Arab American University

Faculty of Graduate Studies

Department of Health Sciences

Master Program in Intensive Care Nursing

Investigating the Coping Strategies and the Needs of Parents of Children with ASD Applied During Confrontation with Community Stigma in the West Bank

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Thesis Approval

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Declaration

I declare that, except where explicit reference is made to the contribution of others, this thesis is substantially my own work and has not been submitted for any other degree at the Arab American University or any other institution.

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Dedication

I dedicate this research to the owner of a fragrant biography and enlightened thought, for he had the first credit in attaining higher education (my beloved father), may God prolong his life. He has been my greatest source of strength, and his belief in me has been my guiding light through this journey.

To my beloved family, who inspire me every day to keep learning and become a better version of myself, your endless support and constant encouragement has been my greatest supporter.

Finally, to all families raising children with autism spectrum disorder, this dedication is an acknowledgment of your sacrifices, courage and perseverance. May this research shed light on your challenges and gives you hope and inspiration in your extraordinary journey.

Esraa Qaddan

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First, we thank God for His grace and blessings on us for completing this study, who helped us overcome all the obstacles and difficult times that we faced throughout the years of our study.

I would like to express my gratitude to my dedicated supervisor, Dr. Sana Abu Dahab, who has been guiding me throughout this journey, and supported my constantly. Her valuable guidance, and appropriate instructions have been crucial in making this research possible.

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Investigating the Coping Strategies and the Needs of Parents of Children with ASD Applied During Confrontation with Community Stigma in the West Bank

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Abstract

This study aims to investigate the coping strategies and needs of parents of children with autism spectrum disorder (ASD) in the West Bank, with a particular focus on community stigma. Since parents of children with ASD often face unique challenges and stresses, this study aims to explore the adaptive and maladaptive coping strategies used by parents while dealing with these challenges and stresses.

The study employed a descriptive, cross-sectional design. The study sample consisted of 100 parents of children with ASD through structured questionnaires. Results revealed that parents primarily rely on adaptive coping strategies such as acceptance, religion and seeking emotional support. On the other hand, maladaptive strategies like substance use and denial are rarely used. The findings also emphasized the importance of family and community support, financial assistance and the ability to access information about ASD.

Moreover, the study indicates that community stigma is a significant barrier, which limits parents' ability to seek support and increase their stress. However, the study results confirmed that parents demonstrated strength and rejected self-blame, which means that they were able to maintain confidence in their parenting abilities despite pressures and community stigma.

Based on the research findings, several recommendations are provided by the researcher. First of all, the researcher emphasized the importance of conducting further research and studies that addresses parents of children with ASD needs. And the importance of raising people's awareness of ASD children and equip their parents with the appropriate information and knowledge which helps reducing the gap between children with ASD and the world around them. In addition, the researcher suggests empowering parents of children with ASD financially. Children with ASD should be provided with scholarships, health insurance, special education, and different types of treatments. This would significantly help them reduce stress and overcome challenges.

Keywords**:** Autism Spectrum Disorder, Coping Strategies, Community Stigma, Parental Needs, West Bank.

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List of Definitions of Abbreviations

Abbreviations	Title
Background	the circumstances or events antecedent to a phenomenon or development
Aim	the directing of effort toward a goal
Methods	a discipline that deals with the principles and techniques of scientific inquiry
Results	to proceed or arise as a consequence, effect, or conclusion
Conclusions	a reasoned judgment
ASD (Autism Spectrum Disorder)	a neurodevelopmental disorder that typically appears by age two, that is variable in expression but is usually diagnosed by persistent impairments in social interaction and communication and by stereotyped patterns of behavior, activities, or interests, and that may be accompanied by cognitive or language impairments
Stigma	a set of negative and unfair beliefs that a society or group of people have about something
Parent	a person who brings up and cares for another
Coping strategies	an action, a series of actions, or a thought process used in meeting a stressful or unpleasant situation or in modifying one’s reaction to such a situation. Coping strategies typically involve a conscious and direct approach to problems
Needs	a condition requiring supply or relief
Community	: a group of people with a common characteristic or interest living together within a larger society
West Bank	area of the Middle East west of the Jordan River
Quantitative	relating to, or involving the measurement of quantity or amount
Study design	the set of methods and procedures used to collect and analyze data in a study
Sample size calculation	the number of observations or individuals included in a study or experiment

Mental health	the condition of being sound mentally and emotionally that is characterized by the absence of mental illness and by adequate adjustment especially as reflected in feeling comfortable about oneself, positive feelings about others, and the ability to meet the demands of daily life
Discrimination	the act, practice, or an instance of discriminating categorically rather than individually
Self-esteem	a confidence and satisfaction in oneself
Depression	a mood disorder that is marked by varying degrees of sadness, despair, and loneliness and that is typically accompanied by inactivity, guilt, loss of concentration, social withdrawal, sleep disturbances, and sometimes suicidal tendencies
Prejudice	an irrational attitude of hostility directed against an individual, a group, a race, or their supposed characteristics
Stereotypes	something conforming to a fixed or general pattern
Intervention	the act of interfering with the outcome or course especially of a condition or process
Professional	characterized by or conforming to the technical or ethical standards of a profession
Questionnaires	a set of questions for obtaining statistically useful or personal information from individuals.

Chapter One: Introduction

1.1. Background

Autism Spectrum Disorder (ASD) is a developmental disorder that affects communication, social interactions, and behavior. Symptoms can vary widely and can include difficulty with verbal and nonverbal communication, difficulty with social interactions, repetitive behaviors, and sensory sensitivities. Children with ASD may also have difficulty with academics, such as reading and writing. ASD is a spectrum disorder, meaning that the symptoms and severity can vary widely from person to person. Some children with ASD may be nonverbal and require assistance with daily living activities, while others may have above-average intelligence and attend mainstream schools(Willsey, Willsey, Wang, & State, 2022).

The incidence of autism spectrum disorder (ASD) varies depending on the population and diagnostic criteria used. According to the Centers for Disease Control and Prevention (CDC), the prevalence of autism among 8-year-old children in the United States in 2016 was 1 in 59, or approximately 1.7%. The prevalence has been steadily increasing in recent years. ASD is more common in males than females, with a ratio of about 4:1. It is also more common in certain racial and ethnic groups, with higher rates reported among non-Hispanic white children and lower rates among Hispanic and Black children. It is important to note that this could be due to factors such as access to healthcare, cultural factors and diagnostic bias(Solmi et al., 2022).

The prevalence ASD varies depending on the population and diagnostic criteria used. According to the World Health Organization (WHO), the global prevalence of autism is estimated to be around 1% of the population. However, this estimate may vary depending on the country and region and may be affected by factors such as access to healthcare and diagnostic criteria. According to the most recent data available, the prevalence of ASD in the Arab countries is not well studied; however, the prevalence of autism in the Middle East is reported to be around 0.5-2%(Francés et al., 2022).

The exact causes of ASD are not fully understood; however, research suggests that it is likely caused by a combination of genetic and environmental factors. Genetic factors: Studies have shown that autism tends to run in families, suggesting that there may be a genetic component to the disorder(Alyami, Naser, Alyami, Alharethi, & Alyami, 2022). Many genes have been identified as being associated with ASD and it is thought that multiple genes may be involved in the development of the disorder. Some genetic conditions such as Fragile X syndrome, Rett syndrome, and tuberous sclerosis are also known to increase the risk of ASD. As for environmental factors, studies have also suggested that certain environmental factors, such as exposure to certain toxins or viruses during pregnancy, may increase the risk of ASD. Other factors that have been associated with ASD include advanced parental age, low birth weight and premature birth. Research has also shown that there may be differences in the way the brain develops in individuals with autism. Studies have found that certain regions of the brain may be larger or smaller, and there may be differences in the way brain cells connect and communicate with each other. It's important to note that ASD is a complex disorder and there is no one singular cause. It's a combination of multiple factors which leads to the disorder(Sidhu & Greene, 2022).

Management for children with ASD typically includes a combination of interventions that address the child's specific needs and abilities. These interventions may include behavioral therapy which aims to improve social interaction and communication skills, as well as reduce inappropriate behaviors with Applied Behavioral Analysis (ABA) being widely used type of behavioral therapy. Speech and language therapy is also widely used with children with ASD as it aims to improve language and communication skills. Occupational therapy aims to improve fine motor skills and daily living skills, such as dressing and eating. Play therapy uses play to improve social interaction and communication skills. On the other hand, some children with ASD may also benefit from medications to manage specific symptoms, such as anxiety or hyperactivity. It is important to note that each child with ASD is unique and the treatment plan should be tailored to meet their specific needs(Ha & Whittaker, 2022).

