregiver Burden

Caregiver burden refers to the level of multifaceted stress that caregivers endure because of taking care of a loved one or family member over an extended period (Liu et al., 2020). Caregiver burden was defined by Stucki and Mulvey (2000) as the strain and duties that come with caring for a family member who has a chronic illness, a disability, or old age. Put more simply, stress along with additional psychological symptoms that family members as well as other informal caregivers go

through while caring for people who have physical or mental illnesses, disabilities, or disorders (APA Dictionary of Psychology, 2018).

Caregiver burden is further described by Zarit and Femia (2008) as the degree to which caregivers felt that taking care of their relative had negatively impacted their emotional, physical, social, and financial well-being. To elaborate, Collins et al. (1994, as cited in Given & Given, 2016) defined caregiver burden as a combination of negative outcomes from caregiving tasks, including psychological distress, health problems, financial and social stress, strained family relationships, and feelings of hopelessness. According to Marvardi et al. (2005), it is the culmination of the financial, social, psychological, and physical strains associated with providing care.

According to Adelman et al. (2014), caregiver burden is a condition that frequently develops in those who are caring for people suffering from chronic illnesses. Furthermore, Zarit and Femia (2008) argued that caregiver burden resulted from a specific, subjective narrative process. According to Nijboer et al. (2000), caregiving is a multifaceted concept that encompasses both positive as well as negative aspects of caregiving. Previous research backs up the notion that caregiver burden's multifaceted nature makes it a complex concept (Savundranayagam et al., 2010; Bastawrous, 2013).

According to the most recent, World Health Organization's (2022)

International Statistical Classification of Diseases and Related Health Problems (11th ed.; ICD-11) diagnostic criteria and the American Psychiatric Association's (2022)

Diagnostic and Statistical Manual of Mental Disorders (5th ed., text rev.; DSM-5-TR), caregiver burden is not considered a clinically diagnosable psychological problem. Yet different degrees of psychopathology tend to be present in people who

have a high caregiver burden. Specific recognizable symptoms or diagnostic criteria differ widely across the available research, as in itself caregiver burden does not constitute a diagnosable disorder (Schaffer, 2022).

Caregiver burden comprises five main elements: *psychological burden*, which may involve anger, irritability, symptoms of depression, trouble with concentration, sadness and grief; *loss of intimacy* within one's relations; *social withdrawal* along with a feeling of loneliness; *physical burden* in caregiving, that may involve exhaustion, tiredness, along with sleep problems; and *financial burden*, that may involve losing a job, increased stress regarding finances when providing care, and trouble to maintain work responsibility (Krishnan & Sood, 2017).

Unlike the components of caregiver burden defined by Krisnan and Sood (2017), Marvardi and colleagues (2005) described five major components of caregiver burden: *developmental burden*, involves elements of social disengagement along with a feeling of discontent regarding their place across their developing lifespan; *time-dependent burden*, denotes the total time that caregivers give to their care receivers; *social burden*, comprises sentiments of relationship discontent, relationship issues, and lower confidence in social or workplace settings; *physical burden*, may involve tiredness and muscular strain as well as sleep problems and physical health issues; and *emotional burden*, encompasses a sense of shame, contempt, as well as disdain towards their care receiver.

Truzzi et al. (2012) provide another description of caregiver burden. They describe caregiver burden in three different components: *emotional exhaustion*, that involves the depletion of emotional reserves and general lack of energy in an individual; *depersonalization*, refers to the emergence of an apathetic relationship

between the caregiver and the patient; and *decreased personal accomplishment*, that is characterized by the inclination to view one's efforts as unsatisfactory and inefficient, both inside as well as outside the context of caregiving.

A possible reason behind the substantial heterogeneity in caregiver burden conceptualizations might be the fact that caregiver burden may occur in the context of many kinds of care-recipient disorders. Each medical illness or disorder, including dementia, autism, cancer, traumatic brain injuries, stroke, and a lot more, tends to pose very distinct challenges to caregivers. Thus, widely disparate descriptions of caregiver burden have resulted from attempts to classify common phenomena shared by caregivers of people with distinct psychological and medical conditions (Adelman et al., 2014). Despite the way it is defined and categorized, caregiver burden is clearly a multidimensional phenomenon which affects many aspects of the life of caregivers, not only delivering care (Schaffer, 2022).

1.2 Coping Strategies

Coping is essentially an attempt to reduce the discomfort brought on by unpleasant situations in life (Mouzon, 2022). According to Compas et al. (2017), coping is an ongoing set of behavioral, emotional, and cognitive alterations that people undertake in the face of stressors and obstacles in life, indicating continuous attempts to adapt and sustain wellbeing. According to Lazarus and Folkman (1984, as cited in Folkman, 2011), coping is a procedure that takes place in the context of a circumstance or event that seems important to the individual and to be more demanding than the person's capacity for dealing.

A coping strategy is defined as an act, a series of acts, or an approach to thinking which is utilized to cope with a stressful or upsetting situation or alter

one's reaction to it (APA Dictionary of Psychology, 2018). Coping strategies, as described by Lazarus and Folkman (1984, as cited in Budimir et al., 2021), are thoughts and behaviors that people adopt to handle both the external and internal demands of stressful situations. This concept gained widespread acceptance (Tennen et al., 2000). Aldwin et al. (2018) defined coping strategies as adaptations that people adopt in the face of stressful situations, including cognitive appraisals, regulating emotions, and behavioral responses. Furthermore, coping strategies were defined by Skinner et al. (2003) as adaptive functioning, which represents effective methods for handling stress and getting desirable results. In addition, coping strategies are described by Carver and Connor-Smith (2010) as regulatory mechanisms, such as attempts to govern thoughts, emotions, and behaviors, that people use to manage stressors and their emotional reactions.

Coping strategies encompass a wide range of reactions, reflecting the multidimensional character of the stressors they seek to manage. Recent empirical and conceptual research has highlighted around twelve basic families of coping, with each one serving numerous functions in managing stress. Notably, six families including information-seeking, self-comforting, problem-solving, accommodation, support-seeking and negotiation are considered adaptive. Whereas the other six namely social isolation, helplessness, submission, escape, opposition, and delegation are considered maladaptive (Skinner & Zimmer-Gembeck, 2016).

Information-seeking is described as acquiring additional knowledge regarding the difficult circumstances to manage stress. Self-comforting on the other hand involves proactively dealing with stress by engaging in self-care and by regulating emotions. Problem-solving is the active pursuit of effective stress-reduction strategies. Accommodation is described as flexible adjustments to difficult circumstances in

order to deal with them. *Support-seeking* involves seeking help and support from people in order to deal with the stressors. Additionally, *negotiation* entails balancing priorities and restrictions imposed by others to find a common ground and manage stressful circumstances (Skinner & Zimmer-Gembeck, 2016).

Social isolation involves removing oneself from social interactions in stressful situations as a self-defense tactic. *Helplessness* is described as giving up on distressing situations which are perceived as out of one's control. *Submission* is regarded as resignation to distressing situations or circumstances leading to a higher chance of experiencing depression. *Escape* entails turning away from tense circumstances in the pursuit of peace. Additionally, *opposition* encompasses fighting off stressors, that may have an association with psychopathology. *Delegation* on the other hand is described as stepping back and delegating the responsibility of dealing with stressful situations on other people (Skinner & Zimmer-Gembeck, 2016).

1.3 Quality of Life

World health organization WHO (1995, as cited in Cai et al., 2021) defined quality of life (QoL) in terms of the way people view their position in life with regard to their standards, objectives, concerns, and expectations, along with the social and cultural context where they reside. Moreover, Ferrans and Powers (1985, as cited in Kimura & Silva, 2009) defined QoL as the degree to which people believe that their social, emotional, and physical health are optimum and rewarding, reflecting their capacity to participate in meaningful pursuits and relations.

Diener (1985, as cited in Theofilou, 2013) characterized QoL as a person's means of gauging the goodness of numerous areas of their lives. These judgements consider the temperament of a person, emotional reactions to life events, feelings of

contentment and fulfillment, as well as satisfaction with a his/her professional and social life. QoL was described by Huppert and So (2013) as the degree to which people experience eudemonic well-being, which is marked by a search for personal development and self-realization along with feelings of fulfillment, meaning, and purpose in life.

Cummins (2015) considered QoL as a multifaceted concept that includes areas of functioning in the psychological, social, physical, and environmental domains as well as objective measures of well-being and subjective perceptions of life satisfaction. Feinstein (1987, as cited in Moons et al., 2006) state that QoL frequently appears to be a broad concept that encompasses a range of elements, including, perceptions, happiness, life situations, behavior, lifestyle, health status, symptoms, functioning, etc. Similarly, Kagawa-Singer et al. (2010), argued that QoL is a multifaceted, subjective feeling of well-being that is culturally formed as people look for safety and security, integrity and purpose in life, and a feeling of belonging within their social circle.

Quality of life is divided into four domains: social relationships,
psychological, physical, and environmental health. The domain of social
relationships encompasses characteristics of a person's sexual life, personal relations,
and the accessibility of support from others. Within the psychological domain,
involves individual's self-perception, existence of negative cognitions, development
of positive attitudes, level of self-esteem, cognitive abilities such as memory and
learning, spiritual or religious convictions, and mental health. The domain of physical
health incorporates several facets of a person's bodily functioning, including mobility,
everyday activities, energy levels, feelings of pain, and sleep quality. The domain of
environmental health includes a person's financial resources, a sense of safety and

security, availability of medical and social services, the overall condition of the physical surroundings where they live, avenues for personal growth and learning, entertainment options, exposure to environmental factors such as noise and air pollution, and the accessibility of transportation (Nejat et al., 2006).

The interplay between caregiver burden, coping strategies, and quality of life has been illuminated through several empirical investigations. Caregivers of children and adolescents who have moderate to severe autistic symptoms report a high caregiver burden, which negatively impacts their quality of life (Marsack-Topolewski & Church, 2019; Patel et al., 2022). Moreover, caregivers' coping strategies, particularly seeking emotional support, planful problem-solving, and positive reappraisal are associated with decreased caregiver burden and increased quality of life (Li et al., 2020; Wang et al., 2022).

1.4 Integrative, Multicomponent, Group-based Cognitive Behavioral Therapy (CBT)

Integrative, Multi-component, Group-based Cognitive Behavior Therapy (CBT) was developed by Daniel Robert Schaffer (2022). It is an intervention for the stress, strain, and burden that the primary informal caregivers of people who require significant support because of any sickness or disorder endure due to the psychological, physical, financial and social demands of caregiving. The goal of this manualized group-based CBT was to provide an integrated, multi-component approach to treatment.

The program encompassed the fundamental principles of cognitive behavioral therapy (CBT), including identifying negative automatic thoughts, challenging, and restructuring them. Along with pure CBT techniques, it encompassed further

intervention techniques like education on the stress and burden associated with the responsibilities of caregiving, supportive interventions, process-oriented interventions, coping strategies including relaxation techniques along with mindfulness as well as behavioral activation (Schaffer, 2022). By offering a multicomponent and group-based intervention, this therapy had been created for providing optimal care in an economical way (Acton & Kang, 2001; Tucker & Oei, 2007; Brown et al., 2011).

The above-mentioned intervention involves eight weekly group sessions, each spanning an hour. The group facilitator encourages open conversation and group support during all sessions to create a supporting and engaging group atmosphere (Röhrle & Strouse, 2008; Beckner et al., 2010; Thrasher et al., 2010). It alleviates caregiver burden, symptoms of depression and anxiety, and role captivity in primary informal caregivers. The strategies and techniques used in this intervention improve the distress tolerance of caregivers and their feelings of independence or agency, lowering their perceived feelings of role captivity and lowering overall caregiver burden (Schaffer, 2022).

1.5 Theoretical Background

1.5.1 Caregiver Burden

Stress Process Model. Stress process model (SPM) which is a popular theoretical framework outlining the connections among stressors, resources, and psychological well-being in the context of caregiving was developed by Pearlin (1990, as cited in Wang et al., 2023). According to this model, the occurrence of a potentially harmful environmental demand i.e., primary objective stressor has an instantaneous effect on the life of caregivers i.e., primary subjective stressor. This

impact might take the form of a sense of overburden or of losing the valued aspects of caregiver and care recipient's relationship. This immediate effect may spread to other spheres of life (secondary role stressors), such as disrupting work life or causing friction within the family, thus raising the risk of poor adaptation (for example, adverse physical or mental health consequences). On the contrary, the primary stressors may be contained by resources like a person's coping mechanisms, which lessens their effect on other roles, relationships, and general wellbeing.

According to SPM, people use two methods to deal with stressors: *coping* and *cognitive appraisal*. *Primary* and *secondary appraisal* are the two components of cognitive appraisal. *Primary appraisal* analyses how stressors are seen as advantageous or harmful, whereas *secondary appraisal* determines what steps an individual may take to avoid damage and alter the likelihood of benefits. People assess whether an environmental experience contributes to their pleasure through cognitive appraisal. *Coping* serves two purposes: first, it regulates stress feelings through *emotion-based coping*, and second, it involves *problem-based coping*, which involves altering problematic environmental interactions that produce distress (Pearlin, 1990, as cited in Wang et al., 2023).

Folkman (2008, as cited in Wang et al., 2023) introduced *meaning-based* and *positive emotional coping* in the revised theory of the stress process, which assumes that if solutions fail, meaning-based coping activates. It may assist people in stimulating re-appraisal and producing positive emotions. These evaluations and emotions may impact the stress process by gathering coping resources as well as offering the needed motivation, maintaining problem-based coping over the long run. Gathering coping resources is the act of gaining social support when coping with stress.

Reconceptualized Uncertainty in Illness Theory. According to Mishel's (2014) reconceptualized uncertainty in illness theory (RUIT), uncertainty is the inability to interpret occurrences associated with illness, including the inability to assign a precise value or make reliable predictions about the course of events. Five aspects are involved in uncertainty in the RUIT model i.e., *antecedents, appraisal*, *coping, self-organization*, and *probabilistic thinking*.

The first component, *antecedent* of uncertainty in the RUIT, the stimulus frame, describes illness events that are prone to triggering uncertainties when they are severe, unexpected, and have unclear consequences for the future. Because caregivers are often unsure of how to deal with the care recipient's symptoms, they can be a source of uncertainty. The second component of the stimuli frame indicates a lack of awareness of the illness course, available treatments, and rules governing the delivery of healthcare services. The third component of the stimuli framework is a conception of structure providers, who provide information as well as social support (Mishel, 2014).

The second component of the RUIT is *appraisal* of an illness event as an opportunity or a threat and the and third component is coping with the event. Appraisals of danger or threat are frequently accompanied by wishful thinking, avoidance, and other unhealthy coping mechanisms. The final two RUIT components (i.e., *self-organization* and *probabilistic thinking*) occur when appraisals and coping mechanisms are adaptive. Reformulating into a new sense of order is a part of *self-organization*. Developing a belief in a conditional world—that is, adapting to uncertainty—is a component of *probabilistic thinking* (Mishel, 2014).

1.5.2 Coping Strategies

Transactional Theory of Stress and Coping. According to Lazarus and Folkman's (1984, as cited in Yuan et al., 2021) transactional theory of stress and coping, people go through a two-stage appraisal process to determine whether the situations or experiences are stressful. During the secondary appraisal, options for coping are specifically taken into consideration, and the use of different coping strategies may have different health outcomes.

According to this theory, there are two types of coping styles: *action-oriented coping*, which consists of all acts or manipulations intended to change the problematic situation, and *emotion-oriented coping*, which includes actions meant to regulate the caregiver's emotional reaction to the problematic situation. While these strategies may work well together, *emotional coping strategies* are more likely to be used when it has been determined that nothing can be done to change the dangerous, upsetting, or difficult circumstances in the environment. On the other hand, when the caregiver believes that the environment can be changed, *action-oriented coping strategies* are more likely to be used (Lazarus & Folkman, 1984, as cited in Yuan et al., 2021).

Health Theory of Coping. The health theory of coping developed by Stallman (2020) classified coping strategies in two categories i.e., *healthy* and *unhealthy* on the basis of the possibility of negative consequences. It recognizes that every coping strategy is adaptive and can initially reduce stress. Conceptually, the categories are comprehensive, clear, functionally homogenous and distinct, mutually exclusive, generative and flexible. This theory represents a hierarchy of strategies throughout the continuum of intensity, internality, and adversity. Social support, self-soothing, relaxing or distracting activities, and professional support are all examples

of *healthy coping strategies*. Whereas *unhealthy coping strategies* include social disengagement, negative self-talk, harmful acts, and suicidality. All coping strategies fall into either of these classifications.

1.5.3 Quality of Life

Bottom-up theory. Bottom-up theory by Diener (2009), is widely used in studies on quality of life (QoL). The bottom-up theory emphasizes the idea that evaluations made in a variety of life domains, including family life, leisure, community, social, financial, as well as spiritual life, and so on, influence overall evaluation of life satisfaction. To put it another way, evaluations of life domains, particularly significant ones, have an impact on evaluation of life as a whole. For instance, if someone believes that their job life is extremely essential, then their overall evaluation of work life will probably have an impact on their overall evaluation of life in general.

Centre for Health Promotion (CHP) Model of QoL. The Centre for Health Promotion (CHP) model of quality of life (QoL) was established by Renwick and Brown (1996, as cited in Alborz, 2017). This model acknowledged that individuals have physical, psychological, and spiritual aspects as well as an inherent need to "belong" to communities in both the social and physical sense. They asserted that, as distinct human beings, every individual follows their unique goals, makes their own choices and decisions.

The three main elements of the CHP QoL Model according to Renwick and Brown (1996, as cited in Alborz, 2017) are *being*, *belonging* and *becoming*. *Being* consists of physical health (including fitness, nutrition, and health), spiritual values and believes (including religious and mystical experiences associated with music and

other arts) and psychological well-being (including feelings and evaluations of oneself e.g., confidence). *Belonging* is constituted of the physical environment (including privacy, safety, etc.), the social surroundings (including meaningful relations with friends as well as family, etc.), as well as the resources available in the community (such as accessibility to jobs, educational, and other services, etc.). *Becoming* encompasses practical activities (such as acquiring knowledge, self-care, and housework), growth-oriented activities (that encourage the formal or informal acquisition of knowledge and skills), and leisure activities (in order to encourage relaxation or a healthy work-life balance).

Moreover, Renwick and Brown (1996, as cited in Alborz, 2017) suggested that control (that is, one's sense of having some control on important options) and potential opportunities (that is, one's view of both current and prospective opportunities) are moderators that could either increase or decrease the significance and enjoyment of certain facets of quality of life.

1.5.4 Integrative, Multicomponent, Group-based Cognitive Behavioral Therapy (CBT)

Two primary theories of cognition and learning served as the cornerstones for the development of cognitive behavioral therapy (CBT) i.e., information-processing theory and social learning theory (Cully & Teten, 2008; Beck, 2020).

The Information Processing Theory. In information processing theory of human cognition, the analogy of a computer or machine is used to explain how an individual's mind processes information. Input is received through senses, processed in the mind and based on that input and the processing method; an output is generated. Past experiences generate schemas which are mental representations or expectations

of a specific situation or event. These schemas might be positive or negative and determine how a message is processed. If in a specific situation a negative schema gets triggered, then it processes an input negatively and produce negative automatic thoughts, which produce negative emotions and maladaptive behavioral reactions (Axelrod, 1973, as cited in Schaffer, 2022).

Social Learning Theory. Social learning theory emphasized the importance of modeling, observation, and imitation in the learning process of individuals. It argued that learning highly depends on the consequences of behaviors, which means that behaviors with adverse outcomes tend to fade, while behaviors with beneficial outcomes are likely to be learned and become habits. Four main tenets form the foundation of social learning theory: (1) paying attention to the behavior being observed; (2) remembering or retaining the behavior that was observed; (3) reproducing the behavior which was observed; and (4) being motivated to repeat the behavior (Bandura & Walters, 1977, as cited in Schaffer, 2022).

When using this information in conjunction with the cognitive behavioral therapy (CBT) paradigm, individuals learn maladaptive behaviors from people in their immediate environment. Furthermore, core beliefs have the potential to direct an individual's attention towards specific observable behaviors and guide their retention, thereby impacting both the reproduction as well as the motivation to reproduce those behaviors. Additionally, when maladaptive behaviors align with a [maladaptive] core belief, they become rewarding (either internally or externally), thereby reinforcing the maladaptive behavioral pattern of the psychopathological presentation (Cully & Teten, 2008; Beck, 2020).

When information processing theory and social learning theory are combined with Beck's concepts of negative automatic thoughts, intermediate beliefs or assumptions, and core beliefs, the result is cognitive behavioral theory (Beck, 2020). The term cognitive behavioral theory is a little confusing because no precise description of a single, cohesive theory underlying CBT is found. Rather, a group of theories emphasizing the significance of both cognitive and behavioral factors in explaining the development and persistence of psychopathology are referred to as cognitive-behavioral theory (Kalodner, 2011).

1.6 Summary of Introduction

Both globally and in Pakistan, there has been a notable rise in the prevalence of autism spectrum disorder (ASD) (McConkey et al., 2019; Khalid et al., 2021). The diagnosis of ASD not only affects the individuals diagnosed but also their caregivers (Torres et al., 2023). Caregivers experience a multifaceted strain and feelings of burden due to the overwhelming demands of providing care to a family member suffering from a chronic disease, disability or disorder which is referred to as caregiver burden (Marvardi et al., 2005; Zarit & Femia, 2008; Liu et al., 2020). It is not a clinically diagnosable condition in ICD-11 (WHO, 2022) or DSM-5TR (APA, 2022) yet different degrees of psychopathology tend to be present in people who have a high caregiver burden (Schaffer, 2022).

Coping strategies are thoughts, behaviors, and emotional responses that people use to deal with stressful situations (Carver & Connor-Smith, 2010; Aldwin et al., 2018; Lazarus & Folkman, 1984, as cited in Budimir et al., 2021). There are 12 families of coping strategies, six adaptive and six maladaptive (Skinner & Zimmer-Gembeck, 2016). Quality of life is a multifaceted concept that involves objective measures and subjective perception of an individual's place in various areas of life as

optimum (Ferrans & Powers, 1985, as cited in Kimura & Silva, 2009; Diener, 1985, as cited in Theofilou, 2013; Cummins, 2015; WHO, 1995, as cited in Cai et al., 2021).

Caregivers of children and adolescents with moderate to severe autistic symptoms report a high caregiver burden, which impacts their quality of life negatively (Marsack-Topolewski & Church, 2019; Patel et al., 2022). Moreover, maladaptive coping strategies to deal with caregiver burden worsens the quality of life and mental health of caregivers (Suen et al., 2021).

Multiple theories and models explain the concept of caregiver burden, coping strategies, and quality of life, along with the link between them: including the stress process model proposed by Pearlin (1990, as cited in Wang et al., 2023), reconceptualized uncertainty in illness theory (RUIT) proposed by Mishel (2014), Lazarus and Folkman's (1984, as cited in Yuan et al., 2021) transactional theory of stress and coping, health theory of coping by Stallman (2020), bottom-up theory of quality of life (QoL) (Diener, 2009), centre for health promotion (CHP) model of QoL proposed by Renwick and Brown (1996, as cited in Alborz, 2017).

Integrative, Multi-component, Group-based Cognitive Behavior Therapy (CBT) developed by Daniel Robert Schaffer (2022) is an intervention for the stress, strain, and burden that the primary informal caregivers of people who require significant support due to any illness or disorder experience due to overwhelming demands of caregiving. The theoretical framework, for the above-mentioned therapy is provided by cognitive-behavioral theory (Beck, 2020) produced by combining information processing theory (Axelrod, 1973, as cited in Schaffer, 2022) and social learning theory (Bandura & Walters, 1977, as cited in Schaffer, 2022) with Beck's concepts of negative automatic thoughts, intermediate assumptions, and core beliefs.

Literature Review

This chapter incorporates existing research on caregiver burden, coping strategies, quality of life (QoL) and the therapeutic efficacy of cognitive behavioral therapy (CBT) in the context of caregivers of individuals with autism spectrum disorder (ASD).

2.1 Caregiver Burden

A study on primary caregivers of autistic children was undertook by Saadhana et al. (2024) to assess their level of perceived psychological burden. The sample consisted of 225 primary caregivers, aged from 25-45 years, who were either members of online support groups for ASD or lived in Hyderabad, India, and had autistic children, aged 1-15 years. The Modified Zarit Burden Interview—22, general information about ASD, and demographic information made up the questionnaire. Results showed that the demographic factors including the caregiver's financial situation, the age at which the child's unusual behavior was first observed by the caregiver, and the psychological burden of the caregiver of an autistic child were found to be significantly correlated. However, the correlation between the caregiver's psychological burden and demographic characteristics such as gender, age, relationship with the child, caregiver's education, and employment status was found to be non-significant.

A qualitative study by Anboohi and colleagues (2023) was carried out to explain the concept of caregiver burden from the perspective of family caregivers of autistic children. Fourteen family caregivers, ranging in age from 30 to 47 years, made up the sample. Data was collected using in-depth, semi-structured interviews.

According to the results, family caregivers endure the caregiving and mental burden of raising their children with ASD in three main categories: context and background, health issues including both physical and mental health, and social support, i.e., both formal and informal support.

A comparison study assessing caregiver burden in autism spectrum disorder and schizophrenia was conducted by Yıldız et al. (2021). Ninety-six family members (between the ages 20 to 70 years) of individuals with ASD (aged 4 to 24 years) and 67 family members (between the ages 26 to 73 years) of individuals with schizophrenia (aged 18 to 64 years) made up the sample. Data was gathered using self-report measures. It was revealed that compared to schizophrenia, ASD had a significantly higher caregiver burden. Additionally, it was discovered that high caregiver burden was significantly predicted by need for self-care, depression, the income level for all family members, self-destructive behaviors, and self-stigma. The factors affecting the high burden remained the same even after the diagnosis was eliminated from the analysis.

In order to evaluate caregiver burden among autistic children's parents,

Ardhanaari et al. (2020) undertook a research study. The self-report questionnaires

were used to measure the caregiver burden of 60 parents aged between 25 and 52

years having autistic children aged 3-18 years. The majority of caregivers

demonstrated an impact on several facets of life. A significant impact on well-being

was shown by 59% of the caregivers, 84% of whom felt anxious and depressed.

Eighty-five percent of the caregivers reported a lack of appreciation for the care they

provided to their children. About 14% of the caregivers had significant impacts on
their relationships with others. The perceived illness severity got impacted in 53% of
caregivers.

Cetinbakis et al. (2020) investigated the factors that contribute to a higher caregiving burden among Turkish mothers of autistic children. Sixty mothers (aged 37.83 years on average) of typically developing children (aged 10.58 years on average) and 62 mothers (with a mean age of 38.11 years) of autistic children (aged 11.53 years on average) made up the sample. Self-report instruments were used. The findings demonstrated that in mothers of Turkish children with ASD, caregiver burden positively correlated with the level of disability, and negatively correlated with the level of life satisfaction. Additionally, dyadic adjustment, higher social support, and lower expressed emotion were all correlated with higher life satisfaction in mothers of autistic children. Furthermore, it was discovered that a mothers' caregiver burden was significantly predicted by their children's autism-related behaviors, disability percentages, as well as poor dyadic adjustment. These factors ultimately led to higher expressed emotions and lower life satisfaction in the mothers.

Furthermore, Sit et al. (2020) examined caregiving burden among informal caregivers of individuals with disabilities. Two hundred and thirty-four informal caregivers of mentally disabled individuals were included in the sample. There were 51 male and 183 female caregivers in the sample. Most of the caregivers (n = 119) were 65 years old or older. Perceived Difficulty Scale (PD), Caregiving Burden Inventory (CBI), DASS-21, and an adapted Chinese Coping Scale were employed. Results revealed that caregiver burden and perceived difficulties were significantly related to stress, anxiety, and depression. While the impact of perceived difficulty on anxiety, and that of caregiving burden on anxiety and depression was exacerbated by external coping, internal coping buffered the impact of perceived difficulty on anxiety as well as depression.

Psychological distress and perceived burden experienced by caregivers of individuals with ASD were examined by Alnazly and Abojedi (2019). The study included 123 Jordanian parents of autistic children, including 94 mothers and 29 fathers. The majority of children (45.5%) were between the ages of seven and nine years. Data was gathered using self-report measures. Results demonstrated that parents had moderately high caregiver burden, experienced negative life changes, along with borderline anxiety as well as depression. The perceived burden associated with the complexity of caregiving tasks was positively related to task completion time and negatively related to caregiving-related outcomes of caregivers. Anxiety levels were positively associated with depression, and the perceived burden of caregiving tasks was associated with both anxiety and depression.

Baykal and colleagues (2019) investigated the relationship between depression and anxiety levels, caregiver burden, and the distribution of symptoms in autistic children. Seventy Turkish children and adolescents, aged from three to 15 years who were diagnosed with ASD and their primary caregivers made up the sample. Self-report measures were used for gathering data. Overall caregiver burden was found to be significantly predicted by autism symptom severity as well as the level of depressive symptoms in caregivers. Moreover, caregiver burden was significantly impacted only by the ABC language domain. It was determined that the symptom cluster impacting the anxiety and depression levels was the body and object use domains of Autism Behavior Checklist.

In a comparative multicenter study on parental burden and related factors among families with autistic children and adolescents, Picardi et al. (2018) included two comparison groups. They compared parents of 359 autistic children and adolescents to parents of 145 age matched individuals having Down syndrome as well

as with 155 individuals with Type 1 diabetes mellitus. Parents aged 40 years on average and their children aged between 5 and 17 years. Findings revealed that parents of autistic children had lesser social support, more frequent psychological distress, and higher objective and subjective burden. As compared to fathers, mothers expressed a higher subjective burden. Moreover, it was found that the objective and subjective burden was significantly positively predicted by the severity of autism symptoms and negatively predicted by social support. Furthermore, the burden of parents was also positively predicted by low adaptive functioning, intellectual disability, and disengagement, engagement, and distractive coping strategies. Hardiness and spiritual well-being were also found to be negative predictors. Furthermore, through social support and coping strategies, some effects were indirect.