Parents of Children with ASD

Parents of children with ASD face numerous challenges in their daily lives. These challenges can have a significant impact on their well-being, family dynamics, and overall quality of life. Children with ASD may have difficulty with basic self-care tasks such as toileting, dressing, and grooming, which can add to the caretaker's daily workload and stress. In addition, school aged children with ASD may have difficulty in traditional educational settings and may require specialized education and support which adds more burden on their parents. Parents may also face societal stigma and stereotypes associated with having a child with ASD, which can be isolating and emotionally taxing. Children with ASD difficulties with communication may have a compounding effect as it may be difficult for parents to understand their needs and wants. Challenging behaviors such as aggression, self-injury, and repetitive behaviors can be challenging for parents to manage. Raising a child with autism can also put a financial strain on families, as they may need to pay for specialized therapies and interventions, additional childcare, and other expenses(Vassiliki Ntre et al., 2022; Turnock, Langley, & Jones, 2022). Beside the financial burden, raising a child with ASD can be emotionally and psychologically demanding. Parents may experience a range of emotions, including sadness, grief, frustration, and guilt. They may struggle with accepting their child's diagnosis, managing their own expectations, and dealing with societal perceptions of ASD. Parents of children with ASD often face uncertainty about their child's future(Mokoena & Kern, 2022). They may worry about their child's long-term independence, employment prospects, and social integration. Planning for the future and securing appropriate support systems can be overwhelming and create anxiety for parents(Bujnowska, Rodríguez, García, Areces, & Marsh, 2019).

Understanding these challenges is crucial for providing appropriate support and interventions to parents and families affected by ASD. The continuous stress associated with parenting a child with unique needs can also lead to burnout and mental health issues. The demands of caregiving, the need for constant supervision, and the unique behavioral challenges of their child may limit their ability to engage in social activities or maintain friendships. The lack of understanding and acceptance from the broader community can further contribute to their isolation. Addressing these challenges requires a comprehensive approach that includes access to quality services, respite care, parental support groups, mental health support, and community acceptance and inclusion. By recognizing and understanding the unique challenges faced by parents of children with ASD, society can work towards creating a more supportive and inclusive environment for these families.

Coping Strategies of Parents of Children With ASD

Parents of children with ASD typically use a combination of different coping strategies to manage the challenges they face. Common coping strategies that have been identified in the literature include seeking social support in which parents often turn to family members, friends, and other parents of children with ASD for support and understanding. Support groups and online forums can also be a valuable source of support for parents. Parents may also use problem-solving strategies to manage specific challenges related to their child's ASD, such as developing a behavior plan or a communication plan. Cognitive strategies, such as reframing negative experiences in a more positive light, to find meaning and purpose in their experiences may also be used by parents of children with ASD. In order to better understand and manage their child's condition, parents often seek information and education about ASD in order. Engagement in self-care practices, such as exercise, mindfulness, and relaxation techniques, to manage stress and maintain their own well-being can be also used as a coping mechanism. Last but not least, parents may seek professional help, such as counseling or therapy, to manage stress and emotional difficulties(Feliu-Soler et al., 2019).

Parents of Children with ASD and Stigma

The concept of stigma is often used to analyze the experience of shame and social exclusion that parents of children with ASD may face. Stigma refers to the negative attitudes and beliefs that a society may hold towards individuals or groups perceived as different or deviant. In the case of parents of children with ASD, they may experience stigma from their community due to the perceived "abnormality" or "difference" of their child's condition, leading to feelings of shame and exclusion(Oduyemi, Okafor, Eze, Akodu, & Roberts, 2021).

Courtesy stigma refers to the negative attitudes, stereotypes, and discrimination directed towards the family members of an individual with a stigmatized condition. In the case of children with ASD, parents may experience courtesy stigma from the general public due to misconceptions about the child's behavior being a result of poor parenting. This can lead to feelings of shame, guilt, and isolation for the parents(Ji, Jiang, & Luo, 2022).

Affiliate stigma, also known as self-stigma, refers to the internalization of negative attitudes and stereotypes by family members of a stigmatized individual. Through repeated exposure to courtesy stigma, parents may begin to internalize these negative attitudes and believe them to be true about themselves and their child. This can lead to a lack of self-esteem, feelings of isolation and hopelessness(A. Papadopoulos et al., 2022).

1.2. Significance of Study

It would provide insight into the specific challenges and difficulties that these parents face in their community, which may differ from those in other cultural or geographic contexts. It would identify the coping strategies that parents use to manage the negative attitudes and beliefs of their community towards their child with ASD, and whether these strategies are effective or not. It would allow for the identification of the specific needs of these parents, such as access to support groups, education, or healthcare, that would aid in addressing the challenges they face. The study could also provide recommendations for service providers and policymakers on how to improve the support and resources available to families of children with ASD in the West Bank. It could also show the impact of community stigma on the family's mental and emotional well-being.

Study has significant implications for understanding the impact of stigma on parents of children with autism spectrum disorder (ASD) and identifying effective coping strategies. The knowledge gained from the study would help occupational therapists (OTs) and other professionals to better understand the challenges faced by these parents and to develop more effective interventions to support them. For occupational therapists specifically, understanding the coping strategies used by parents of children with ASD could inform the development of interventions that support the parents in managing the negative attitudes and beliefs of their community. This could include providing education on the importance of inclusion and acceptance, as well as connecting parents to support groups and other resources that can help them cope with the challenges they face. In addition, the findings of this study would be beneficial to other professionals such as teachers, psychologists, and social workers who work with families of children with ASD, as it would provide them with a deeper understanding of the impact of community stigma on these families and the effective coping strategies that can be applied. Overall, this proposed study would be important to develop a better understanding of the impact of community stigma on parents of children with ASD, which will help professionals to design more effective interventions and support systems to these families.

1.3. Aim of the Study

To provide a deeper understanding of the coping strategies, needs, and level of stigma of parents of children with ASD.

1.4. Objectives

Objective 1: Evaluating Coping Strategies Utilized by Parents of Children with ASD

- To measure the coping strategies employed by parents of children with ASD using the Brief-COPE questionnaire.
- To identify the most commonly used coping strategies among parents and determine their effectiveness in managing stress related to community stigma.

Objective 2: Assessing the Needs of Parents of Children with ASD

- To identify the specific needs of parents of children with ASD using the Family Needs Survey.
- To explore the areas where parents require additional support, resources, and services to effectively care for their children and meet their own needs.

Objective 3: exploring parents of children with ASD feeling of stigma

Objective 4: to examine if there are any significant differences in the coping strategies utilized by parents of children with ASD based on demographic factors such as gender, mother education level, and father education level.

Chapter Two: Literature review

2.1. Introduction

The research problem being addressed in this study is the coping strategies and needs of parents of children with autism spectrum disorder (ASD) when facing community stigma. The study aims to explore the challenges that these parents face and the ways in which they cope with the stigma and discrimination they experience from their community. The research aims to identify the specific needs of these parents and to understand the impact that community stigma has on their lives and the lives of their children with ASD. The ultimate goal of this study is to inform the development of support systems and interventions to better assist these parents in their efforts to navigate the challenges posed by community stigma.

I searched academic databases: Use the keywords to search academic databases such as PubMed, Psych INFO, and Google Scholar and Identify keywords: Identify relevant keywords related to your research problem, such as "autism spectrum disorder," "community stigma," "parent coping strategies," "parent needs,

2.1.1 Stigma and Discrimination:

Many studies have found that individuals with autism spectrum disorder and their families often experience stigma and discrimination from their communities. This stigma can take many forms, including negative attitudes, prejudice, and social exclusion.

This study, based on the model proposed by Link and Phelan (2001), aimed to investigate the impact of stigma on families with children with autism spectrum disorder (ASD). The study involved 502 families from the Simons Simplex Collection and found that stigma plays a significant role in predicting how difficult life is overall for parents of children with autism. The study also found that autism behaviors contribute both to the difficulty families experience in raising a child with autism and to the stigma processes, such as stereotyping, rejection, and exclusion, associated with those behaviors. The findings suggest that addressing community stigma is crucial for improving the lives of families with children with autism spectrum disorder (Kinnear, Link, Ballan, & Fischbach, 2016).

This cross-sectional study aimed to determine the prevalence of self- and enacted stigma among parents of children with autism spectrum disorder (ASD) in Riyadh, Saudi Arabia. The study involved 163 participants from the Centre for Autism Research at King Faisal Specialist Hospital & Research Centre and used a questionnaire to gather data on demographic information, experiences as a parent, and social experiences. The results showed that 33.7% of the parents felt stigmatized, with mothers feeling more stigmatized than fathers. 66.3% of the parents did not feel stigmatized, while 25.8% experienced enacted stigma. The study found that there was no significant association between the level of stigmatization and the gender of the autistic child, consanguinity, severity of the ASD, or family income. The authors conclude that there is a need for psychological intervention and increased public awareness to help families cope with stigmatization and to protect the rights of individuals with autism(Alshaigi et al., 2020).

Autism can be understood as a stigmatized identity that can be hidden. The literature on autistic people's experiences with stigma and coping strategies is synthesized here for the first time in a systematic review. 27 of the 2877 studies were screened for inclusion in this review. According to the reviewed literature, autistic people are acutely aware of being stereotyped, judged, and discriminated against by others. Additionally, autistic individuals exhibit signs of internalizing stigma, making them more prone to low self-worth and deteriorating mental health. According to the included studies, autistic people may employ the following strategies to manage the effects of stigma: self-advocacy, selective disclosure, and camouflage, as well as positive reframing and identity reconstruction. However, the evidence regarding these strategies' usefulness and efficacy is sparse and mixed. The inclusion of autistic populations with a wider range of intellectual abilities in future studies, as well as the investigation of interventions that can assist autistic people in coping with stigma, should supplement interventions that aim to reduce autistic stigma. It is imperative that researchers and practitioners carefully consider the messages they are conveying about autism because of the power of language in perpetuating and challenging stigma(E. Han, K. Scior, K. Avramides, & L. Crane, 2022).

This study found that among the 230 parents of children with autism spectrum disorder in Lagos, Nigeria, the majority had poor knowledge of the condition. More mothers (17.1%)

reported negative experiences (enacted stigma) compared to fathers (9.1%), and the majority of both parents (83.5%) internalized the stigma. The study also found a low-moderate correlation between enacted and internalized stigma. The in-depth interviews revealed that many parents experienced negative effects on their families and negative experiences of stigma(Oduyemi et al., 2021).

The purpose of this study was to understand the experiences of immigrant Sri Lankan Tamil parents of children with autism spectrum disorder (ASD) in Southern Ontario, Canada. The study used qualitative methods, including in-depth interviews, to gather data and analyzed the data using content analysis. The results showed that the parents generally felt satisfied with the cultural competence of the current autism systems but also experienced significant immigrant-related barriers that were not fully addressed. The study highlights the need for improving cultural awareness among occupational therapists providing interventions for children with ASD(Shanmugarajah, Rosenbaum, & Di Rezze, 2022).

2.1.2. Coping Strategies

Coping strategies refer to the various methods that parents of children with autism spectrum disorder (ASD) use to manage the stress and challenges associated with caring for a child with this condition. Coping strategies can be categorized as problem-focused, emotion-focused, or avoidance-focused. In literature, common coping strategies used by parents of children with ASD include seeking support from family and friends, seeking information about the condition, engaging in self-care activities, participating in community activities, and accepting the child's diagnosis. Other coping strategies that have been reported in the literature include seeking professional support, managing the child's behavior, seeking respite care, and adapting to the child's needs. It is important to note that different families may use different coping strategies depending on their individual circumstances and cultural backgrounds(Haytham, Khuan, Ying, & Hassouneh, 2022).

This study aimed to explore the perceptions and coping strategies of parents of children with autism spectrum disorder (ASD) in Mpumalanga Province, South Africa. The data was collected through face-to-face semi-structured interviews with 12 primary caregivers of children with ASD, and analyzed using thematic content analysis. The results revealed two themes: (1) caregivers' understanding and misconceptions of ASD and (2) coping mechanisms used in dealing with the challenges of caring for a child with ASD. The five subthemes identified were: lack of knowledge, cultural beliefs, prayer, strong support system, and acceptance. The conclusion suggests that more awareness campaigns on ASD are needed to increase parents' understanding of the condition and that an understanding of cultural beliefs could assist health care professionals in developing culturally-accepted care practices and enhances parents' coping skills(Shilubane & Mazibuko, 2020).

In Iran review 11 articles found that parents of children with autism spectrum disorder (ASD) use two main coping mechanisms: problem-focused and emotion-focused coping. Mothers were found to use emotion-focused coping more often than fathers, who used problem-focused coping more frequently. The review highlights the need for healthcare providers to develop supportive interventions to improve coping mechanisms among parents of children with ASD(Haytham et al., 2022).

In Malaysia the study aims to explore the coping strategies of parents of children with autism spectrum disorder (ASD). It involved conducting in-depth interviews with 21 parents of children with ASD. The data collected was analyzed using thematic analysis, resulting in three main themes: acceptance and positive outlook, reaching for helping hands, and understanding autism and finding its solutions. The findings provide insight into the unique coping strategies used by parents of children with ASD, which could help healthcare providers, authorities, and communities to address specific needs and provide relevant support measures(Yaacob, Yaacob, Zulkifli, & Muhamad, 2022).

This study aimed to investigate the coping strategies used by mothers of children with autism spectrum disorder (ASD) and their relationship to maternal stress and depression. A total of 143 mothers participated in the study, and they completed questionnaires related to demographic characteristics, depression, family crisis coping strategies, and parenting stress. The study found that mothers with higher education levels used better coping strategies (reframing) and that increased daily hours spent on child care and child medication were also associated with better coping strategies. The study also showed that mothers who had lower scores in mobilizing family support and accepting help were more likely to be affected by family life. The findings suggest that coping strategies of mothers of children with ASD are associated with several factors related to caregiver personal characteristics, child treatment, and family characteristics. The results highlight the importance of mental health professionals considering these factors to support mothers in their coping strategies (V. Ntre et al., 2022).

Study suggests that parents of children with disabilities use different coping strategies compared to parents of children without disabilities. Specifically, they tend to use more avoidance coping strategies, such as avoidance of the situation or self-blame, and also tend to use more approach coping strategies, such as seeking social support or active problem-solving. These results highlight the need for targeted interventions and support for parents of children with disabilities, to help them better manage stressful situations and improve their overall well-being. Healthcare providers and mental health professionals should be aware of the unique challenges faced by these parents and provide them with the necessary resources and support to overcome these challenges(Alós, García, & Maldonado, 2022).

The study aimed to explore the relationship between resilience in parents of children with autism spectrum disorder (ASD) and their children's resilience. Fifty parents of children with ASD, aged 13 years or younger, across various Canadian provinces participated in an online survey. The results showed that parental resilience was positively correlated with household income and negatively correlated with parental stress. Additionally, children's resilience was positively associated with their social participation at home and in the community. The findings suggest that increasing children's participation may enhance their resilience(Ghanouni & Eves, 2023).

This study aimed to understand the perceptions and coping strategies of parents of children with autism spectrum disorder (ASD). The data was collected through face-to-face semi-structured interviews with 12 primary caregivers who were purposefully selected from three schools in Mpumalanga Province, South Africa. The data was analyzed using thematic content analysis. The results of the study showed two main themes: caregivers' understanding and misconceptions of ASD, and the coping mechanisms used in dealing with the challenges of caring for a child with ASD. Five subthemes were identified: lack of knowledge, cultural beliefs, prayer, strong support system, and acceptance. The findings suggest that more awareness campaigns are needed to increase parents' understanding of ASD and that cultural beliefs should be considered when developing care practices for parents of children with ASD(Shilubane & Mazibuko, 2020).

This systematic literature review aimed to summarize the current state of knowledge regarding the impact of autism spectrum disorder (ASD) on parents in Arab countries. A total of 24 publications were included in the review, which were conducted in 10 countries including Saudi Arabia, Jordan, Egypt, Kuwait, Bahrain, and Oman among others. No studies were found in the remaining Arab countries. The studies explored various aspects of the impact of ASD on parents, such as their emotional and psychological well-being, stress levels, and coping strategies. This systematic literature review aimed to examine the impact of autism spectrum disorder (ASD) on parents in Arab countries. 24 studies were included, consisting of 20 quantitative studies and 4 qualitative studies, conducted in 10 Arab countries. The majority of the studies found that parents of children with ASD experienced negative effects on their mental health and wellbeing, with poor quality of life and increased risk of psychological disorders. Religious coping was the most common coping strategy used by parents. The review highlights the need for further research with larger and more diverse samples, as well as varied research and data collection methods, to better understand the challenges faced by parents raising children with ASD in Arab countries(Alkhateeb, Hadidi, & Mounzer, 2022).

2.1.3. Parent Needs

Studies have shown that parents of children with autism spectrum disorder (ASD) have specific needs that are important for their well-being and their child's development. These needs may include:

Emotional support: Many parents face stigma and isolation in the community, and they need emotional support from friends, family, and support groups. Practical support: Practical support such as respite care, transportation, and access to appropriate services can help relieve the burden of care giving for parents. Information and education: Parents often require up-to-date and evidence-based information about their child's condition, available treatments, and educational options.

Professional support: Mental health support and counseling services can help parents manage the stress of caring for a child with ASD. Access to quality healthcare: Access to high-quality health care, including behavioral therapies and medical treatments, is crucial for children with ASD and their families. Financial support: Many families face significant financial challenges in caring for a child with ASD and need financial support to access the services they require(Kalankesh, Shahrokhi, Dastgiri, Gholipour, & Feizi-Derakhshi, 2020; Weissheimer, Santana, Ruthes, & Mazza, 2020).