Pandey and Sharma (2018) investigated perceived burden among caregivers of autistic children. Sixty-one parents of autistic children living in Kathmandu Valley of Nepal were included in the study. The children aged 7.9 years, and the caregivers aged 33.6 years on average. The Zarit Burden Interview-22 was used. The findings demonstrated that caregivers had moderate to severe caregiver burden. Moreover, the caregiver burden was found to be significantly correlated with education level, anxiety, and depression.

2.2 Coping Strategies

A latent profile study on coping strategies of mothers of children who had attention deficit hyperactivity disordered (ADHD) and autism spectrum disorder (ASD) was carried out by Berenguer et al. (2024). The study included 90 mothers whose children had ADHD and ASD. Three coping profiles i.e., *poor coping* (17.77%), avoidance coping (40%), and adaptative coping (42.22%) based on various coping strategies were identified in the results. In comparison to the other two

profiles, the *low coping* profile had a greater degree of dysfunctionality and exhibited significant differences in social support, parenting stress, and social, behavioral, and sleep issues of children.

In a research study, Hasan and ALsulami (2024) examined the perceived psychological status of family caregivers of autistic children and the impact of coping strategies and self-esteem. The sample comprised 93 parents of autistic children. The results demonstrated that parents of autistic children experienced high anxiety, moderate depression, and mild stress. Additionally, parents of autistic children had low levels of self-esteem. As compared to fathers of autistic children, mothers used maladaptive coping strategies more often and had higher psychological distress, and lower self-esteem.

Brien-Bérard and Rivières-Pigeon (2023) carried out a qualitative investigation on the marital bond and coping strategies of parents of children with autism spectrum disorder (ASD). The sample included 42 parents, 13 fathers and 29 mothers of autistic children and adolescents. The age range of children and adolescents was 4-17 years. Data was collected using semi-structured interviews. Results revealed that research participants used three types of coping strategies to deal with stress and strengthen their marital bonds. First, parents' need for me-time or respite was satisfied by *individual coping*. Second, *dyadic coping* gave couples a means of mutual support and cooperative problem-solving for family challenges. Lastly, *social support coping* was crucial in helping parents access much-needed resources and yet have some time for respite and quality time as a couple.

The challenges, experiences, and coping strategies of parents of children with autism spectrum disorder (ASD) living in United States (US) and the Arab World

were compared by Ayyash et al. (2023). Four hundred parents of children with ASD comprised the sample; 165 of them were from Arab nations, while the remaining 235 were non-Arab Americans. The age range of children was 5-14 years. The findings showed that American parents were more satisfied with the diagnostic procedure as a whole than were parents in Arab nations. The two most valuable coping strategies, according to parents in both nations, were obtaining information /self-education regarding autism, and acceptance and/or religion. Parents in Arab nations reported being less satisfied with the diagnostic procedure overall than parents in the United States. Compared to US parents, the lack of community support was a greater problem for Arab parents.

A qualitative study on the coping strategies employed by Taiwanese parents of autistic children was carried out by Wei-Chih et al. (2023). In-person interviews with a sample of 14 Taiwanese parents, one father and 13 mothers, ranging in age from 34 to 52 years, of autistic children whose ages ranged from six to 19 years, were performed. It was discovered that Taiwanese parents of ASD children employed emotion and problem-focused coping strategies to cope with psychological impacts of parenting. Emotion-focused strategies included acceptance and adaptation, whereas problem-focused strategies encompassed management, support, and communication. The results demonstrated that both coping strategies were effective in dealing with particular instances and circumstances. Moreover, children's external behaviors and parents' mental health both improved with social and clinical support.

To ascertain the level of stress, depression, and anxiety experienced by Slovenian parents of autistic children and their coping strategies, Demšar and Bakracevic (2023) carried out a research study. Forty-two parents, aged 38 years on average, of autistic children (aged 6.29 years on average) were included in the

research. Self-report measures were utilized for data collection. The findings demonstrated that mothers as compared to fathers experienced higher levels of stress and anxiety-related symptoms. Moreover, it was found that positive reinterpretation and growth as coping strategies were negatively related to anxiety and depression, and positively related to life satisfaction and perceived social support. The adoption of acceptance strategies was significantly more common among those with higher educational levels.

Lewis et al., (2022) carried out mixed-method research to explore coping strategies of parents of Black children with autism spectrum disorder (ASD). Twenty-two mothers aged 27 to 61 years, of autistic children aged 3 to 17 years filled out the Ways of Coping Questionnaire and participated in semi-structured interviews. Findings revealed that parents dealt with complicated stressors by utilizing a variety of coping strategies, occasionally combining multiple strategies. Along with expressing a need for inclusive areas where they could interact with other parents who they believed could better relate to the stressors they faced, parents also reported a need for increased social support from providers.

Begum et al. (2020) examined the educational level and coping strategies of Bangladeshi parents of autistic children. Bangladeshi parents of autistic children comprised the sample. An interviewer administered questionnaires on coping strategies to gather data. The following eight types of coping strategies were chosen based on the results: confrontive coping, planful problem-solving, self-controlling, escape-avoidance, distancing, social support seeking, accepting responsibility, and positive reappraisal. Moreover, parents' educational level and accepting responsibility coping strategy was significantly correlated to each other.

Antonopoulou and colleagues (2020) conducted research on the influence of anxiety and emotional expressiveness in the family and parenting and coping strategies among parents of children with and without autism. The sample included 50 parents of autistic children and 50 parents of children with normal development. The parents aged 41.2 years on average. Data was collected using self-report instruments. Results revealed that in comparison to parents of normally developing children, parents of autistic children experienced higher anxiety, higher negative emotional expressiveness, and a less authoritative parenting style. Moreover, the coping strategies of the two parent groups did not significantly differ from one another. Furthermore, it was revealed that for both groups of parents, low anxiety and positive emotional expressiveness were predictive of effective coping strategies, and nurturing parenting styles.

A systematic review on coping strategies of parents of autistic children was done by Vernhet et al. (2019). Eleven articles were chosen out of 156 publications that were found using an electronic search that followed PRISMA guidelines. Coping strategies of parents were evaluated by using a variety of self-report measures. Research showed that in comparison to parents of children with normal development, parents of autistic children utilized more avoidance coping strategies and less social support-seeking coping strategies. Additionally, parental stress was reduced, and quality of life was improved by problem-focused coping, however, emotion-focused coping was a risk factor for change.

2.3 Quality of Life

A research on quality of life among Hungarian parents of autistic individuals was carried out by Volgyesi-Molnar et al. (2024). The study included parents of 842 individuals, including 521 parents of autistic individuals (ASD) along with 321

parents of neurotypical persons (NT). The age range of care recipients was 0-49 years. Standardized questionnaires were implemented to collect data. The findings revealed that parents of autistic individuals had significantly lower quality of life across all scale domains. Furthermore, the sense of coherence, social support, estimated relative income, and severity of depressive symptoms were all strong predictors of parental quality of life.

Davy and colleagues (2024) carried out cross-sectional research to evaluate the impact of leisure, workforce participation, and community on quality of life (QoL) of primary and secondary caregivers of children with ASD. The sample consisted of 88 primary caregivers i.e., mothers, and 63 secondary caregivers i.e., fathers of autistic children aged 7 to 12 years. An online questionnaire was used to measure for gathering data. Results revealed that primary caregivers reported more perceived responsibility for household and childrearing responsibilities, fewer work hours, more time pressure, and less participation in preferred activities when compared to secondary caregivers. Both caregivers reported comparable levels of parental stress, leisure frequency, and quality of life. Furthermore, it was revealed that for primary and secondary caregivers alike, caregiver participation was a significant predictor of QoL. But when caregiver well-being was incorporated into the model, participation's distinct impact on quality of life was diminished, especially for secondary caregivers.

A research on parents' quality of life, adult attachment, and child adjustment among parents of autistic children and adolescents was conducted by Musetti et al. (2024). The sample consisted of 188 parents of autistic children and adolescents. The age range of children and adolescents was 6-18 years. A series of self-report questionnaires were used for data collection. Findings revealed that parents' quality of

life was positively related to prosocial behaviors, and secure attachment style, whereas, it was negatively related to children's total problems, and fearful attachment.

Dai et al. (2024) studied the significance of social support and parenting self-efficacy for family's quality of life of newly diagnosed autistic children over one year. At a tertiary hospital in Guangzhou, China, 156 newly diagnosed ASD children and their parents participated in Wave 1, while 110 children and parents were followed up in Wave 2 after one year. It was found that overall satisfaction with the family quality of life (FQoL) improved, while satisfaction with material or physical well-being declined. Furthermore, there was an improvement in the FQoL overall importance rating, but it was not statistically significant. Parents with greater levels of subjective social support and higher parental self-efficacy were more satisfied with FQoL. Additionally, parents who used social support more effectively placed a greater value on FQoL.

A multifactorial evaluation of quality of life (QoL) of Moroccan parents of autistic children was carried out by Nouira et al. (2024). The sample comprised 68 parents of autistic children. The age range of children was six to 16 years. Self-report measures were used for gathering data. It was found that while QoL of both parents was similar, mothers experienced more symptoms of depression than fathers did. Moreover, all parents' physical and mental health was compromised, but mothers were more severely affected than fathers, especially in families with more than three children and poor incomes.

A mixed methods study was conducted by Faden et al. (2023) for investigating the stress, perceived social support, as well as quality of life (QoL) of parents of children with neurodevelopmental disorders (NDD). Data was gathered from 63

parents of children with neurodevelopmental disorders under 16 years of age. The parents ranged in age from 25 to 65 and beyond. Four of those parents were then subjected to semi-structured interviews to obtain a more thorough insight. The findings showed that parents of children having severe symptoms had lower quality of life and higher parental stress than parents of children having moderate or mild symptoms. Additionally, as compared to all other disorders, parents of autistic children had lower quality of life. Moreover, mothers and fathers did not vary significantly in terms of QOL or parental stress. Furthermore, qualitative results revealed that the most significant challenges faced by parents were familial, financial, and well-being concerns.

Eapen et al. (2023) studied quality of life among parents of autistic children from transcultural viewpoint. There were 1,121 parents or caregivers in the sample, representing seven different countries: Australia (n=96), Hungary (n=522), Malaysia (n=116), Romania (n=140), Singapore (n=97), Spain (n=87), and the United Kingdom (n=63). Parents ranged in age from 35 to 48 years on average. The QoLA questionnaire was utilized. Results revealed that although the impact of ASD characteristics remained highly comparable across cultures, however there was likely variation in cultural factors influencing the parents' QoL across the various nations.

An integrative literature search on quality of life (QoL) of parents of autistic children was conducted by Turnage and Conner (2022). A thorough electronic search yielded 15 pertinent articles with a total of 5565 participants. It was found that compared to those individuals who did not have autistic children, parents of autistic children had poorer quality of life with regard to their physical, social, psychological, as well as spiritual well-being. Moreover, autism symptom severity was found to be

the strongest negative predictor of parents' QoL. However, the level of education of the parents and child's ASD severity were protective factors for the parents' QoL.

In a qualitative research, Abolkheirian and colleagues (2022) explored the perception of parents of autistic children about their quality of life. Thirty-one Tehranian parents (mean age=40.39 years) along with school counsellors made up the sample. Children's average age was 10.17 years. Data was collected using semi-structured interviews. Findings indicated that participants experienced a wide range of challenges and crises to cope with in their everyday lives. The elements that were found to decrease quality of life were divided into 20 subthemes and six main themes. The main themes were family relationships, parenting, daily living, health, community-related, and financial challenges.

Moreover, in Arar city of Saudi Arabia, Alenazi and colleagues (2020) examined the impact of autism on quality of life (QoL) of parents. The cross-sectional study included 84 parents of autistic children, 54.8% of whom were under 40, and 45.2% of whom were over 40 years of age. Self-report instruments were used. The results showed that 63.1% of parents had poor QoL. The primary domains impacted were role restrictions brought on by emotional issues, and energy or fatigue. In addition, the presence of low caregivers' income, unemployment, and female gender were significant factors associated with poor QoL. Moreover, the first birth order of autistic children and the long duration of the disorder were related to poor parental QoL.

2.4 Cognitive Behavioral Therapy (CBT) for Caregivers

Abdelaziz and colleagues (2024) examined role of problem-solving appraisal in cognitive behavioral therapy (CBT) for the psychological distress of mothers of

autistic children. The sample comprised 60 mothers in total i.e., 30 in the control group and 30 in the intervention group. The participants' mean age was 34.80 years, most of them being between the ages of 20 and 40 years and their children being in the 4–12 year age range. The CBT group, which consisted of four groups of seven to eight participants each, attended weekly sessions lasting 60 minutes for three months, during which they were trained in problem-solving appraisal within the framework of a CBT curriculum. Before and after the program, all mothers completed self-report questionnaires. When compared to control group, the intervention group had a significant reduction in depression, stress, anxiety, as well as in general psychological distress at post assessment level. Additionally, they demonstrated significant improvement in approach-avoidance style, problem-solving confidence, and self-control. The tailored CBT program significantly enhanced the psychological well-being of Egyptian mothers of children with ASD.

A research on cognitive behavioral therapy (CBT) was carried out by Onyishi et al. (2023) to investigate its efficacy for psychological distress in parents of autistic children. Ninety-seven parents of autistic children living in Enugu's Nigerian state were included in the sample. Random assignment was used to assign participants into two groups: 48 participants in CBT group and 49 participants in waitlist comparison (WLC) group. Throughout a 12-week period, the CBT group engaged in a weekly 2-hour CBT program. Sel-report instruments were used to gather data. Findings showed that, in comparison to the WLC, all aspects of psychological distress were significantly reduced in the CBT group at post and follow-up levels of assessment. Furthermore, it was shown that CBT intervention had an impact on the global psychological distress score.

A systematic review on cognitive-based interventions (CBIs) for improving the psychological health and well-being of parents of children with developmental disabilities was conducted by Li et al. (2023). A search was conducted across six databases to find randomized controlled trials (RCTs). A total of 25 RCTs with 1915 parents were found. Findings revealed that in comparison to the active or inactive control groups, CBIs increased parent-child interactions, and parental well-being after the intervention and decreased stress, anxiety, depressive symptoms, as well as distress in parents. Positive results were found in the subgroup analysis of the efficacy of interventions utilizing CBT and mindfulness-based interventions. The review also determined optimal length of the intervention and target of participants. Moreover, the kind of developmental disorders that children had affected the outcomes of CBIs.

Ruiz-Robledillo and Moya-Albiol (2015) investigated the efficacy of a cognitive-behavioral intervention program for the health of caregivers of autistic individuals. The study included 17 parents who had raised their autistic children for about 14 years including 10 females and seven males with an average age of 52 years. The care recipients were 13 boys and four girls, with a 75% disability rate on average. Results revealed a significant reduction in caregiver burden immediately after the intervention. Additionally, as compared to baseline, they had improved mood states, fewer somatic symptoms, and lower levels of depression at post assessment as well as one month follow up level.

The efficacy of cognitive behavioral group therapy for parental stress among mothers of autistic children was evaluated by Izadi-Mazidi et al. (2015). Sixteen mothers of autistic children (mean age=37.7 years) made up the sample. The autistic children were 13 boys and three girls (mean age=7.5 years). Abidin Parenting Stress scale was used. Parents took part in seven cognitive behavior group therapy sessions.

The results revealed that parenting stress and parenting distress subscales scores on the pretest and post-test differed significantly, but non significantly on the other subscales.

2.5 Indigenous Researches

2.5.1 Caregiver Burden

A cross-sectional research was carried out by Nighat et al. (2024) on caregiver strain and its determinants among parents of autistic children. The sample comprised 403 parents of autistic children from Karachi city of Pakistan. Results revealed that 88.3% of the parents experienced moderate to severe levels of caregiver strain. Lower caregiver strain was strongly predicted by a higher level of education, a higher family income, and the care recipient's age group. A higher level of caregiver strain was significantly correlated with the care recipient's predisposition to self-harm, length of diagnosis (i.e., more than five years), and social disengagement in the care recipient.

In Karachi, Pakistan, Aftab et al. (2023) studied caregiver strain and its related factors in autism spectrum disorder. Seventy-six caregivers of autistic children from Aga Khan University Hospital's inpatient and outpatient psychiatric units in Karachi, Pakistan, were included in the study. The sample included 61 females and 15 males aged 37.09 years on average. Caregiver Strain Questionnaire (CGSQ) was utilized. Overall caregiver strain (including subjective and objective) was rated to be mild by 40.8%, moderate by 47.4%, and severe by 11.8% of respondents. Around 50% of the individuals experienced mild objective strain, but 59.2% of them subjectively reported moderate strain. Moreover, subjective strain and internalized subjective strain were shown to be related to participant gender.

Mumtaz et al. (2022) investigated how mothers of autistic children from Pakistani cultural backgrounds perceived stress and burden. The study included 84 mothers ranging in age from 23 to 60 years who had autistic children aged three to 16 years from several special education centers located in Lahore. The data was gathered using self-report measures. The findings indicated that 53.6% of mothers experienced moderate to severe burden. Moreover, it was revealed that caregiver burden and parental stress were significantly positively correlated with each other. Furthermore, a significant association between maternal stress and the severity of child's autism and medication, and between maternal burden and the age of the child was revealed.

A study on caregiver burden and life satisfaction of parents of autistic children was carried out by Khan et al. (2021). Seventy-one caregivers of children with ASD from various cities of Pakistan's Punjab region made up the sample. The sample included 55 females and 16 males between the ages of 20 to 55 years. Self-report questionnaires were used. Findings indicated that caregiver burden and life satisfaction were significantly and negatively correlated with each other. Moreover, it was revealed that caregiver burden significantly and negatively predicted life satisfaction.

Akram et al. (2019) studied caregiver burden, perceived social support, as well as suicidal ideation in mothers of autistic children. The sample included 339 mothers of 7-12 year old autistic children from Islamabad, Lahore, Gujrat, Gujranwala, Jhelum, and Sialkot, Pakistan. Standardized instruments were used for data collection. The results indicated a significant positive correlation between caregiver burden and suicidal ideation. However, perceived social support was found to be significantly negatively related to caregiver burden and suicidal ideation. Moreover, suicidal ideation was negatively impacted by perceived social support, however, it was

positively impacted by the caregiver burden. Furthermore, it was revealed that perceived social support served as a significant moderator between caregiver burden and suicidal ideation.

2.5.2 Coping Strategies

A cross-sectional study on coping strategies employed by Pakistani parents of children with autism spectrum disorder was conducted by Quaid-Johar (2021). The study included 150 participants in total, out of which 74.2% were primary caregivers aged 32.2 years on average and their corresponding autistic children aged 7.1 years on average. BREF-COPE standardized questionnaire was utilized for gathering data. Results revealed that while 64.5% of parents understood the reality of the situation, 51.6% of parents typically focused on their efforts with their children. Furthermore, 12.9% consumed alcohol or used antidepressants, yet the majority turned to people for emotional support to feel better. Overall, only 16.1% of parents could incorporate coping strategies into their daily routines.

A study on stress and coping strategies of parents of autistic children and children with hearing impairment was conducted by Ishtiaq et al. (2020). The sample included 200 parents of children with hearing impairment (HI) and 100 parents of children with autism. The age range of parents was 20-60 years. The Coping Strategies Inventory, the Parental Stress Scale, and the basic demographic sheet were used for data collection. The findings showed that the level of parental stress was similar for parents of autistic children and hearing impairments. Moreover, the most common coping strategy employed by parents of children with hearing impairments was problem-focused engagement, followed by problem-focused disengagement. In

the autistic group, problem-focused engagement was the most commonly employed coping strategy, followed by emotion-focused coping.

Munir et al., (2020) investigated psychological distress, social interaction anxiety, and coping strategies among mothers having autistic children. One hundred mothers from various hospitals and institutes in Lahore, Pakistan, were included in the study. Mothers aged 32.63 years on average, while children's average age was 7.54 years. The Social Interaction Anxiety Scale (SIAS), Coping Strategy Questionnaire (CSQ), and Kessler Psychological Distress Scale (KPDS) were used. Findings demonstrated a significant association between psychological distress, social interaction anxiety, and coping strategies in mothers of autistic children. Additionally, research demonstrated that social interaction anxiety in mothers of autistic children was positively predicted by active distractive coping.

2.5.3 Quality of Life

Abd-Alnabi and Sachet (2022) carried out research on quality of life of parents of autistic children. The sample included 120 parents of autistic children. The age range of parents was 26-56 years and that of their children was 1-10 years. Self-report measures were used for data collection. According to the study's findings, 58.3% of parents had poor quality of life (QoL). Furthermore, parents' QoL and their income, social status, educational level, kinship, and duration of their child's diagnosis were significantly correlated with each other.

A research on locus of control, quality of life, and perceived social support among mothers of autistic and normally developing children was conducted by Khan et al. (2022). Data was gathered from 200 mothers, including 100 mothers of autistic children and 100 mothers of normally developing children. Ages of children varied

from 3 to 13 years. Urdu translated self-report instruments were used for gathering data. Findings indicated significantly lower quality of life and perceived social support in mothers of autistic children than in mothers of normally developing children. Moreover, mothers of children with autism had a significantly stronger locus of control than mothers of normally developing children. Furthermore, in mothers of autistic children, a significant positive association was found between perceived quality of life and social support.

Kausar et al. (2021) investigated the moderating role of perceived social support in the relationship between perceived stress and quality of life (QoL) in parents of special needs children. A sample consisted of 300 parents, including 146 fathers and 154 mothers aged 25 to 60 years who had boys or girls aged 5 to 18 years who had autism spectrum disorder or intellectual disability were chosen from special education and healthcare centers in Kharian, Lalamusa, Gujrat, and Gujranwala, Pakistan. Self-report measures were utilized for gathering data. Results showed statistically significant associations between parental perceived stress, QoL, and perceived social support. Moreover, in the targeted parents, perceived social support was a significant moderator between perceived stress and QoL.

During the Covid-19 epidemic, Ali et al. (2021) assessed quality of life (QoL) of parents having disabled children. Three hundred and one parents aged 15 to 40 years and above were enlisted in the sample; 151 of whom had children without disabilities and 150 of whom had children with developmental disabilities, including learning disabilities (LD), autism spectrum disorder (ASD), global developmental delay (GDD), cerebral palsy (CP), attention deficit hyperactivity disorder (ADHD), and speech delays. The age range of their children was 2 to 18 years. Urdu translated self-report instruments were utilized for data collection. The findings revealed that the

QoL of parents having children with disabilities was poorer than parents of children without disabilities. Moreover, significant difference was found in the environmental as well as physical domains of parents' QoL between parents of children with and without disabilities.

A research on the impact of behavioral problems in autistic children on the quality of life (QoL) of mothers was carried out by Waheed et al. (2020). One hundred individuals participated in the study including 50 mothers and 50 children with autism diagnoses. Mothers were 45 years old on average, with children aged 10.50 years on average. Data was gathered using questionnaires. QoL of mothers was shown to be significantly negatively correlated with behavioral problems associated with autism in their children. Moreover, it was revealed that the quality of life was higher in postgraduate, working mothers, and mothers living in joint family systems compared to those mothers whose education level was lower, were non-working, and lived in the nuclear family system. Furthermore, autism-related behavioral problems were lower in children of postgraduate, working mothers, and mothers living in joint family systems.

2.5.4 Cognitive behavioral Therapy (CBT) for Caregivers

Mahmood and Sadiq (2019) examined the efficacy of cognitive behavioral therapy for burden, perceived stress, as well as for coping in caregivers of Thalassemia patients. The sample comprised 40 caregivers (both mothers and fathers) aged 30 to 40 of children aged 6 to 12 diagnosed with beta-thalassemia. A control group and an experimental group consisting of twenty participants each were created. The experimental group received therapy in 10–12 sessions, while the control group received no intervention. The Burden Assessment Scale, Perceived Stress Scale, and

Coping Assessment Scale were employed. According to the findings, perceived stress, burden, and coping significantly differed across pre and post assessment levels.

Additionally, it was revealed that following intervention, problem-focused coping significantly increased while emotional-focused coping significantly decreased.

Furthermore, a significant difference was seen between the experimental and control groups following the intervention, as well as a significant multivariate effect on the variables under investigation.

The efficacy of cognitive behavioral therapy for dementia caregivers was evaluated by Ali and Bokharey (2015). Eight participants were chosen from psychiatric and neurology clinics in Lahore, Pakistan. The sample included both male and female informal caregivers of patients with moderate severity level of dementia. The age range of caregivers was 40 to 75 years. Ten sessions were held over the course of 5-8 weeks as part of the therapeutic process. Questionnaires were used for pre and post-assessment. Results revealed that the intervention significantly improved the mental and physical health of caregivers while also reducing their perceived subjective and objective burden and anger.

Ali and Bokharey (2015) investigated anger, burden, and physical health of male and female dementia caregivers. Ten individuals were selected from Pakistani neurological and psychiatric facilities in Lahore. Informal male and female dementia caregivers aged 18 years and older were included in sample. Over five weeks, ten therapy sessions were held twice a week. Every session lasted for forty-five minutes. Pre- and post-treatment assessments were conducted with the subjects. The findings demonstrated a significant difference in caregiver burden, with women having a lower caregiver burden than men.

2.6 Caregiver Burden, Coping Strategies, and Quality of Life

Fong et al. (2023) investigated the various coping strategies of parents of autistic children in families with high vs low family quality of life (FQoL) ratings. Twelve Korean immigrant parents aged 30 to 59 years who had children with autism were included in the study, six of whom belonged to the group with a high FQoL and six of whom to the group with low FQoL. In their interviews, parents distinguished between three categories of coping strategies: problem, emotion, and adjustment-focused coping strategies. Parents with high FQoL, often used problem-focused coping strategies. Parents with both high and low FQoL, used emotion-focused coping strategies. Parents with high FQOL often mentioned the value of their faith and religious beliefs in coping with unpleasant emotions. Moreover, there were variations in adjustment-focused strategies across both groups. Those in the high FQoL group tended to expound more on their child's strengths in a variety of dimensions, whereas parents in the low FQoL group struggled in reframing their child's disability optimistically.

A systematic review on the relationship between parental stress, positive reappraisal coping, and quality of life (QoL) of parents of autistic children was carried out by Suen et al. (2021). Five databases were used to search for the literature. Only 29 articles, all cross-sectional studies that investigated ASD, were considered out of 5043 publications. The review sample comprised of 8392 parents. Majority of study participants in almost all the included studies were mothers. The findings showed that parents of autistic children reported significantly high stress levels, which was associated with poor QoL and the ineffective usage of coping strategies. A higher QoL was associated with adaptive coping strategies, whereas a lower QoL was related to maladaptive coping strategies. In addition, a significant inverse relationship was

found between parental stress, positive reappraisal coping, and QoL of parents of autistic children. Additionally, parental stress was found to be mitigated by positive reappraisal coping, which also served as a possible mediator between parental stress and QoL.

Marsack-Topolewski and Church (2019) used a mixed methods approach to investigate the impact of caregiver burden on quality of life (QoL) of parents of autistic adults. Three hundred and twenty parents aged 50 years and above who had an adult autistic child made up the sample. Online surveys and follow-up interviews were carried out. The QoL of parents was found to be significantly affected by developmental as well as financial burden. The strongest predictor of quality of life was found to be developmental burden which negatively impacted QoL. Qualitative results revealed that many parents experienced all four burdens.

A research on caregiver burden, coping strategies, and depression symptoms among Taiwanese mothers of autistic adolescents was carried out by Lin (2015). Sixty mothers of autistic adolescents between the ages of ten and 19 filled out written self-report surveys. Results showed that lower caregiver stress as well as fewer depressive symptoms were often related to a higher usage of problem-focused coping as opposed to emotion-focused coping. Moreover, problem-focused coping significantly buffered high caregiver burden. In particular, the coping strategies of actively confronting, suppressing competing activities, and planning moderated the relationship between caregiver burden and depressive symptoms in mothers.

2.7 Summary of Literature Review

Parents of autistic children experienced moderate to severe caregiver burden (Pandey & Sharma, 2018; Alnazly & Abojedi, 2019; Mumtaz et al., 2022; Aftab et al.,

2023) which was significantly positively correlated with child's autism features (Cetinbakis et al., 2020; Nighat et al., 2024) stress, and anxiety (Alnazly & Abojedi, 2019; Sit et al., 2020) and negatively correlated with life satisfaction (Cetinbakis et al., 2020; Khan et al., 2021). Moreover, its significant positive predictors were poor dyadic adjustment (Cetinbakis et al., 2020), self-stigma (Yıldız et al., 2021), depressive symptoms (Baykal et al., 2019), severity of ASD symptoms (Mumtaz et al., 2022), distraction and disengagement coping strategies, and its negative predictors were social support, spiritual well-being (Picardi et al., 2018), education level, and income level (Nighat et al., 2024).

The usage of maladaptive coping strategies was more prevalent among parents of autistic children (Vernhet et al., 2019; Hasan & ALsulami, 2024), thereby increasing parent's stress levels (Suen et al., 2021). However, adaptive coping strategies were positively related to quality of life (QoL), and negatively related to depression and anxiety (Suen et al., 2021; Demšar & Bakracevic, 2023). Moreover, problem focused, and emotion focused coping strategies were frequently identified (Ishtiaq et al., 2020; Wei-Chih et al., 2023). Problem focused coping strategies served as a protective factor for stress and burden, and improved QoL (Lin, 2015; Vernhet et al., 2019), whereas emotion focused coping strategies served as a risk factor for impairment (Vernhet et al., 2019). Moreover, positive reappraisal coping strategy mediated the relationship between parental stress and QoL.