This qualitative study aimed to identify the needs of families of children with autism spectrum disorder (ASD) from both specialists and parents' perspectives. Semi-structured in-depth interviews were conducted with 19 ASD specialists and 23 parents of children with ASD. The results showed that the main needs of families from the perspective of experts were divided into nine themes, including knowledge, skills, attitude, social needs, financial needs, educational needs, mental health services, ability to handle other family issues, and ability to deal with the specific child's problems. From the perspective of the parents, the needs were divided into four themes, including information, service, support, and financial needs. The study concludes that understanding the needs of families is important for better addressing those needs by professionals, parents, and policymakers(Kalankesh et al., 2020).

The shift in perspective towards French parents of children with autism spectrum disorder (ASD) as essential partners of care professionals has led to the development of parent training programs aimed at helping these parents deal with the specific challenges of raising a child with ASD. In a study, three such programs were investigated for their social validity from the parents' perspective. The results showed that all three programs had good social validity, with good attendance rates and high levels of satisfaction among parents. The authors of the study suggest that more parents should be given the opportunity to participate in such programs to better support them in raising their children with ASD(Sankey, Derguy, Clément, Ilg, & Cappe, 2019).

Needed by families highlighted the need for information on diagnosis and assessment, support services, educational programs and interventions, behavioral and communication strategies, financial support and legal rights, mental health support, and care management. Conclusion: The results of this integrative literature review showed that families of children with ASD face many challenges and need access to comprehensive and up-to-date information about the condition, its treatments, and support services. Provision of appropriate information can support families to better understand and manage the needs of their child with ASD(Weissheimer et al., 2020).

The objective of the scoping review was to explore the perceptions, experiences, and needs of culturally and linguistically diverse families of children with autism in the UK and the USA. 32 articles were included in the review, with 25 conducted in the USA and 7 in the UK. The findings revealed that family perceptions of autism are influenced by a lack of knowledge, and experiences include social stigma and difficulties in accessing services. The needs indicated the need for culturally sensitive interventions, information in multiple languages, and parent-professional collaboration. These findings have implications for research, policy, and practice(Papoudi, Jørgensen, Guldberg, & Meadan, 2021). (Chung et al. 2016). The findings of these studies suggest that parents of children with autism from culturally and linguistically diverse backgrounds have specific needs in terms of information and support, which can vary based on cultural and linguistic differences. These needs highlight the importance of developing culturally sensitive interventions and providing information in multiple languages to support these families. It is also crucial for professionals to collaborate with families and engage in open communication to understand their needs and provide the necessary support.

2.1.4 Effectiveness of Different Interventions and Support Systems for Parents of Children with ASD

There is a growing body of research on the effectiveness of different interventions and support systems for parents of children with autism spectrum disorder (ASD). Some of the most studied interventions include:

Parent Training Programs: Parent training programs are designed to provide parents with the skills and knowledge needed to manage and support their child with ASD at home. These programs typically cover topics such as behavior management, communication strategies, and stress management. Research has shown that parent training programs can be effective in reducing stress and improving parent-child relationships for parents of children with ASD.

Behavioral Interventions: Behavioral interventions, such as applied behavior analysis (ABA), have been found to be effective in improving social skills, communication, and adaptive behavior in children with ASD. These interventions typically involve a team of therapists who work one-on-one with the child to reinforce appropriate behaviors and reduce challenging behaviors.

Social Skills Groups: Social skills groups provide opportunities for children with ASD to practice social skills and develop peer relationships in a structured and supportive environment. Research has shown that social skills groups can be effective in improving social skills, communication, and self-esteem in children with ASD.

Support Groups: Support groups provide a place for parents of children with ASD to connect with others who are facing similar challenges. These groups can provide emotional support, information, and resources for parents, and can help reduce feelings of isolation and stress.

Respite Care: Respite care provides temporary relief for parents by providing care for their child with ASD, allowing the parents to take a break from their caregiving responsibilities. Research has shown that respite care can be effective in reducing stress and improving quality of life for parents of children with ASD.

It is important to note that the effectiveness of these interventions may vary depending on individual needs and circumstances. It is recommended that families work with a professional to identify the interventions and support systems that are best suited for their specific needs and circumstances.

2.2.5 Gap in the Literature Review

Lack of studies in a specific geographic location: There might be limited research on the experiences of parents of children with ASD in the West Bank, making it difficult to draw conclusions about the effectiveness of interventions and support systems in that particular region, Limited use of standardized measures: There might be limited use of standardized measures to assess the experiences of parents of children with ASD, making it difficult to compare findings across studies and to draw valid conclusions about the effectiveness of interventions and support systems.

In summary, the current literature has established that community stigma is a significant challenge for parents of children with autism spectrum disorder, and that effective coping strategy and support systems are needed to help these parents navigate these challenges. The current body of research has also identified the specific needs of these parents and the impact that community stigma can have on their lives, as well as highlighting promising interventions and support systems for this population.

Chapter Three: Methodology

3.1. Study Design

A Descriptive cross-sectional study was used as an appropriate design for investigating the coping strategies and needs of parents of children with ASD as well as parental stigma related to having a child with ASD in the West Bank.

3.2. Study Sample

The target sample for this study were parents of children with ASD. The inclusion criteria were (1) parents of children with a confirmed diagnosis of ASD, (2) parents who reside in the West Bank, (3) parents whose children are between the ages of 3 and 12 years. The exclusion criteria were (1) Parents of children with intellectual disability, (2) parents who cannot read Arabic, and (3) parents who were unable to complete the questionnaires due to visual or physical impairment understand the language used in the questionnaires.

3.3 Sample Size Calculation

The sample size for this study was determined using the formula:

n = (Z^2 * P * (1-P)) / d^2

Based on a confidence level of 95% and a margin of error of 5%, with an estimated proportion of 0.5, the calculated sample size was 384. However, due to practical constraints and the available resources, a convenience sample of 100 participants was obtained.

3.4. Measures

Coping Orientation to Problems Experienced (Brief-COPE)

The Brief-COPE is a 28-item self-report questionnaire that measures an individual's coping strategies in response to stress. Each two items reflect a coping strategy with a total of

14 coping strategies; (1) *Active coping (*efforts to manage or solve a stressor directly), (2) *planning* (Organizing and arranging activities to reach a goal), (3) *Emotional support* (Receiving emotional support from others), (4) *Instrumental support* (Receiving practical help or support from others), (5) *Positive reframing* (Looking at a stressful situation in a more positive light), (6) *Acceptance* (Accepting a stressful situation as it is), (7) *Religion* (Turning to religious or spiritual beliefs for comfort and support), (8) *Humor* (Using humor to cope with stress), (9) *Venting* (Releasing emotions related to the stressor), (10) *Denial* (Refusing to acknowledge the stressor or its implications), (11) *Substance use* (Using alcohol or drugs as a coping mechanism), (12) *Behavioral disengagement* (Giving up or withdrawing from a situation in response to stress), (13) *Self-distraction* (Diverting attention away from the stressor), (14) *Self-Blame.* Scales 1 through 8 can be regarded as adaptive, whereas scales 9 through 14 are presumably maladaptive. Participants are asked to rate how frequently they use each of the 14 coping strategies in response to stress on a 5-point Likert scale, ranging from "never" to "very often.", according to the following score, “never” = 1, “rarely” = 2, “sometimes” = 3, “often” = 4, “very often” = 5, thus higher scores indicate more use of the specific coping strategy. To generate a subscale score, the sum of the two items composing the specific subscale was calculated. The Brief-cope takes approximately 10-15 minutes to complete and is available in several languages.

The Brief- COPE has been found to have good reliability and validity in previous research. Several studies have reported high levels of internal consistency, with Cronbach's alpha coefficients ranging from 0.75 to 0.89. Additionally, the Brief- COPE has been shown to have good construct validity, meaning that it accurately measures coping strategies in response to stress.

For the Arabic version of the brief COPE, the test-retest reliability was computed to confirm that Arabic brief coping was constant across time. It was confirmed that it can be used for clinical study as well as clinical practices. (Alghamdi, 2020). The Arabic brief COPE consist of the same number of items and subscales as the English one.

Family Needs Survey

The Family Needs Survey (FNS) is a tool used to assess the needs of families of children with special needs, including those with ASD. The purpose of the survey is to gather information about the support, resources, and services that families need to care for their children and meet their own needs. The results of the survey can be used to identify areas where families need additional support. The survey consists of 35 items which assess needs in seven areas; information (7items), family and social support (8 items), financial aspects (6 items), explaining the child's condition to others (5 items), childcare (3 items), professional support (3 items), and community services (3 items). Parents are asked to rate their need for each item with ‘no support needed’ = 1, ‘a little support needed’ = 2 and ‘a lot of support needed’ = 3, thus, higher scores indicate higher need expressed by parents. To calculate the needs for each area, the items that pertains to each area are averaged.