Quality of life (QoL) of parents of autistic children was significantly lower than parents of mainstream children and with other disorders (Alenazi et al., 2020; Ali et al., 2021; Abd-Alnabi & Sachet, 2022; Khan et al., 2022; Volgyesi-Molnar et al., 2024). Moreover, both primary and secondary caregivers reported similar levels of QoL (Faden et al., 2023; Davy et al., 2024; Nouira et al., 2024). Furthermore, QoL

was significantly positively correlated with perceived social support (Kausar et al., 2021; Khan et al., 2022; Dai et al., 2024), income (Alenazi et al., 2020; Abd-Alnabi & Sachet, 2022), and education level (Waheed et al., 2020; Abd-Alnabi & Sachet, 2022). However, QoL was significantly negatively correlated with child's problem behaviors (Waheed et al., 2020; Musetti et al., 2024) and unemployment (Alenazi et al., 2020; Waheed et al., 2020). Moreover, developmental burden was found to be the strongest negative predictor of QoL (Marsack-Topolewski & Church, 2019).

Cognitive behavioral therapy (CBT) interventions significantly reduced anxiety, depression, stress, psychological distress, as well as caregiver burden (Izadi-Mazidi et al., 2015; Onyishi et al., 2023; Li et al., 2023; Abdelaziz et al., 2024), and significantly improved parental wellbeing at post assessment and 1 month follow up levels in caregivers of autistic children (Li et al., 2023; Abdelaziz et al., 2024).

2.8 Rationale

In the past few decades, there has been a notable rise in the prevalence of ASD (McConkey et al., 2019), with an estimated 350,000 children in Pakistan having ASD (Khalid et al., 2021). The diagnosis of autism not only alters the life of the diagnosed child but also brings about significant changes in the lives of caregivers (Hansen et al., 2018; Mercado et al., 2021).

Literature indicates that caregivers of autistic children and adolescents experience higher psychological distress, higher caregiver burden, poorer mental health, more symptoms of anxiety and depression, as well as lower quality of life (QoL) in comparison to caregivers of children and adolescents without ASD or with other disorders (Turnage & Conner, 2022; Warreman et al., 2023; Faden et al., 2023). Moreover, high caregiver burden lowers quality of caregivers (Marsack-Topolewski

& Church, 2019). And caregivers use different coping strategies to deal with the stress experienced due to the excessive demands of caregiving. The use of maladaptive coping strategies lowers the QoL of caregivers whereas, use of adaptive coping strategies improves their QoL (Suen et al., 2021).

Existing research highlights the significance of caregiver burden-reduction treatments due to the possible influence of caregiver's well-being on caregiving and the resulting decrease in caregiver burden (Osborne et al., 2008; Giallo et al., 2013; Silaule et al., 2023). However, both internationally and in Pakistan, there is a scarcity of research on investigating the efficacy of interventions for alleviating caregiver burden (Jabeen et al., 2024). And those limited researches mostly used unidimensional interventions (such as psychoeducational, communication, coping strategies, or CBT interventions) rather than integrative interventions for reducing caregiver burden (Schaffer, 2022). And literature suggests that integrative treatment approaches produce better effects (Gallagher-Thompson & Coon, 2007; Walter & Pinquart, 2020). Moreover, in Pakistan, no study has yet investigated the efficacy of integrative, multicomponent, group-based cognitive behavioral therapy (CBT) for reducing caregiver burden, improving coping strategies, and quality of life among caregivers of children and adolescents with autism spectrum disorder. Therefore, there is a need to investigate the efficacy of this novel treatment approach for this neglected population (Jabeen et al., 2024).

2.9 Objective (Phase 1)

 To screen the individuals who are caregivers of children and adolescents with autism spectrum disorder for high caregiver burden.

2.10 Objectives (Phase 2)

- To assess the efficacy of Integrative, Multi-component, Group-based
 Cognitive Behavior Therapy (CBT) for reducing caregiver burden in
 caregivers of children and adolescents with autism spectrum disorder.
- To assess the efficacy of Integrative, Multi-component, Group-based
 Cognitive Behavior Therapy (CBT) for improving coping strategies in
 caregivers of children and adolescents with autism spectrum disorder.
- To assess the efficacy of Integrative, Multi-component, Group-based
 Cognitive Behavior Therapy (CBT) for improving quality of life of caregivers
 of children and adolescents with autism spectrum disorder.

2.11 Hypotheses (Phase 2)

- Integrative multicomponent, group-based cognitive behavioral therapy (CBT) will reduce caregiver burden (*time dependence, developmental, physical, social, and emotional*) at post assessment level in caregivers of children and adolescents with autism spectrum disorder.
- Integrative multicomponent, group-based cognitive behavioral therapy (CBT)
 will increase the usage of active coping strategies and decrease the usage of
 passive coping strategies at post assessment level in caregivers of children and
 adolescents with autism spectrum disorder.
- Integrative multicomponent, group-based cognitive behavioral therapy (CBT) will improve quality of life (physical, psychological, social, and environmental) at post assessment level in caregivers of children and adolescents with autism spectrum disorder.

Method

The current research consisted of two phases. *Phase 1* involved screening of caregivers for intervention groups. *Phase 2* was an outcome study in which the efficacy of Integrative, Multi-component, Group-based Cognitive Behavior Therapy (CBT) for caregivers of children and adolescents with autism spectrum disorder was investigated.

3.1 Phase 1

3.1.1 Sample and Sampling Technique

Phase 1 included a sample of N=52 caregivers of children and adolescents with autism spectrum disorder (ASD) including fathers, n=6 and mothers, n=46. The age range of the caregivers was between 26-60 years (M = 36.85, SD = 7.25). The sample was recruited from public and private autism centers, hospitals, and special education institutes of Islamabad. Nonprobability purposive sampling technique was employed in the current study.

3.1.1.1 Inclusion Criteria.

- Those participants were included, who were primary caregivers of children and adolescents under the age of 18 years with moderate to severe levels of autism spectrum disorder.
- Only parents were considered primary caregivers.

3.1.1.2 Exclusion Criteria.

 Those participants were excluded, who were with severe medical or mental health problems.

3.1.2 Operational Definition

- **3.1.2.1 Caregiver Burden.** Caregiver burden refers to caregiver's feelings of burden caused by various challenges such as time commitment, financial pressure, developmental challenges, and emotional difficulties caregivers encounter while performing their caregiving responsibilities. On caregiver burden inventory (CBI), a total score of 36 or higher indicates that the individual has high caregiver burden (Novak & Guest, 1989, as cited in Schaffer, 2022).
- 3.1.2.1.1 Time Dependence Burden. Time dependence burden is defined as feelings of burden experienced by caregivers due to time constraints (Novak & Guest, 1989, as cited in Schaffer, 2022).
- 3.1.2.1.2 Developmental Burden. Developmental burden can be defined as caregivers' feelings of being behind in their developmental level as compared to their contemporaries (Novak & Guest, 1989, as cited in Schaffer, 2022).
- 3.1.2.1.3 Physical Burden. Physical burden is defined as caregivers' feelings of persistent weariness and deterioration of their physical health (Novak & Guest, 1989, as cited in Schaffer, 2022).
- 3.1.2.1.4 Social Burden. Social burden implies caregivers' feelings of role conflict, including disputes with their partner or other family members regarding the management of their care recipient's needs, feelings of being disregarded and neglected by others, and limiting the time as well as the energy they invest in relations or their jobs (Novak & Guest, 1989, as cited in Schaffer, 2022).
- **3.1.2.1.5** *Emotional Burden.* Emotional burden refers to unpleasant feelings of caregivers towards their care recipients, which might be caused by care recipient's

unpredictable and sometimes odd behavior, as well as feelings of guilt about such socially undesirable feelings (Novak & Guest, 1989, as cited in Schaffer, 2022).

- **3.1.2.2 Coping Strategies.** Coping strategies are cognitive and behavioral techniques used by people to deal with internal and external demands that they consider to be beyond their capacities or overwhelming (Rosas-Santiago et al., 2017).
- 3.1.2.2.1 Active Coping. Active coping refers to those coping strategies that entail proactively dealing with risks and their repercussions. High on score active coping subscale of Coping Strategies Scale for Primary Informal Caregivers (CSSPIC) scale represents more usage of active coping strategies (Rosas-Santiago et al., 2017).
- 3.1.2.2.2 Passive Coping. Passive coping is characterized by strategies such as rejection, denial, and passive acceptance of risks. High score on passive coping subscale of Coping Strategies Scale for Primary Informal Caregivers (CSSPIC) scale represents more usage of passive coping strategies (Rosas-Santiago et al., 2017).
- **3.1.2.3 Quality of Life.** Quality of life (QOL) refers to subjective evaluation of a person regarding their overall life situation taking into consideration the cultural and value systems they are a part of, along with their goals, standards, expectations, and concerns. High scores on WHO Quality of Life Scale-Brief (WHOQOL-Brief) means that the individual has good quality of life (WHO, 1996, as cited in Kelley-Gillespie, 2009).
- 3.1.2.3.1 Physical Health. Physical health is described as a person's subjective evaluation of various aspects of body function, such as mobility, daily activities, energy levels, sense of pain, and quality of sleep. High score on physical health

domain of WHO Quality of Life Scale-Brief (WHOQOL-Brief) means that the individual has good physical health (WHO, 1996, as cited in Nejat et al., 2006).

3.1.2.3.2 Psychological Health. Psychological health implies self-perception of an individual, the presence of negative cognitions, the development of positive attitudes, self-esteem, cognitive abilities including memory and learning, spiritual or religious beliefs, and mental health. High score on psychological domain of WHO Quality of Life Scale-Brief (WHOQOL-Brief) means that the individual has good psychological health (WHO, 1996, as cited in Nejat et al., 2006).

3.1.2.3.3 Social Relationships. Social relationships refer to subjective perception of an individual regarding their sex life, personal relationships, and availability of support from others. High score on social relationships domain of WHO Quality of Life Scale-Brief (WHOQOL-Brief) means that the individual has good social relationships (WHO, 1996, as cited in Nejat et al., 2006).

3.1.2.3.4 Environmental Quality of Life. Environmental quality of life implies a person's subjective evaluation of their financial resources, sense of safety and security, access to social and medical services, the state of their physical surroundings overall, opportunities for learning and personal development, options for entertainment, exposure to environmental factors like noise and air pollution, and the ease of transportation. High score on environment domain of WHO Quality of Life Scale-Brief (WHOQOL-Brief) means that the individual has good environmental quality of life (WHO, 1996, as cited in Nejat et al., 2006).

3.1.3 Assessment Measures

In *phase 1* of the present research, the following three measures and demographic information sheet were used for assessment:

- Demographic information sheet
- Caregiver Burden Inventory (CBI)
- Coping Strategies Scale for Primary Informal Caregivers (CSSPIC)
- WHO Quality of Life Scale-Brief (WHOQOL-Brief)

3.1.3.1 Demographic Information Sheet. The researcher developed a sheet to obtain information from research participants related to their age, gender, education, employment status, family structure, number of children, relationship with the care recipient, daily caregiving hours, utilization of respite care from maids or family members and their number of hours of assistance and information about their care recipient (age, gender, level of severity of autism spectrum disorder, and the duration of institutional care in years).

3.1.3.2 Caregiver Burden Inventory (CBI). The Caregiver Burden Inventory (CBI) was used to measure caregiver burden. CBI is a comprehensive self-report inventory designed to evaluate how burdened caregivers feel about their caregiving responsibilities. It consists of 24 items and has five subscales: *time-dependence burden, developmental burden, physical burden, social burden,* and *emotional burden*. A 4-point Likert scale with the following response options ($0 = not \ at \ all, 1 = very \ little, 2 = moderately, 3 = much, or 4 = very much)$ is used to rate each item. Higher scores indicate a greater burden. On CBI total burden scale, those with a score of 36 or above are considered to have an elevated need for interventions designed to lower their caregiver burden. The Cronbach's alpha reliability of each subscale is as follows: ($\alpha = .85$) for time-dependence burden, ($\alpha = .87$) for developmental burden, ($\alpha = .86$) for physical burden, ($\alpha = .69$) for social burden, and ($\alpha = .81$) for emotional burden. Additionally, the total burden scale demonstrates internal consistency with $\alpha > .80$ (Novak & Guest, 1989).

3.1.3.3 Coping Strategies Scale for Primary Informal Caregivers

(CSSPIC). Coping strategies were assessed by Coping Strategies Scale for Primary Informal Caregivers (CSSPIC) developed by Rosas-Santiago and colleagues in 2017. CSSPIC is a self-report measure, originally adapted from the Extreme Coping Scale of López -Vázquez and Marván (2004) for application to informal caregivers. CSSPIC consists of 20 items and a 5-point Likert scale (1 = strongly disagree to 5 = strongly agree) is used to rate each item. It comprises two factors; the first, named active coping, is made up of the same 14 items of the original scale (López-Vázquez & Marván, 2004), and has a Cronbach's alpha of .837. The second factor, named passive coping, includes six of the original scale's 12 items (López-Vázquez & Marván, 2004) and has a Cronbach's alpha of .718. The CSSPIC is a valid, and reliable instrument with an overall reliability of .743 (Rosas-Santiago et al., 2017).

3.1.3.4 WHO Quality of Life Scale-Brief (WHOQOL-Brief). Quality of life (QOL) was assessed by the World Health Organization Quality of Life-BRIEF (WHOQOL-BRIEF). It is a shorter version of the WHOQOL-100 (WHOQOL Group, 1994), a commonly used tool for evaluating quality of life. The WHOQOL-BRIEF comprises 26 items in total, two general and 24 corresponding to each of the 24 facets that form the original instrument and cover the four domains of *physical*, *psychological*, *social*, *and environmental*. Multiple aspects are used to represent each domain. Questions were constructed to fall into four categories on a 5-point Likert-type scale: intensity (nothing–extremely), capacity (nothing–completely), evaluation (very dissatisfied–very satisfied; very bad–very good), and frequency (never–always). The physical subscale's items 3 and 4 as well as the psychological subscale's item 26 are back scored. The WHOQOL-Brief is a reliable and valid instrument. The four

domain scores' Cronbach alpha values vary from.66 to.84, indicating good internal consistency. (WHOQOL Group, 1998).

3.1.4 Procedure

Prior to commencing the study, the university's competent authorities approved the research topic. Before using the assessment tools to collect data, permission was taken from the respective authors for using study scales. For data collection official permission was obtained from public and private autism centers, hospitals, and special education institutes of Islamabad city via a letter from the Department of Professional Psychology, Bahria University, Islamabad. The informed consent and information sheet was created to inform the participants about the study's rationale, ensure confidentiality, and their right to withdraw from the study at any time throughout the evaluation. Informed consent was obtained from caregivers of children and adolescents, diagnosed with autism spectrum disorder who were receiving services from above mentioned institutes, for their participation after they had been completely informed about the study. All study participants were informed about the purpose of the study. Following that, questionnaires were distributed to them.

3.1.5 Ethical Considerations

While conducting *phase 1* of the current study, the following ethical considerations were considered.

- The research topic was approved by the university's competent authorities.
- Permission to use the scales was obtained from the respective authors.
- Before data collection, heads of institutes were informed about the nature of the study and their permission was obtained for data collection.

- Informed consent was obtained from participants after completely briefing them about the study.
- The participants were kept anonymous, and the confidentiality of the data was preserved.
- The results were presented accurately.