Results of studies suggest that the FNS is a reasonably valid measure of family needs Previous research with parents of children with developmental disabilities has reported that the FNS maintains good reliability within these populations. Cronbach’s alpha for FNS total score in the present study was 0.88. The FNS was translated into Arabic in by Alallwi (2022) using forward – backward translation method.

Parents' Self-Stigma Scale (PSSS)

The Parents' Self-Stigma Scale (PSSS) provide valuable insights into the self-stigma experienced by parents of children with ASD. It can help you understand the psychological impact of self-stigma on these parents and contribute to a deeper understanding of their needs and challenges. The PSSS consists of 11 items with a response on Likert Scale 1 – 5; Never, Rarely, Sometimes, Often, Almost all the time. The score ranges from 11 – 55 with higher scores indicating higher stigma.

Validity and reliability of the PSSS have been assessed in previous research studies. Studies have examined the relationship between the PSSS and related constructs, such as psychological distress, parental stress, and perceived social support. These studies have found significant associations, suggesting that the PSSS is capturing the construct of self-stigma in parents of children with ASD(Eaton et al., 2019). The PSSS has demonstrated good internal consistency in previous studies, with Cronbach's alpha coefficients typically ranging from acceptable to high (e.g., alpha values > 0.70). (Eaton et al., 2019).

As we were unable to find an Arabic version of the PSSS, we conducted an Arabic translation following Beaton et al. (2000)'s standards for the cross-cultural validation of instruments as follows:

Stage 1 – **Forward Translation** which was conducted by two translators; an assistant professor of Allied Medical Sciences, and an English teacher.

Stage 2 – **Synthesis**: The translators completed stage I, and the researcher, acting as an observing recorder, carried out the synthesis. During this process, certain items were revised, and the rationale for these changes was provided.

Table (3.1) Parents' Self-Stigma Scale (PSSS) – Forward Translation Stage

Number of items	**Item title in the original version**	**Modified item**	**Justification**
10	"I am self-conscious about being a parent of a child with problems."	"I am sensitive about the difficulties associated with parenting a child with special needs."	The word "problems" have more negative meaning.
7	"It is not my fault that my child has his/her problem."	"My child's difficulties are not a reflection of my parenting."	The word "fault" implies blame and personal responsibility for the child's condition
5	"I am ashamed that my child has his/her problem."	"I am ashamed of the situation my child is in."	The word "ashamed" carries a heavier emotional state, and a more significant psychological impact
8	"I am embarrassed to be a parent of a child with problems."	"I feel awkward or uncomfortable about the challenges my child faces."	The modified sentence conveys a sense of responsibility and sacrifice.
2	"The way I have raised my child has contributed to his/her problem."	"I question whether my parenting approach has been the most effective for my child."	The world "question" has a nicer tone.

Stage 3 – **Backward translation** which was conducted by an English native. The backward translation came out almost identical to the original questionnaire, except for the following items.

Table (3.2) Parents' Self-Stigma Scale (PSSS) – Backward Translation Stage

Number of items	**Item title in the original version**	**Modified item**	**Justification**
1	"I am not a good enough parent**.**	"I don't feel like I am a good enough parent for my child."	The modified statement focuses on the emotional struggles.
3	"I am a good parent, no matter what others say."	"I believe I am a good parent, despite any criticisms."	The word “believe” implies emphasizing.
3	"I am the best parent I can be."	"I am committed to being the best possible parent for my child."	Both sentences have the same meaning, but the modified one is more formal.

Stage 4 – **Expert committee**: In the fourth stage of translating a parents' self-stigma scale, the expert committee, consisting of an assistant professor and a lecturer from the field of Allied Medical Sciences, carefully evaluated each translation.

Stage 5 - **Test of the Prefinal Version**: In the fifth stage, then final survey was tested with 10 participants who reported that the terms and instructions in the assessments were clear, straightforward, and easy to understand. They did not encounter any difficulties while completing the questionnaires. As a result, the translation was officially approved as the final Arabic version of the PSSS.

Demographics

This section collected information about the parents' name, age, occupation, educational level, place of living, and family income.

3.5. Procedure

The study will recruit a sample of parents of children with ASD from local support groups, schools, and clinical centers. Participants will be screened to ensure that they are the primary caretakers of a child with ASD and are willing to participate in the study.

Parents who met the inclusion criteria—(1) having a child with a confirmed ASD diagnosis, (2) residing in the West Bank, and (3) having a child aged 3 to 12 years—were given information sheet, a consent form, and the measurement tools, all written in Arabic to ensure cultural appropriateness. Before data collection, participants received the information sheet and invitation letter, which explained the study's purpose and procedures. If they agreed to participate, they provided formal written consent, after which data collection began.

The researcher provided the participants with clear details about the study's goals, process, and the criteria for including or excluding participants. The researcher also took time to answer any questions from the participants.

3.6. Data Analysis:

Collected data will be analyzed using a variety of statistical methods to gain insights into the coping strategies and needs of parents of children with autism spectrum disorder. The following statistical approaches will be employed:

Descriptive Statistics: Descriptive statistics will be used to summarize the characteristics of the sample and provide an overview of the frequency and distribution of coping strategies and family needs reported by the participants. This analysis will help in understanding the overall patterns and trends in the data.

3.7. Ethical Consideration

The study is being carried out by the Helsinki Declaration, has been approved by an Arabic-American university, and has been approved by the Palestinian Ministry of Health's research ethical committee. Before participation, parental consent forms and assent from mothers were obtained. Because the research involves human subjects, strict ethical principles must be followed. The participants were asked to consent and are assured that their participation or information would not be used against them. They were also guaranteed their right to privacy and anonymity. Anonymity is preserved by coding the participants and erasing the names associated with the numbers.

3.8. Privacy

Confidentiality is protected by preventing unauthorized access to the data. All mothers who participate in the study are fully informed about the research's purpose and assured that their anonymity will be maintained during analysis the and reporting of the findings. Patients were reassured that the data would not be associated with any individual names to protect their anonymity and confidentiality.

3.9. Harm

Participation will not produce no harm to the participants, and their names would never be revealed to anyone.

Chapter Four: Results

4.1. Characteristics of the Sample

According to Table 1, 77% of the children were males, with 55% aged between 4 and 8 years. The majority of children live with both parents (93%). In terms of language, 48% use single words, and 26% are non-verbal. Around 52% of children exhibit compulsive behaviors, and 70% attend school or a care institution. Furthermore, 98% of families report having no other member with a disability.

Table (4.1): Characteristics of the sample

Variables		Frequencies	n(%)
Gender of the child	Male	**77**	77%
	female	23	23%
Age of the child	less than 4 years	18	18%
	(4-8)	55	55%
	Above 8 years	27	27%
who does the child live with	Mother and Father	93	93%
	Mother only	6	6%
	extended family	1	1%
who diagnosed the child	General pediatrician	36	36%
	pediatric neurologist	64	64%
the child's linguistic level	non-verbal words	26	26%
	single words	48	48%
	sentences, not dialogues	18	18%
	conversation	8	8%
Does the child exhibit compulsive behaviors?	Yes	52	52%
	No	48	48%
Does the child attend school or a care institution?	Yes	70	70%
	No	30	30%
Does the child play with siblings, relatives, or neighbors?	Yes	71	71%
	No	29	29%
Does the child face difficulties in eating?	Yes	23	23%
	No	77	77%
Does the child have difficulties sleeping?	Yes	20	20%
	No	80	80%
Living place	City	48	48%
	village	35	35%
	Camp	17	17%
Income	1000-2000	28	28%
	2001-3000	29	29%
	3001-4000	26	26%
	more than 4001	17	17%
	Total	**100**	**100%**

Table 2 shows parents' demographics. Most of the sample (69%) had 4 or less children, with half of the sample having post graduate education. Percentage of working fathers (93%) is higher than the percentage of working mothers (23%).

Table (4.2): Parent's demographics.

Variables		Frequencies	Percentage
Number of children	≤ 4 Children	69	69%
	> 4 children	20	20%
Do any of your family members have a disability?	Yes	2	2%
	No	98	98%
Mother Education Level	≤ post-secondary	45	45%
	> post-secondary	55	55%
mothers age	20-30 years	22	22%
	31-40 years	57	57%
	More than 40 years	21	21%
Mother's work	Notworking/Housewife	77	77%
	Working	23	23%
Father education level	≤ post-secondary	51	51%
	> post-secondary	49	49%
Father age	20-30 years	4	4%
	31-40 years	54	54%
	More than 40 years	42	42%
fathers work	Not working	7	7
	Working	93	93
	Total	**100**	**100%**

Q1: What coping strategies do parents of children with ASD commonly employ?