3.2 Phase 2

Phase 2 was an outcome study in which the efficacy of Integrative, Multicomponent, Group-based Cognitive Behavior Therapy (CBT) for caregivers of children and adolescents with autism spectrum disorder was investigated.

3.2.1 Research Strategy

Qusai- Experimental research strategy was used.

3.2.2 Research Design

Pretest posttest research design was used.

3.2.3 Sample and Sampling Technique

The sample consisted of N=9 mothers. Two intervention groups were formed based on location feasibility, with group 1 (n=5), and group 2 (n=4) who were screened in *phase 1*. The age range of participants was between 31-54 years (M = 40.33, SD = 8.41). The sample was recruited from Behavior And Special Education Services (BASES), and Rehabilitation Centre for Children with Developmental Disorders (RCCDD), Islamabad using a non-probability purposive sampling technique.

3.2.3.1 Inclusion Criteria.

- Those caregivers were included who scored 36 or above on caregiver burden inventory (CBI).
- Those caregivers were included who had been available for the scheduled time for group treatment.

3.2.4 Intervention

Integrative, Multi-component, Group-based Cognitive Behavior Therapy (CBT) was developed by Daniel Robert Schaffer (2022). It is an intervention for the stress, strain, and burden that the primary informal caregivers of people who require significant support because of any sickness or disorder endure because of the psychological, financial, social, and physical demands of caregiving. It alleviates caregiver burden, symptoms of depression and anxiety, and role captivity in primary informal caregivers. The strategies and techniques used in this intervention improve the distress tolerance of caregivers and their feelings of independence or agency, lowering their perceived feelings of role captivity and lowering overall caregiver burden. The above-mentioned intervention involves eight weekly group sessions, each spanning an hour (Schaffer, 2022).

3.2.4.1 Treatment Protocol.

No. of	Rationale	Techniques
sessions	To improve	Introduction to the group
2	To improve understanding of caregiver	Introduction to the group, Overview of group therapy,
	burden and distress.	Rules of group sessions,
	burden and distress.	Education about caregiver stress.
	To reduce physical	_
	stress level, thereby	Education on relaxation strategies and their benefits,
	alleviating overall caregiver	In-group examples of three common
	burden and enhancing	relaxation strategies i.e., deep breathing,
	distress tolerance.	progressive muscle relaxation, and guided
	distress tolerance.	imagery.
3	To reduce overall	Education on mindfulness
	absorption in caregiving-	Mindfulness Activity- Mindfulness of
	related stressors to reduce	Breathing.
	perceived levels of role	
	captivity.	
4	To enhance distress	Education and discussion on pleasant
	tolerance, boost a sense of	activities and consequent stress reduction.
	personal agency, and	Discussion and planning of pleasant
	increase feelings of mastery	activities for themselves and their care
	and life satisfaction.	recipients for the coming week.
		Discussion on barriers for pleasant
		activities and plans to overcome them.
5 & 6	To help in	Introduction to negative automatic
	approaching stressors with	thoughts as well as cognitive distortions.
	more accurate appraisals,	Identification of negative thoughts and
	and lower distress levels.	cognitive distortions.
78	TF C 41 C 4 1	Thought challenging.
	To further foster and	Group discussion on problem behaviors of
	utilize group social support	their care recipients.
	in real-time from an interpersonal perspective	Group or peer support and social support. Group discussion on how these problem
	and group-based problem	behaviors can be managed or group-based
	solving.	problem solving.
	To avoid the pain	Summary and reflection on prior sessions.
	associated with termination	Discussion on what the group members
	and prevent relapse.	found most helpful in therapy.
	r	Reflection on personal growth.
		Discussion on strategies that had been
		learnt in previous sessions which can be
		continually used even after the end of
		therapy.

(Schaffer, 2022).

3.2.5 Procedure

Firstly, permission was sought from the developer of the therapy for its utilization in the present study. For conducting therapeutic sessions, Behavior And Special Education Services (BASES), and Rehabilitation Centre for Children with Developmental Disorders (RCCDD) were approached. After a briefing about the nature of therapy, permission was taken from the heads of above-mentioned institutes for conducting therapeutic sessions.

The target was to give therapy to 15 participants. For intervention groups, the participants were selected from *phase 1* based on their obtained score (above cut-off) on caregiver burden inventory. From *phase 1*, 35 participants scored high on caregiver burden. But 26 participants did not give consent for therapy. Initially, two intervention groups were formed based on the feasibility of location and time: group 1 (n=5) and group 2 (n=6), but later group 2 retained 4 participants (n=4) (one left due to medical issues, one went to another city).

After providing complete information about therapeutic sessions, and their participation rights informed consent was taken from the participants. The schedule for conducting intervention sessions was made and then sessions were started accordingly. With each intervention group, 8 sessions were carried out. Following the conclusion of the sessions, post assessment was conducted utilizing the same assessment scales used in *phase 1* to evaluate the effectiveness of the intervention for caregivers of children and adolescents with autism spectrum disorder. Statistical analyses were carried out and results were accurately reported.

3.2.6 Therapy Sessions

3.2.6.1 Session One. Session one included an introduction to the group, an overview of group therapy process, and a discussion of the rules and norms for the sessions. Additionally, participants received education on caregiver stress. Following that they were encouraged to record their level of caregiver distress throughout the duration of therapy to foster ongoing insight into these symptoms.

3.2.6.2 Session Two. Session two began with the discussion on the level of caregiver stress that the participants experienced and their highest daily rating during the last week. Then education on relaxation strategies, and their benefits for reducing stress levels (Beck, 2020) was discussed. They were provided in-group examples of three common relaxation strategies i.e., deep breathing, progressive muscle relaxation, and guided imagery. Each relaxation strategy was taught to the participants and was rehearsed during the session. The participants were given homework of practicing a minimum of one relaxation strategy every day and of filling the caregiver stress symptom checklist. The participants were provided handouts of the guidelines for practicing relaxation strategies along with worksheets to track their daily rating of caregiver stress and that of relaxation. They were also provided links of audio recordings for the strategies taught in the session, to help them practice those strategies outside of the session accurately.

3.2.6.3 Session Three. Session three began with a brief review of the last session and discussed their home practice of relaxation and their level of caregiver stress. Then education was provided about mindfulness followed by a group discussion, and the in-session practice of mindfulness of breathing activity, again followed by a group discussion. Then participants were given homework of practicing

mindfulness for a minimum of 5 to 10 minutes every day, and to carry on practicing relaxation strategies and filling caregiver stress symptom checklist in the following week. In the end, participants were provided worksheets to track their practice of mindfulness, relaxation, and caregiver stress, along with audio recording of the mindfulness of breathing activity.

3.2.6.4 Session Four. Session four centered around behavioral activation through pleasant activities. Similar to the other sessions, this one was psychoeducational and skills-based, combining support and education with behavioral skills emphasis of behavioral activation. In the start of the session, home practice of mindfulness and relaxation, along with the participant's level of caregiver stress was discussed. Then education and discussion on pleasant activities and their potential to alleviate stress ensued. In addition to discussing and encouraging safety throughout this process, participants were asked to plan a minimum of two pleasant activities for the next week i.e., one for themselves and one with their care recipients. A pleasant activity scheduling worksheet was given to the participants. Furthermore, they were encouraged to talk about barriers in performing pleasant activities along with strategies to get over them. In the end they were given the homework of pleasant activities and were asked to continue the previous homework.

3.2.6.5 Session Five. Identifying negative automatic thoughts was the main focus of session five. It began with a quick recap of the previous session on pleasant activities followed by a check-in process of the homework. With the use of examples, education on automatic thoughts and the relationship between situations, thoughts, emotions, and physiological and behavioral reactions was given. A little group discussion on the same topic came next. After giving the participants, a handout on cognitive distortions and giving them some time to read it, the researcher continued to

explain with examples. Following that, a group discussion was encouraged, and the participants were asked to identify the cognitive distortions they use.

Subsequently, participants received thought record part one along with an example of how to identify negative automatic thoughts and associated emotions. A group discussion ensued, during which they were encouraged to provide further instances of their own. In the end, they were given the homework that required them to track their automatic thoughts and cognitive distortions over the next week, and to continue the previous homework.

3.2.6.6 Session Six. Challenging and reframing negative thoughts was the main focus of session six. The session began with a quick recap of the last session on identifying automatic thoughts and cognitive distortions, followed by a check in process to review their homework. Participants were then educated about thought challenging in which they were taught multiple ways to challenge their thoughts including identifying the evidence for and against the negative automatic thought, imagining what they would say to a friend, looking at the actual likelihood of the thought, and weighing the pros and cons of the thought etc. The participants were then provided thought record part two which was discussed with an example, followed by a group discussion. Then a handout on 20 questions to challenge negative automatic thoughts was provided to the participants to review and following a group discussion on it. In the end, the participants were given homework to practice thought challenging in the following week along with previous homework.

3.2.6.7 Session Seven. Session seven began with a quick recap of last session on thought challenging along with a check in process to review homework. This session was completely discussion based. The participants were asked to share their

ways of coping and dealing with the problematic behaviors of their autistic children and adolescents. After that some general strategies for reducing problem behaviors in autistic children and adolescents were discussed. For further information on managing problem behaviors links of websites were shared. In the end they were asked to continue the previous homework.

3.2.6.8 CBT Session Eight. Session eight was a concluding session. In this session, the main goals were to review the therapy that had been administered so far, discuss the things that group members felt were most beneficial, and provide an open and supportive environment for them to process, reflect on, and share any benefits they realized from their treatment. Moreover, session eight met aims of termination planning and relapse prevention by allocating time to discuss the particular techniques acquired in earlier sessions which they could continue after the termination of treatment. At the end of the session, a Facebook link for a support group on autism was shared with the client.

3.2.7 Ethical Considerations

While conducting *phase 2* of the current study, the following ethical considerations were considered.

- Permission for utilizing the therapeutic protocol was obtained from its developer.
- For conducting therapeutic sessions permission was taken from the head of institutes.
- Before conducting therapy, heads of institutes and participants were briefed about the research as well as the nature of therapy.

- Informed consent was obtained from participants for their participation in therapy.
- The participants were kept anonymous, and the confidentiality of the data was preserved.
- The results were presented accurately.

Results

The present study was aimed at investigating the therapeutic efficacy of integrative, multicomponent, group-based cognitive behavioral therapy (CBT) for caregivers of children and adolescents with autism spectrum disorder. In step I descriptive statistics were calculated for the demographic characteristics for *phase 1* and *phase 2* of the present study. Additionally, the descriptive statistics and reliability analysis were also calculated for caregiver burden, coping strategies, and quality of life for *phase 1* and *phase 2* of present study.

In step II, one-way repeated measures analysis of variance (ANOVA) to examine the differences in caregiver burden, coping strategies, quality of life across pre assessment and post assessment level was executed for *phase* 2 of present study.

4.1 Phase 1

4.1.1 Descriptive Statistics

Descriptive statistics for demographic characteristics (age, gender, education, employment status, family structure, number of children, relationship with the care recipient, daily caregiving hours, utilization of respite care from maids or family members and their number of hours of assistance) of participants and their care recipients (age, gender, level of severity of autism spectrum disorder, and the duration of institutional care in years) are presented. Also, the descriptive statistics and reliability analysis of caregiver burden, coping strategies, quality of life, and their subscales are presented.

Table 4.1Descriptive Statistics of Demographic Characteristics of the Sample, (N=52).

Sample Characteristics	f	%	M	SD
Age			36.85	7.25
Gender				
Male	6	11.5		
Female	46	88.5		
Education (years)			16.27	2.68
Employment Status				
Employed	19	36.5		
Unemployed	33	63.5		
Family Structure				
Nuclear	33	63.5		
Joint	19	36.5		
Number of Children			2.59	1.40
Relationship with Care-recipient				
Mother	46	88.5		
Father	6	11.5		
Hours of Caregiving Per Day			16.54	8.73
Respite Care				
Yes	27	51.9		
No	25	48.1		
Hours of Respite Care Per Day			6.19	9.38
Age of Care-recipient			7.10	3.49
Gender of Care-recipient				
Boys	44	84.6		
Girls	8	15.4		
Severity of Autism Spectrum Disorder				
Moderate	42	80.8		
Severe	10	19.2		
Care-recipient's Duration of Institutional Care (years)			2.21	1.96

Note. M=mean, SD=standard deviation, f=frequency, %=percentage.

Table 4.1 shows that the average age of participants was 36.85 years with a standard deviation of 7.25. In a total sample of 52 participants, 11.5% were male participants, whereas 88.5% of participants were females. Moreover, their average years of education was 16.28 with a standard deviation of 2.68. Furthermore, 36.5% of the participants were employed, whereas 63.5% were unemployed. Additionally, 63.5% of the participants had a nuclear family structure, whereas 36.5% had a joint

family structure. They had an average number of 2.59 children with a standard deviation of 1.40.

Out of 52 participants, 88.5% of participants were mothers, and 11.5% were fathers of children and adolescents with autism spectrum disorder. The average hours of caregiving per day were 16.54 with a standard deviation of 8.73. Moreover, 51.9% of participants received respite care with an average of 6.19 hours of respite care per day and a standard deviation of 9.38, whereas 48.1% participants did not receive respite care.

The average age of care recipients was 7.10 years with a standard deviation of 3.49. Out of 52 care recipients, 84.6% of care recipients were boys, whereas 15.4% were girls. Moreover, 80.8% of care recipients had moderate level of severity of autism spectrum disorder, whereas 19.2% had severe level of severity. Furthermore, the average duration of therapies received by the care recipients was 2.21 years with a standard deviation of 1.96.

4.1.1.1 Descriptive Statistics and Reliability Analysis.

Table 4.2

Descriptive statistics and Cronbach's Alpha for Caregiver Burden, Coping Strategies, and Quality of Life in Caregivers of Children and Adolescents with Autism Spectrum Disorder (N=52).

***			a=	Ra		
Variables	k	M	SD	Actual	Potential	- α
Caregiver Burden	24	40.17	15.83	9-73	0-96	.89
Time Dependence	5	12.71	4.57	2-20	0-20	.86
Developmental Burden	5	10.17	5.02	1-20	0-20	.81
Physical Burden	4	6.25	4.13	0-16	0-16	.81
Social Burden	5	6.19	4.38	0-18	0-20	.74
Emotional Burden	5	4.85	4.55	0-17	0-20	.86
Coping Strategies	20					
Active Coping	14	55.81	9.81	27-69	14-70	.87
Passive Coping	6	18.85	5.67	9-29	6-30	.77
Quality of Life	26	89.04	13.26	55-120	26-130	.91
Physical Health	7	23.46	4.04	13-31	7-35	.69
Psychological Health	6	20.02	3.56	10-27	6-30	.72
Social Relationships	3	10.08	2.61	4-15	3-15	.75
Environmental QoL	8	28.40	4.12	17-39	8-40	.76

Note. $QoL = quality of life, k = number of items, M = mean, SD = standard deviation, <math>\alpha = Cronbach$'s Alpha.