As the data was not normally distributed, Medians and quartiles was used to analyze the data regarding coping strategies. Table 3 shows that parents of children with ASD primarily rely on acceptance (8) and religion (8) as coping strategies, emphasizing the importance of finding solace in spiritual beliefs and accepting their situation. Active coping, instrumental support, and positive reframing each have a median of 7, indicating that parents frequently use problem-solving, seeking assistance, and maintaining a positive perspective. On the other hand, substance use (2) and behavioral disengagement (2) have the lowest median scores, suggesting that these maladaptive strategies are rarely employed. In general Palestinian parents of children with ASD use adaptive coping strategies more frequently than maladaptive coping strategies.

Table (4.3): Coping Strategies Employed by Parents of Children with ASD

variables	Median (Q25-Q75)	Adaptive vs. Maladaptive
COPE Acceptance	8 (6-8)	Adaptive
COPE Religion	8 (7-8)	Adaptive
COPE Active coping	7 (6-8)	Adaptive
COPE instrumental support	7 (6-8)	Adaptive
COPE Positive reframing	7 (6-8)	Adaptive
COPE Planning	7 (6-8)	Adaptive
COPE emotional support	6 (5-8)	Adaptive
COPE Venting	5 (4-6)	Adaptive
COPE Self distraction	4 (2-5)	Maladaptive
COPE Denial	4 (3-6)	Maladaptive
COPE_Self_blame	4 (2-6)	Maladaptive
COPE Behavioral disengagement	2 (2-4)	Maladaptive
COPE Substance use	2 (2-2)	Maladaptive
COPE Humor	2 (2-3.75)	Maladaptive
COPE_adaptive_coping	52 (46-57)	
COPE_maladaptive_coping	23 (18-26.75)	

Q2: What are the specific needs of parents of children with ASD are as identified through the Family Needs Survey?

Table 4 summarizes the needs of parents of children with ASD showing that family and social support represents the highest need followed by the need to have more information. Parents express the least need in childcare, professional support, and community services.

Table (4.4): Parents' Needs for Children with ASD: Family Needs Survey.

Needs Category	Median (Q25-Q75)
Information	20 (16.25-21)
Family and social Support	22(18-24)
Financial support	14.5(11-18)
Explaining to Others	12(10-14)
Child Care	9(7-9)
Professional Support	9(7-9)
Community Services	9(7.25-9)

Q3: What is the level of self-stigma among parents of children with ASD?

Stigma results for parents of children with ASD are shown in Table 5. As the score range for stigma is 11 – 55, it seems that parents of children with ASD generally experience a low level of self-stigma.

Table (4.5): Self-Stigma Levels Among Parents of Children with ASD.

variable	Median (Q25-Q75)
Stigma Total	21 (18-26)

Q4: Are there any significant differences in the coping strategies utilized by parents of children with ASD based on demographic factors such as gender, mother education level, and father education level?

Table 5 reveals no statistically significant differences in coping strategies among mothers of children with ASD based on education level, as all p-values exceed 0.05. This suggests that strategies like self-distraction, active coping, denial, emotional support, and religion are similar between mothers with and without post-secondary education.

Table (4.6): Differences in Coping Strategies Among Mothers of Children with ASD Based on Education Level

Mother_Education_level		N	Mean Rank	Sum of Ranks	p-value
COPE_Self_distraction	≤ post-secondary	45	52.43	2359.50	0.533
	> post-secondary	55	48.92	2690.50	
COPE_Active_coping	≤ post-secondary	45	45.60	2052.00	0.107
	> post-secondary	55	54.51	2998.00	
COPE_Denial	≤ post-secondary	45	49.37	2221.50	0.719
	> post-secondary	55	51.43	2828.50	
COPE_Substance_use	≤ post-secondary	45	52.58	2366.00	0.143
	> post-secondary	55	48.80	2684.00	
COPE_emotional_support	≤ post-secondary	45	49.24	2216.00	0.687
	> post-secondary	55	51.53	2834.00	
COPE_instrumental_support	≤ post-secondary	45	49.92	2246.50	0.850

	> post-secondary	55	50.97	2803.50	
COPE_Behavioral_disengagement	≤ post-secondary	45	53.33	2400.00	0.332
	> post-secondary	55	48.18	2650.00	
COPE_Venting	≤ post-secondary	45	50.43	2269.50	0.983
	> post-secondary	55	50.55	2780.50	
	> post-secondary	55	52.80	2904.00	

Mother education level		N	Mean Rank	Sum of Ranks	P - Value
COPE_Positive_reframing	≤ post-secondary	45	46.09	2074.00	0.146
	> post-secondary	55	54.11	2976.00	
COPE_Planning	≤ post-secondary	45	44.81	2016.50	0.056
	> post-secondary	55	55.15	3033.50	
COPE_Humor	≤ post-secondary	45	53.50	2407.50	0.286
	> post-secondary	55	48.05	2642.50	
COPE_Acceptance	≤ post-secondary	45	49.11	2210.00	0.629
	> post-secondary	55	51.64	2840.00	
COPE_Religion	≤ post-secondary	45	49.06	2207.50	0.596
	> post-secondary	55	51.68	2842.50	
COPE_Self_blame	≤ post-secondary	45	52.33	2355.00	0.559
	> post-secondary	55	49.00	2695.00	
COPE_adaptive_coping	≤ post-secondary	45	47.69	2146.00	0.380
	> post-secondary	55	52.80	2904.00	
COPE_maladaptive_coping	≤ post-secondary	45	52.34	2355.50	0.565
	> post-secondary	55	48.99	2694.50	

Table 6 indicate no statistically significant differences in the coping strategies used by fathers of children with ASD based on their education level, as all values are above 0.05. This suggests that factors such as self-distraction, active coping, denial, emotional support, and other strategies do not differ significantly between fathers with and without post-secondary education. Therefore, education level does not appear to significantly impact the coping strategies of these fathers.

Table (4.7): Differences in Coping Strategies Among Fathers of Children with ASD Based on Education Level

Father education level		**N**	**Mean Rank**	**Sum of Ranks**	**p-value**
COPE Self distraction	≤ post-secondary	51	48.99	2498.50	0.583
	> post-secondary	49	52.07	2551.50	
COPE Active coping	≤ post-secondary	51	46.48	2370.50	0.136
	> post-secondary	49	54.68	2679.50	
COPE Denial	≤ post-secondary	51	48.74	2485.50	0.527
	> post-secondary	49	52.34	2564.50	
COPE Substance use	≤ post-secondary	51	48.96	2497.00	0.221
	> post-secondary	49	52.10	2553.00	
COPE emotional support	≤ post-secondary	51	47.82	2439.00	0.333
	> post-secondary	49	53.29	2611.00	
COPE instrumental support	≤ post-secondary	51	47.89	2442.50	0.336
	> post-secondary	49	53.21	2607.50	
COPE Behavioral disengagement	≤ post-secondary	51	49.76	2538.00	0.776
	> post-secondary	49	51.27	2512.00	
COPE Venting	≤ post-secondary	51	49.49	2524.00	0.718
	> post-secondary	49	51.55	2526.00	
COPE Positive reframing	≤ post-secondary	51	46.23	2357.50	0.112
	> post-secondary	49	54.95	2692.50	
COPE Planning	≤ post-secondary	51	47.88	2442.00	0.321
	> post-secondary	49	53.22	2608.00	
COPE Humor	≤ post-secondary	51	50.85	2593.50	0.887
	> post-secondary	49	50.13	2456.50	
COPE Acceptance	≤ post-secondary	51	50.12	2556.00	0.881
	> post-secondary	49	50.90	2494.00	
COPE Religion	≤ post-secondary	51	50.88	2595.00	0.874
	> post-secondary	49	50.10	2455.00	
COPE Self blame	≤ post-secondary	51	48.30	2463.50	0.430
	> post-secondary	49	52.79	2586.50	
COPE adaptive coping	≤ post-secondary	51	46.45	2369.00	0.153
	> post-secondary	49	54.71	2681.00	
COPE maladaptive coping	≤ post-secondary	51	48.06	2451.00	0.390
	> post-secondary	49	53.04	2599.00	

Table 7 shows that there are no significant differences in the coping strategies used by parents of children with ASD based on the child's gender, as all p-values are above the 0.05 threshold. Specifically, there is no statistically significant variation in strategies such as self-distraction, active coping, denial, substance use, emotional support, instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, self-blame, adaptive coping, and maladaptive coping between parents of male and female children with ASD.

Table (4.8): Differences in Coping Strategies Among Parents of Children with ASD Based on Child's Gender.