Table 4.2 shows the descriptive statistics, including the mean, standard deviation, actual and potential ranges, and internal consistency using Cronbach's alpha reliability of caregiver burden (time dependence burden, developmental burden, physical burden, social burden, emotional burden), coping strategies (active coping, passive coping), and quality of life (physical health, psychological health, social relationships, environmental quality of life) in caregivers of children and adolescents with autism spectrum disorder.

The reliability evaluation exhibited excellent reliability for quality of life; very good reliability for caregiver burden, *time dependence burden*, *developmental burden*,

physical burden, and emotional burden; good reliability for social burden, passive coping, psychological health, social relationships, and environmental quality of life; and acceptable reliability for physical health.

4.2 Phase 2

4.2.1 Descriptive Statistics

Descriptive statistics for demographic characteristics (age, gender, education, employment status, family structure, number of children, relationship with the care recipient, daily caregiving hours, utilization of respite care from maids or family members and their number of hours of assistance) of participants and their care recipients (age, gender, level of severity of autism spectrum disorder, and the duration of institutional care in years) are presented. Also, the descriptive statistics and reliability analysis of caregiver burden, coping strategies, and quality of life and their subscales are presented.

Table 4.3Descriptive Statistics of Demographic Characteristics of the Sample, (N=9).

Sample Characteristics	f	%	M	SD
Age			40.33	8.41
Gender				
Female	9	100		
Education (years)			16.22	2.54
Employment Status				
Unemployed	9	100		
Family Structure				
Nuclear	7	77.8		
Joint	2	22.2		
Number of Children			3.11	2.03
Relationship with Care-recipient				
Mother	9	100		
Hours of Caregiving Per Day			20.89	5.42
Respite Care				
Yes	2	22.2		
No	7	77.8		
Hours of Respite Care Per Day			0.75	1.49
Age of Care-recipient			7.96	3.84
Gender of Care-recipient				
Boys	7	77.8		
Girls	2	22.2		
Severity of Care-recipient's Diagnosis				
Moderate	9	100		
Care-recipient's Duration of Institutional Care			3.06	1.70
(years)				

Note. M=mean, *SD*=standard deviation, *f*=frequency, %=percentage.

Table 4.3 shows that the average age of participants was 40.33 years with a standard deviation of 8.41. In a sample of 9 participants, 100% of the participants were females. Moreover, their average years of education was 16.22 with a standard deviation of 2.54. Moreover, 100% of participants were unemployed. Additionally, 77.8% of participants had a nuclear family structure, whereas 22.2% had a joint family structure. They had an average number of 3.11 children with a standard deviation of 2.03.

Out of 9 participants, 100% were mothers of children and adolescents with autism spectrum disorder. The average hours of caregiving per day were 20.89 with a standard deviation of 5.42. Moreover, 22.2% of participants received respite care with an average of 0.75 hours of respite care per day and a standard deviation of 1.49, whereas 77.8% participants did not receive respite care.

The average age of care recipients was 7.96 years with a standard deviation of 3.84. Moreover, 77.8% of care recipients were boys, whereas 22.2% were girls. Furthermore, 100% of care recipients had moderate level of severity of autism spectrum disorder. Moreover, the average duration of therapies received by the care recipients was 3.06 years with a standard deviation of 1.70.

4.2.1.1 Descriptive Statistics and Reliability Analysis.

Table 4.4Descriptive statistics and Cronbach's Alpha for Caregiver Burden, Coping Strategies, and Quality of Life in Caregivers of Children and Adolescents with Autism Spectrum Disorder (N=9).

				Ranges		
Variable	k	M	SD	Actual	Potential	α
Caregiver Burden	24	51.06	14.60	36-73	0-96	.86
_	24	44.78	10.17	32-59	0-96	.69
Time Dependence Burden	5	14.22	3.93	9-20	0-20	.80
	5	12.00	<i>3.78</i>	7-18	0-20	.85
Developmental Burden	5	14.00	3.39	9-18	0-20	.70
	5	8.67	2.78	5-15	0-20	.60
Physical Burden	4	8.22	3.11	4-13	0-16	.68
	4	7.67	3.24	2-13	0-16	.68
Social Burden	5	8.28	6.33	1-18	0-20	.86
	5	5.33	3.16	1-10	0-20	.73
Emotional Burden	5	6.33	6.32	0-17	0-20	.93
	5	2.67	2.06	1-7	0-20	.63
Coping Strategies	20					
Active Coping	14	56.89	4.729	51-64	14-70	.60
	14	57.11	3.621	53-62	14-70	.76
Passive Coping	6	15.78	3.528	9-21	6-30	.82
	6	11.89	3.790	8-19	6-30	.66
Quality of Life	26	86.89	10.29	76-102	26-130	.86
	26	96.67	6.40	88-110	26-130	.81
Physical Health	7	23.22	2.279	20-27	7-35	.62
	7	24.89	2.205	22-29	7-35	.72
Psychological Health	6	20.78	3.270	16-25	6-30	.65
	6	21.89	2.028	19-26	6-30	.62
Social Relationships	3	9.00	2.693	5-12	3-15	.63
-	3	11.89	1.764	10-15	3-15	.62
Environmental QoL	8	27.44	3.504	21-32	8-40	.69
	8	30.89	3.060	25-35	8-40	.68

Note. Non-italicized=pre, Italicized=post, QoL = quality of life, k = number of items, M = mean, SD = standard deviation, $\alpha = Cronbach$'s Alpha.

Table 4.4 shows the descriptive statistics, including the mean, standard deviation, actual and potential ranges, and internal consistency using Cronbach's alpha reliability of caregiver burden (time dependence burden, developmental burden,

physical burden, social burden, emotional burden), coping strategies (active coping, passive coping), and quality of life (physical health, psychological health, social relationships, environmental quality of life) in caregivers of children and adolescents with autism spectrum disorder at pre- and post-assessment levels.

The reliability evaluation exhibited excellent reliability for *emotional burden* at pre assessment level; very good reliability for caregiver burden, *social burden*, *passive coping* at pre assessment level, *time dependence burden*, and quality of life at pre and post assessment level; good reliability for *developmental burden* at pre assessment level, *social burden*, *active coping*, and *physical health* at post assessment level; and acceptable reliability for caregiver burden, *developmental burden*, *emotional burden* at post assessment level, *physical burden* at pre and post assessment level, *active coping* at pre assessment level, *passive coping* at post assessment level, all subscales of quality of life at both pre and post assessment level except *physical health* subscale at post assessment level.

4.2.2 One-Way Repeated Measures Analysis of Variance (ANOVA)

It was hypothesized that integrative multicomponent, group-based cognitive behavioral therapy (CBT) would reduce caregiver burden (time dependence, developmental, physical, social, and emotional), increase the usage of active coping strategies and decrease the usage of passive coping strategies, and improve quality of life (physical, psychological, social, and environmental) at post assessment level in caregivers of children and adolescents with autism spectrum disorder. One-way repeated measures analysis of variance (ANOVA) was executed to assess the efficacy of integrative, multicomponent, group-based cognitive behavioral therapy (CBT).

Table 4.5Results of One-Way Repeated Measures Analysis of Variance Examining Differences in Caregiver Burden in Caregivers of Children and Adolescents with Autism Spectrum

Disorder Across Pre and Post Assessment Levels (N=9).

Variable	Pre		Post		F (1,8)	Partial η²
	\overline{M}	SD	М	SD	=	_
Time Dependence Burden	14.22	3.93	12.00	3.78	228.57***	.966
Developmental Burden	14.00	3.39	8.67	2.78	16.79^{**}	.677
Physical Burden	8.22	3.11	7.67	3.24	.22	.026
Social Burden	8.28	6.33	5.33	3.16	3.46	.302
Emotional Burden	6.33	6.32	2.67	2.06	4.57^{*}	.363

Note. ***p<.001, **p<.05; *M*=*Mean*; *SD*=*Standard Deviation*; η ²=*Effect Size.*

Table 4.5 shows the results of one-way repeated measures analysis of variance indicating significant mean differences in caregiver burden across pre and post assessment levels in caregivers of children and adolescents with autism spectrum disorder. Multivariate analysis revealed that the integrative multicomponent group-based cognitive behavioral therapy (CBT) significantly reduced overall caregiver burden in the caregivers at post assessment level with F(9,72) = 9.30, p<.001, with a large effect size (partial $\eta^2=.538$). Moreover, univariate analysis evidenced a significant reduction in *time dependence burden*, *developmental burden*, and *emotional burden* in caregivers at post assessment level with a large effect size. Whereas no significant difference was found in *physical* and *social burden* across pre and post assessment levels.

Figure 4.1

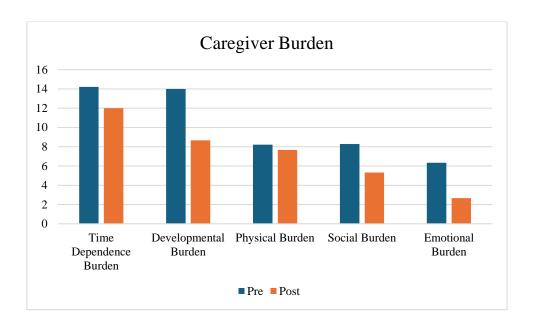


Table 4.6

Results of One-Way Repeated Measures Analysis of Variance Examining Differences in Coping Strategies in Caregivers of Children and Adolescents with Autism Spectrum Disorder Across Pre and Post Assessment Levels (N=9).

Variable	P	Pre		Post		Partial η²
	\overline{M}	SD	M	SD	•	-
Coping Strategies						
Active Coping	56.89	4.73	57.11	3.62	.04	.005
Passive Coping	15.78	3.53	11.89	3.79	11.98**	.600

Note. **p < .01; M = Mean; SD = Standard Deviation; $\eta^2 = Effect Size$.

Table 4.6 shows the results of one-way repeated measures analysis of variance indicating that the integrative multicomponent group-based cognitive behavioral therapy (CBT) significantly reduced the usage of *passive coping* strategies at post assessment level in caregivers. And the value of partial eta squared indicated large effect size. Whereas no significant mean difference was found in *active coping* strategies across pre and post assessment levels in caregivers.

Figure 4.2

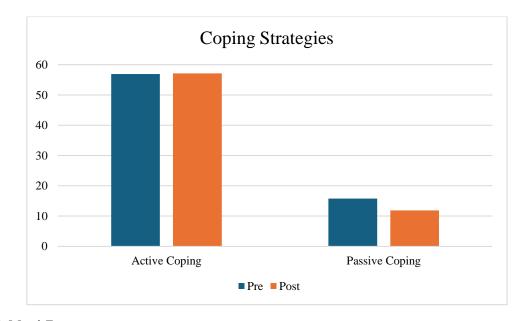


Table 4.7

Results of One-Way Repeated Measures Analysis of Variance Examining Differences in Quality of Life in Caregivers of Children and Adolescents with Autism Spectrum

Disorder Across Pre and Post Assessment Levels (N=9).

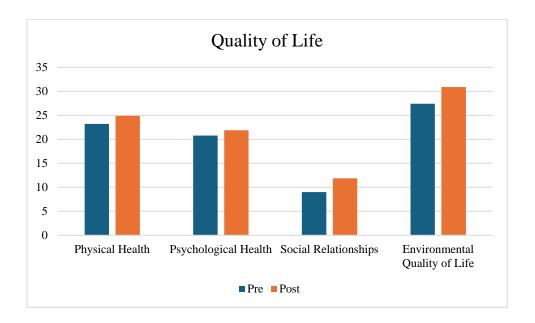
Variable	P	Pre		Post		Partial η²
	\overline{M}	SD	М	SD	-	_
Physical Health	23.22	2.28	24.89	2.20	2.56	.243
Psychological Health	20.78	3.27	21.89	2.03	.72	.083
Social Relationships	9.00	2.69	11.89	1.76	9.56^{*}	.544
Environmental QoL	27.44	3.50	30.89	3.06	5.69^{*}	.415

Note. QoL = quality of life; *p<.05; M=Mean; SD=Standard Deviation; η ²=Effect Size.

Table 4.7 shows the results of one-way repeated measures analysis of variance indicating mean differences in quality of life and its subscales across pre and post assessment levels in caregivers of children and adolescents with autism spectrum disorder. Multivariate analysis revealed that the integrative multicomponent groupbased cognitive behavioral therapy (CBT) significantly improved overall quality of life in the caregivers at post assessment level with, F(7,56) = 82.90, p<.001 with a

large effect size (partial η^2 =.912). Moreover, the results from univariate analysis evidenced a significant improvement in the *social relationships*, and *environmental quality of life* of caregivers at post assessment level with a large effect size. Whereas no significant difference was found in *physical health*, and *psychological health* across pre and post assessment levels.

Figure 4.3



4.3 Summary of Findings

One-way repeated measures analysis of variance (ANOVA) revealed that the integrated multicomponent group-based cognitive behavioral therapy (CBT) significantly reduced overall caregiver burden (time dependence burden, developmental burden, emotional burden) and the usage of passive coping strategies at post assessment level. Moreover, it significantly improved overall quality of life (social relationships, and environmental quality of life) of caregivers of children and adolescents with autism spectrum disorder at post assessment level. Whereas results were non-significant for other subdomains.

Discussion

The current study was aimed at investigating the therapeutic efficacy of integrative, multicomponent, group-based cognitive behavioral therapy (CBT) for caregiver burden, coping strategies, and quality of life in caregivers of children and adolescents with autism spectrum disorder. In this chapter, the results of the current study are linked to previous researches on cognitive behavioral therapy (CBT) for caregivers, as the above-mentioned therapy is the offshoot of CBT (Schaffer, 2022).

It was hypothesized that integrative multicomponent, group-based cognitive behavioral therapy (CBT) will reduce caregiver burden (time dependence, developmental, physical, social, and emotional) at post assessment level in caregivers of children and adolescents with autism spectrum disorder. The findings of the current study showed significant reduction in overall caregiver burden (time dependence burden, developmental burden, and emotional burden) at post assessment level.

Whereas no significant reduction was found in physical burden and social burden.

These findings are supported by literature as the results of a pilot trial of cognitive behavioral therapy revealed that caregiver burden was significantly reduced at post assessment level and benefits were maintained at 3 months follow up level in caregivers of patients with Parkinson's disease (Mosley et al., 2021). Moreover, a study was carried out to examine the efficacy of CBT for reducing caregiver burden in caregivers of individuals with Thalassemia and the results revealed a significant reduction in caregiver burden after the intervention (Mahmood & Sadiq, 2019). Similarly, another study evidenced that CBT was effective in reducing caregiver burden in caregivers of dementia patients (Ali & Bokharey, 2015). Furthermore, Ruiz-

Robledillo and Moya Albiol (2015) also found in their study that caregiver burden was significantly reduced in caregivers of autistic individuals after receiving CBT.

Reduction in *time dependence burden* also aligns with literature, as a study conducted by Budiman et al. (2020) provided evidence that CBT was found to be effective for improving self-efficacy, which reduced the time spent on tasks (Garcia, 2020) and was associated with decreased feelings of burden related to caregiving tasks (Ramzani et al., 2019). Similarly, previous research also supports the reduction in *developmental* and *emotional burden* at post assessment level. A study carried out by Biliunaite and colleagues (2021) examined the effectiveness of an internet-based CBT for informal caregivers and found a significant reduction in developmental burden at the post-assessment level. Moreover, a meta-analysis suggested that CBT was an effective intervention for reducing emotional burden experienced by caregivers (Kwon et al., 2017).