Gender		N	Mean Rank	Sum of Ranks	p-value
COPE Self distraction	male	77	48.76	3754.50	0.256
	female	23	56.33	1295.50	
COPE Active coping	male	77	49.60	3819.50	0.551
	female	23	53.50	1230.50	
COPE Denial	male	77	48.24	3714.50	0.146
	female	23	58.07	1335.50	
COPE Substance use	male	77	49.57	3817.00	0.185
	female	23	53.61	1233.00	
COPE emotional support	male	77	50.51	3889.50	0.993
	female	23	50.46	1160.50	
COPE instrumental support	male	77	49.29	3795.00	0.422
	female	23	54.57	1255.00	
COPE Behavioral disengagement	male	77	49.84	3837.50	0.646
	female	23	52.72	1212.50	
COPE Venting	male	77	47.88	3686.50	0.092
	female	23	59.28	1363.50	
COPE Positive reframing	male	77	48.12	3705.00	0.112
	female	23	58.48	1345.00	
COPE Planning	male	77	50.66	3900.50	0.916
	female	23	49.98	1149.50	
COPE Humor	male	77	49.51	3812.50	0.477
	female	23	53.80	1237.50	
COPE Acceptance	male	77	48.10	3704.00	0.092
	female	23	58.52	1346.00	
COPE Religion	male	77	50.95	3923.00	0.739
	female	23	49.00	1127.00	
COPE Self blame	male	77	50.19	3864.50	0.841
	female	23	51.54	1185.50	
COPE adaptive coping	male	77	49.51	3812.00	0.530
	female	23	53.83	1238.00	
COPE maladaptive coping	male	77	47.77	3678.00	0.084
	female	23	59.65	1372.00	

Chapter Five: Discussion

5.1 Introduction

The current study aimed to investigate the coping strategies and needs of parents of children with ASD in the West Bank. In addition, we investigated the level of stigma experienced by parents of children with ASD.

To begin with, one of the study aims is to explore the perceptions and coping strategies of parents of children with ASD. The findings of this objective indicate that parents of children with ASD rely on acceptance and religion as coping strategies in response to stress and challenges. Acceptance plays a central role for parents with children with ASD. Studies suggest that acceptance allows parents to adjust their expectations and develop a more adaptive mindset, ultimately leading to better psychological well-being. According to Pottie and Ingram (2008), parents who adopt an acceptance-based approach experience lower levels of distress and greater emotional stability. This strategy helps in reducing feelings of helplessness and enables parents to focus on their child's abilities rather than limitations (Lai et al., 2015). As for religion, previous studies highlight that religious faith provides a sense of meaning and community, reducing the sense of isolation that parents often experience (Ekas et al., 2009). In particular, parents who perceive their child's condition through a spiritual lens often report greater resilience and life satisfaction (Graham et al., 2016). Religion also fosters social connections, as parents often seek support from faith-based communities, which can offer both emotional and practical assistance.

Moreover, active coping, instrumental support, and positive reframing were the most used coping strategies by parents with children with ASD. Active coping refers to engaging in problem-solving acts to manage stress, for example, seeking out services for their child such as education, and healthcare, and organizing daily routines to accommodate their child’s needs. Studies indicated that parents who proactively engage with educational and healthcare systems experience a greater sense of control and competence in managing their child's needs (Ludlow et al., 2012). While instrumental support reflects parents’ tendency to reach out to others for tangible help. Karst and Van Hecke (2012) found that parents who actively seek support from therapists, teachers, and autism specialists report lower levels of stress and improved coping capacity. These findings reinforce the idea that external support networks play a vital role in helping parents manage the challenges associated with ASD. Finally, a positive reframing strategy allows parents to focus on their child's unique qualities and the rewarding experience of parenting an ASD child, which keeps them optimistic and reduces their feelings of frustration. Hastings and Taunt (2002) found that parents who adopt a positive outlook and recognize their child's achievements experience less stress and greater emotional resilience. Moreover, studies suggest that shifting focus from deficits to strengths enhances overall family well-being and contributes to a more positive parent-child relationship (Zhang et al., 2015).

Overall it was obvious from our finding that Palestinian parents of children with ASD employ adaptive coping mechanisms more frequently than maladaptive coping mechanisms. The finding that parents rarely resort to substance use and behavioral disengagement is encouraging and suggests a high level of adaptive coping among parents. Previous research has highlighted that maladaptive coping strategies, such as avoidance and substance use, are associated with poorer mental health outcomes (Dunn et al., 2001). The low prevalence of these strategies indicates that most parents actively seek constructive ways to manage stress, which may be attributed to increased awareness and availability of autism-related support services. Substance use and behavioral disengagement are rarely used by parents as coping strategies, most probably due to the cultural effect that prohibits such behaviors.

The study also provides valuable insight into the needs of parents raising children with ASD. Family and social support stands out as the highest need, which reflects the critical role of emotional support such as peer connections, support groups, and relationships that offer understanding and encouragement in managing the stresses of raising a child with ASD. Parents of children with ASD often experience higher levels of stress and isolation compared to parents of typically developing children (Karst & Van Hecke, 2012). Emotional support from peers, support groups, and close relationships provides parents with encouragement, a sense of belonging, and practical advice to navigate their parenting journey (Clifford & Minnes, 2013). Social support has also been linked to reduced parental depression and increased coping efficacy (Boyd, 2002).

Moreover, support groups create opportunities for parents to share experiences, gain insight from others who understand their struggles, and develop effective coping mechanisms. Studies have found that peer support helps alleviate emotional distress and enhances parents' ability to manage their child's condition (Ekas et al., 2016).

In addition, parents' need for information to better understand their child's conditions and needs is highly prioritized. Our findings highlight the critical need for information about ASD, which is consistent with previous research showing that parents often feel unprepared and lack sufficient knowledge to address their child’s developmental needs (Brown et al., 2012). Understanding ASD symptoms, available interventions, and educational rights is essential for effective caregiving (Mackintosh et al., 2012). Educational workshops, online resources, and guidance from professionals have been shown to empower parents, equipping them with strategies to support their child's development and advocate for their needs (Iadarola et al., 2015). Furthermore, knowledge about ASD reduces parental anxiety and fosters a more proactive approach in seeking therapies and services (Dababnah & Parish, 2013).

Moreover, the findings of the study suggest that financial support is a concern when raising a child with ASD. Financial concerns are another significant challenge for parents of children with ASD. Therapy costs, medical expenses, and specialized services contribute to financial strain, a finding echoed in several studies. Research indicates that families raising a child with ASD face significantly higher healthcare expenses, often struggling to afford behavioral therapy, occupational therapy, and specialized education (Cidav et al., 2012). Studies also show that parents may need to reduce work hours or leave employment entirely to provide adequate care, further exacerbating financial difficulties (Kogan et al., 2008). A significant number of mothers in our study indicated that they don’t work. The decision of not to work could be due to the compiled responsibility of having a child with ASD. Given these challenges, there is a strong need for policies that provide financial relief, such as insurance coverage, government subsidies, and access to affordable intervention programs (Zuckerman et al., 2014).

Out study identified the difficulty parents face in explaining ASD to others, which reflects broader societal challenges regarding ASD awareness. Research indicates that misunderstandings and stigma around ASD can lead to social exclusion, judgment, and a lack of acceptance from extended family and the community (Gray, 2002). Public awareness campaigns, education initiatives, and community training programs can play a vital role in fostering greater acceptance and reducing misconceptions about ASD (Neely-Barnes et al., 2011). When communities are well-informed, families experience less isolation and greater social integration, leading to improved emotional well-being for both parents and children.

Overall, the findings suggest that emotional support, access to information, and financial assistance are the most pressing needs and challenges for parents with ASD children. Therefore, addressing these areas can significantly improve the quality of life for these families.

Our finding that parents of children with ASD experience low levels of self-stigma is particularly interesting, as much of the existing literature highlights stigma as a common challenge faced by these parents. However, recent studies suggest that stigma levels can vary based on multiple factors, such as cultural attitudes, community support, and parental coping mechanisms (Mak & Cheung, 2010). The results of our study align with emerging evidence that many parents are developing a stronger sense of self-assurance and resilience, which has significant implications for their emotional well-being and parenting efficacy. The results emphasized the parents’ strong sense of self-assurance and their belief in their capabilities as caregivers. It also suggests that many parents adopt a positive and affirming view of their role as parents despite the challenges associated with raising a child with ASD. This positive attitude is crucial for the parent’s mental health and their ability to provide consistent support for their child. The researcher believes that these results emphasize the importance of maintaining the parents’ confidence in their parenting skills and the need to sustain efforts to create a supportive environment for these parents.

Furthermore, the study found no statistically significant differences in the coping strategies utilized by parents of children with ASD based on demographic factors such as gender, mother's education level, and father's education level. This emphasizes the shared nature of mothers in giving care and facing challenges while raising children with ASD regardless of their education level. We found similar findings with regards to coping strategies and father’s educational level.Finally, the study found that a child’s gender does not seem to influence how parents cope with the challenges of raising a child with ASD. To illustrate, raising a child with ASD comes with similar challenges, regardless of the child’s gender.