Furthermore, the non-significant reduction in *physical* and *social burden* after the intervention is also in line with literature. As Jain (2018) found in his research study that CBT did not significantly improve the physical health of parents of special children. Moreover, the results of a randomized controlled trial (RCT) revealed a non-significant reduction in social burden at post assessment level in informal caregivers (Biliunaite et al., 2021).

In addition, it was hypothesized that integrative multicomponent, group-based cognitive behavioral therapy (CBT) will increase the usage of *active coping strategies* and decrease the usage of *passive coping strategies* at post assessment level in caregivers of children and adolescents with autism spectrum disorder. And the results of the current study demonstrated a significant decrease in the usage of *passive coping*

strategies at post assessment level. However, results were non-significant for active coping strategies.

The findings of a study carried out by Demir and Ercan (2022) provide support for the findings of the current study, as while examining the efficacy of CBT for reducing ineffective coping strategies a significant reduction was found at post assessment level. However, the literature shows mixed findings for the effectiveness of CBT for improving coping strategies, with some studies indicating no change in coping strategies before and after the intervention (Bourdon et al., 2019).

Moreover, it was hypothesized that integrative multicomponent, group-based cognitive behavioral therapy (CBT) will improve quality of life (physical, psychological, social, and environmental) at post assessment level in caregivers of children and adolescents with autism spectrum disorder. And the findings of the current study showed a significant improvement in the overall quality of life (social relationships, and environmental quality of life) at post assessment level. Whereas no significant difference was found in physical health and psychological health across pre and post assessment levels.

Literature suggests that CBT improves the quality of life (QoL) of caregivers, as a pilot trial carried out by Biliunaite et al. (2021) evidenced that CBT improved the QoL of caregivers. Similarly, another study found significant improvement in QoL of caregivers of patients with Parkinson's disease after receiving cognitive behavioral therapy (Mosley et al., 2021). Moreover, a systematic review by Lee and colleagues (2020) also suggested CBT as an effective treatment for improving QoL of caregivers.

Moreover, a significant improvement in *social relationships*, and environmental quality of life and non-significant improvement in *physical health* and psychological health at post assessment level of intervention align with the results of the following studies. A pretest posttest study carried out by Kalpana and Panda (2023) revealed that CBT significantly improved social relationships and environmental health of caregivers. In addition, another study found that CBT did not significantly improve physical and psychological health of caregivers of special children (Jain, 2018).

5.1 Conclusion

The prevalence of autism spectrum disorder (ASD) is rising both globally and in Pakistan (McConkey et al., 2019; Khalid et al., 2021). And the caregivers of children and adolescents with moderate to severe autism spectrum disorder are experiencing high caregiver burden (Pandey & Sharma, 2018). Moreover, the usage of maladaptive passive coping strategies to deal with caregiver burden is worsening the quality of life and mental health of caregivers (Suen et al., 2021). Caregiver' mental health is very crucial for improving not just their own quality of life but also the quality of life of their care recipients by making them better able to provide care (Osborne et al., 2008; Giallo et al., 2013).

The results of the present study provide evidence that integrative multicomponent group-based cognitive behavioral therapy (CBT) is effective for reducing the overall caregiver burden (time dependence, developmental, and emotional burden) of caregivers, for decreasing the usage of passive coping strategies for dealing with their stressors, and for improving their overall quality of life (social relationships, and environmental quality of life). However, the above-mentioned therapy does not prove to be effective for reducing caregivers' physical and social burden, for increasing the usage of active coping strategies, and for improving the physical and psychological health of caregivers.

These findings highlight the significance of incorporating psychotherapeutic interventions in routine support services to support caregivers of children and adolescents with autism spectrum disorder in Pakistan and across the globe.

5.2 Limitations and Suggestions

Some limitations of the current study along with some important suggestions for future research are mentioned below.

- One limitation of the present study was a small sample size. Therefore,
 research on large sample sizes is needed.
- Another limitation was the absence of a follow up assessment. Therefore,
 Future research may focus on incorporating follow-up assessments to
 investigate the sustainability of positive effects of the therapy outcomes.
- As only mothers received therapy, therefore, the findings of the current study are not generalizable to fathers and other caregivers. Therefore, research on more diverse samples such as secondary caregivers, caregivers of individuals with other neurodevelopmental and psychological disorders as well as with medical conditions is needed. Moreover, future studies may investigate gender differences in treatment response.
- Future research may include a control group for improving the robustness of
 the study design and for providing stronger evidence for the efficacy of the
 therapeutic protocol used in the present study. Additionally, comparative
 studies on different evidence-based caregiver burden reduction treatments may
 also be conducted.

5.3 Implications

The current study's findings highlight many crucial implications for research and practice.

- The present study's findings provide evidence for the efficacy of integrative, multicomponent, and group-based cognitive behavioral therapy (CBT) for caregivers of children and adolescents in Pakistan.
- This study can bring governments' attention to the large need for training professionals who can assist caregivers.
- Moreover, it highlights the importance of incorporating structured CBT interventions in routine support services for caregivers of children and adolescents with ASD.
- Furthermore, the present study's findings have an important implication for future research on investigating the potential indirect benefits of psychotherapeutic interventions received by caregivers on their care recipients.

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APPENDICES

APPENDIX A

Detailed Information Sheet

I am Sehar Khalid, a final year student of MS Clinical Psychology at the Department of Professional Psychology, Bahria University Islamabad. I am conducting research on "Therapeutic Efficacy Of 'Integrative, Multicomponent, Group-Based Cognitive Behavioral Therapy' (CBT) For Caregivers of Children and Adolescents with Autism Spectrum Disorder" under the supervision of Dr. Afreen Komal. You are invited to take part in this research study but before your decision to participate in this research study, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully.

Purpose of The Study

The purpose of this study is to investigate Integrative, Multicomponent, Group-Based Cognitive Behavioral Therapy' (CBT) for caregivers of children and adolescents with autism spectrum disorder to reduce level of caregiver burden, improve coping skills and quality of life.

What You Will Be Asked to Do?

You will sign this consent form to participate in this study. Then you will be required to fill in a set of questionnaires that will take approximately 15 to 20 minutes. The questionnaires include questions about caregiver burden, coping strategies that you use to deal with the stressful situations that arise while providing care to your care-recipients and about your quality of life. Then you will be required to attend in-person weekly group sessions consisting of 4 to 8 participants. The duration of each session will be of around 1 to 1 and half hour. And the total duration of the study will be around 8 weeks. During the therapy, you will be assigned a homework at the end of every session which will involve practicing the skills and techniques taught during the session and tracking the progress on the worksheets provided. At the end of the therapy, you will be required to fill the questionnaires again.

What Will Happen to Your Responses to The Questionnaires?

Your responses on the questionnaires will be stored in a computer file. Only the researcher and the university professor who is supervising my study will have access to these computer files. In reporting the results of this study, all answers from all participants will be combined and it will not be possible to identify any particular individual's responses. Thus, the anonymity and confidentiality of the data will be maintained.

Your Rights

Your participation is voluntary, and you have the right to withdraw from participation at any time without giving a reason. Nothing bad will happen to you as a result.

Your Decision

It is up to you to decide whether or not to take part in this study. If you decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you have any queries regarding study or participation, feel free to contact on sehar.786.khalid@gmail.com.

Supervisor Student

Dr. Afreen Komal Sehar Khalid

Thank you for taking the time to read the information sheet.

Informed Consent Form

I Mr./Ms	state that I voluntarily
agree to participate in the l	Masters of Science research entitled "Therapeutic Efficacy
Of 'Integrative, Multicomp	ponent, Group-Based Cognitive Behavioral Therapy' (CBT)
For Caregivers of Children	and Adolescents With Autism Spectrum Disorder"
conducted by Sehar Khalio	l, under the supervision of Dr. Afreen Komal at the
Department of Professiona	l Psychology, Bahria University, Islamabad. The researcher
has explained the purpose	and procedure of the research to me. She has informed me
that I may withdraw from	participation at any time without prejudice and penalty.
Furthermore, she has assur	red me that the information that I am giving will be used for
research purposes only and	l will be kept confidential and anonymous.
Signature of Researcher	Signature of Participant
.	~ .
Date:	Date:

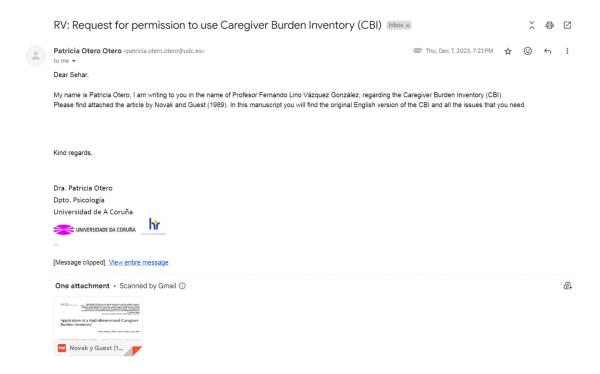
APPENDIX B

Demographic Information Sheet

1. Your Age:
2. Your Gender
a. Maleb. Female
3. How many years of education you have obtained to this point:
4. Which statement best describes your occupational employment status?
a. Employed, full timeb. Unemployed
5. Family Structure
a. Nuclear (separate i.e., only your Spouse and Children)b. Joint family
6. Your Number of Children:
7. Your relationship with the care recipient (i.e., your child with Autism Spectrum Disorder)
a) Motherb) Fatherc) Other (please specify)
8. Approximately how many hours per day do you spend providing care for your care recipient?
9. Do you receive any respite care (i.e., help in taking care of your child with Autism Spectrum Disorder) from maids or family members? If yes, for how many hours per day?
a) No
b) Yes (specify numbers of hours per day)
Information About Care Recipient (i.e., your child with Autism Spectrum Disorder)
10. Age:
11. Gender
12. Level of severity of Autism Spectrum Disorder (please mark the severity level diagnosed by a professional)
a. Moderateb. Severe
13. For how many years your child has been receiving institutional care?

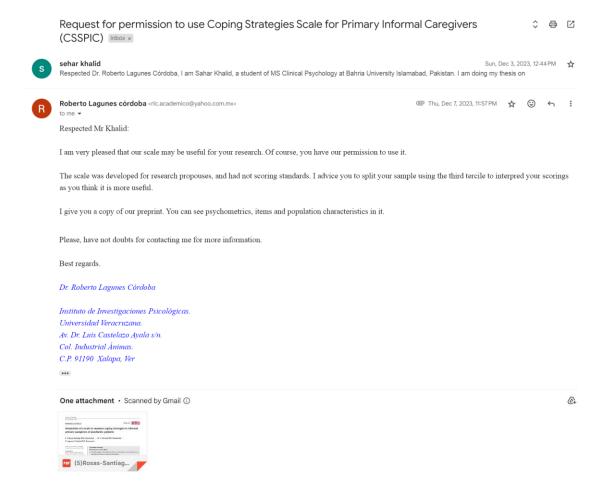
APPENDIX C

Permission for Caregiver Burden Inventory (CBI)



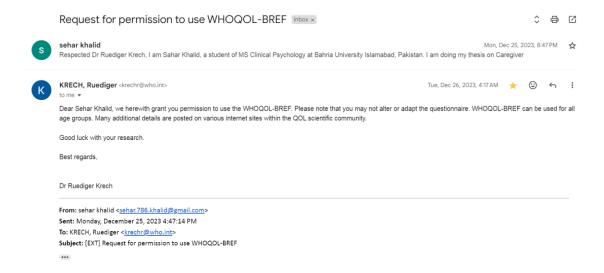
APPENDIX D

Permission for Coping Strategies Scale for Primary Informal Caregivers (CSSPIC)



APPENDIX E

Permission for WHO Quality of Life Scale-Brief (WHOQOL-Brief)



APPENDIX F

Permission for Integrative, Multicomponent, Group-Based Cognitive Behavioral

Therapy (CBT)

Request for Permission to use "Online, Integrative, Multi-Component, Group-Based Cognitive 🗘 🖨 🗵 Behavior Therapy (CBT) for the Reduction of Caregiver Burden" intervention in my MS thesis Inbox x



sehar khalid

Dec 25, 2023, 8:44 PM 🏠 Respected Dr. Jennifer Flaherty, I hope this message finds you well. I Sehar Khalid, a student of MS Clinical Psychology from Bahria University Islamabad, Pakis

□ Dec 28, 2023, 6:35AM
 ★
 ②
 ←
 :

Dan Schaffer <dschaffer290@gmail.com>

Hello, Sehar,

This is Dr. Daniel Schaffer. Dr. Jennifer Flaherty forwarded me your email regarding using my therapy manual for your research. First off, I'd like to apologize for not responding to your prior emails. Since I graduated from my doctoral program, I no longer use that email address, so you probably received the "blocked" notification due to it being an inactive email

Thank you for reaching out, and I'm very excited to hear you would like to use the therapy manual for your research. Applying the intervention to caregivers of persons with autism / ID sounds like a very interesting and worthwhile study, and I wish you all the best. You are welcome to use the treatment manual. The full manual is included in the appendices of the published dissertation document, along with copies of all the necessary handouts. I've attached a copy of the full PDF dissertation document here

Because the dissertation is published through ProQuest, it does have copyright protection. You have my permission to use the manual so long as it is cited appropriately. If you are using APA 7th edition citation guidelines, you can cite it as follows (APA 7th Ed guidelines for a published doctoral dissertation):

Schaffer, D. R. (2022). Implementing an online, integrative, multi-component, group-based cognitive behavior therapy (CBT) for the reduction of caregiver burden in primary familial caregivers of persons with dementia: a preliminary test of feasibility. [Doctoral dissertation, Virginia Consortium Program in Clinical Psychology]. ODU Digital Commons. DOI 10.25777/dm22-x-696.

If you have any additional questions, please feel free to reach out to me at this email address (dschaffer290@gmail.com). I would be happy to consult on any questions you may

Thank you again, and I wish you all the best in your studies! Dan Schaffer

Daniel (Dan) Schaffer, Ph.D Licensed Psychologist (He/Him/His pronouns) "But nothing's ever perfect. Earth turns on a tilted axis, just doing the best it can.'

APPENDIX G

Data Collection Letter



February 14, 2024

TO WHOM IT MAY CONCERN

REQUEST FOR DATA COLLECTION

It is stated that Ms. Sehar Khalid Enrollment No. <u>01-275222-018</u> is a student of MS Clinical Psychology Bahria University Islamabad Campus conducting research on "Caregiver Burden, Coping Strategies, Quality of Life and Therapeutic Efficacy of Integrative Multi-component Group based Cognitive Behavioral Therapy (CBT) for Caregivers of Individuals with Special Needs" under supervision of undersigned. It is requested that kindly allow her to collect the data from your esteemed institution.

Regards.



Or. Afreen Komal Assistant Professor Bahria School of Professional Psychology Bahria University E-8 Islamabad

APPENDIX H

Plagiarism Report

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