To conclude, this study sheds light on coping strategies and needs of parents raising children with ASD in the West Bank and their felt level of stigma. The findings reveal that most parents rely on adaptive coping strategies such as acceptance, and religion in order to manage emotional and practical challenges and stresses. On the other hand, they rarely use maladaptive strategies, such as substance use or denial. Moreover, the study highlights the importance of enhancing family and social networks and accessing reliable information about ASD, and financial situation. Despite these challenges, the data of the study emphasized that parents rejected self-blame, and were able to maintain confidence in their parenting abilities as caregivers, which protects them from harmful stigma.

5.2 Recommendations

In this section, the researcher provides some suggestions that were developed from data analysis from chapter four and mainly based on the needs of parents of children with ASD.

- The current study recommends conducting further researches that address parents of children with ASD needs in order to raise the community's awareness of ASD. Ongoing studies and research give feedback about what is helping parents, what's not, and what meets their needs. Moreover, the researcher emphasizes the importance of involving parents in research and studies. Involving parents in research ensures that these researches reflect real concerns and provide them with a support system that truly addresses their needs.
- The researcher emphasizes the importance of increasing public awareness and knowledge in order to understand autism spectrum disorder (ASD). For example, public awareness campaigns can use various platforms, such as social media and community events. Raising public awareness plays a vital role in reducing stigma and misunderstanding against children with ASD and their families.
- The researcher confirms the importance of providing culturally appropriate information in order to equip the parents with the knowledge they need to better understand ASD. For example, printed materials and online educational resources would ensure that all parents can access important information on effective coping and effective communication techniques.
- The researcher suggests providing parents with accessible counseling and therapy services by offering financial support to make counseling affordable for families who can't afford therapy fees. This could significantly help them manage stress and overcome challenges, as well as develop effective coping strategies to maintain their mental health and improve communication within the household.
- The researcher also recommends organizing workshops for parents to help them stop blaming their self and feel good about themselves. Self-help programs help parents understand themselves and their child's conditions, and focus on identifying negative thoughts in order to replace them with positive affirmations.
- The researcher also recommends implementing financial assistance programs for parents of children with ASD. Parents of these children often need financial support for therapy, special education, and services. For example, parents of children with ASD should be able to have health insurance that covers autism therapy or get

discounts for ASD-related treatments. Moreover, the researcher suggests that governments should provide parents of children with ASD with scholarship programs to help families enroll their children in schools with better resources for autism, which improves children’s outcomes and reduces stress on parents.

References

Alkhateeb, J. M., Hadidi, M. S., & Mounzer, W. (2022). The impact of autism spectrum disorder on parents in arab countries: a systematic literature review. *Frontiers in Psychology,* 4114.

Alós, F. J., García, A. G., & Maldonado, M. A. (2022). Coping strategies in parents of children with disabilities: A case-control study. *Brain and Behavior, 12*(8), e2701.

Alshaigi, K., Albraheem, R., Alsaleem, K., Zakaria, M., Jobeir, A., & Aldhalaan, H. (2020). Stigmatization among parents of autism spectrum disorder children in Riyadh, Saudi Arabia. *International Journal of Pediatrics and Adolescent Medicine, 7*(3), 140-146.

Alyami, H. S., Naser, A. Y., Alyami, M. H., Alharethi, S. H., & Alyami, A. M. (2022). Knowledge and attitudes toward autism spectrum disorder in Saudi Arabia. *International Journal of Environmental Research and Public Health, 19*(6), 3648.

Bailey Jr, D. B., & Blasco, P. M. (1990). Parents' perspectives on a written survey of family needs. *Journal of Early Intervention, 14*(3), 196-203.

Botha, M., & Frost, D. M. (2020). Extending the minority stress model to understand mental health problems experienced by the autistic population. *Society and mental health, 10*(1), 20-34.

Bujnowska, A. M., Rodríguez, C., García, T., Areces, D., & Marsh, N. V. (2019). Parenting and Future Anxiety: The Impact of Having a Child with Developmental Disabilities. *Int J Environ Res Public Health, 16*(4). doi:10.3390/ijerph16040668

D'Alò, G. L., De Crescenzo, F., Amato, L., Cruciani, F., Davoli, M., Fulceri, F., . . . Nardocci, F. (2021). Impact of antipsychotics in children and adolescents with autism spectrum disorder: a systematic review and meta-analysis. *Health and quality of life outcomes, 19*, 1-19.

Eaton, K., Ohan, J. L., Stritzke, W. G., & Corrigan, P. W. (2019). The parents' self-stigma scale: Development, factor analysis, reliability, and validity. *Child Psychiatry & Human Development, 50*, 83-94.

Feliu-Soler, A., Pérez-Aranda, A., Montero-Marín, J., Herrera-Mercadal, P., Andrés-Rodríguez, L., Angarita-Osorio, N., . . . Luciano, J. V. (2019). Fifteen years controlling unwanted thoughts: A systematic review of the thought control ability questionnaire (TCAQ). *Frontiers in Psychology, 10,* 1446.

Francés, L., Quintero, J., Fernández, A., Ruiz, A., Caules, J., Fillon, G., . . . Soler, C. V. (2022). Current state of knowledge on the prevalence of neurodevelopmental disorders in childhood according to the DSM-5: a systematic review in accordance with the PRISMA criteria. *Child and Adolescent Psychiatry and Mental Health, 16*(1), 27.

Ghanouni, P., & Eves, L. (2023). Resilience among Parents and Children with Autism Spectrum Disorder. *Mental Illness, 2023*.

Ha, V. S., & Whittaker, A. (2022). "Pray to all four directions": a qualitative study of syncretic care seeking by Vietnamese families for their children with autism spectrum disorder. *Disability and Rehabilitation,* 1-12.

Han, E., Scior, K., Avramides, K., & Crane, L. (2022). A systematic review on autistic people's experiences of stigma and coping strategies. *Autism Res, 15*(1), 12-26. doi:10.1002/aur.2652

Han, E., Scior, K., Avramides, K., & Crane, L. (2022). A systematic review on autistic people's experiences of stigma and coping strategies. *Autism Research, 15*(1), 12-26.

Haytham, A.-O., Khuan, L., Ying, L. P., & Hassouneh, O. (2022). Coping mechanism among parents of children with autism spectrum disorder: a review. *Iranian Journal of Child Neurology, 16*(1), 9.

Ji, B., Jiang, X., & Luo, Y. (2022). Autistic childrens age difference in affiliate stigma and resilience of their parents in China: A cross-sectional study. *Archives of Psychiatric Nursing, 39,* 7-12.

Kalankesh, L. R., Shahrokhi, H., Dastgiri, S., Gholipour, K., & Feizi-Derakhshi, M.-R. (2020). Identifying the Needs of Families of Children with Autism Spectrum Disorder from Specialists and Parents' Perspectives: A Qualitative Study. *Iranian Journal of Psychiatry and Behavioral Sciences, 14*(4).

Kinnear, S. H., Link, B. G., Ballan, M. S., & Fischbach, R. L. (2016). Understanding the Experience of Stigma for Parents of Children with Autism Spectrum Disorder and the Role Stigma Plays in Families' Lives. *J Autism Dev Disord, 46*(3), 942-953. doi:10.1007/s10803-015-2637-9

Leedham, A., Thompson, A. R., Smith, R., & Freeth, M. (2020). 'I was exhausted trying to figure it out': The experiences of females receiving an autism diagnosis in middle to late adulthood. *Autism, 24*(1), 135-146.

Mokoena, N., & Kern, A. (2022). Experiences of siblings to children with autism spectrum disorder. *Front Psychiatry, 13,* 959117. doi:10.3389/fpsyt.2022.959117

Ntre, V., Papanikolaou, K., Amanaki, E., Triantafyllou, K., Tzavara, C., & Kolaitis, G. (2022). Coping Strategies in mothers of children with autism spectrum disorder and their relation to maternal stress and de-pression. *Psychiatriki, 33,* 210-218.

Ntre, V., Papanikolaou, K., Amanaki, E., Triantafyllou, K., Tzavara, C., & Kolaitis, G. (2022). Coping Strategies in mothers of children with autism spectrum disorder and their relation to maternal stress and depression. *Psychiatriki, 33*(3), 210-218. doi:10.22365/jpsych.2022.068

Oduyemi, A. Y., Okafor, I. P., Eze, U. T., Akodu, B. A., & Roberts, A. A. (2021). Internalization of stigma among parents of children with autism spectrum disorder in Nigeria: a mixed method study. *BMC psychology, 9,* 1-12.

Özaydin, L., Karaçul, F. E., Kayhan, N., Büyüköztürk, S., Karahan, S., & Simeonsson, R. J. (2021). Assessing Needs of Parents with Children with Disabilities in Turkey. *Psycho-Educational Research Reviews, 10*(3), 255-267.

Papadopoulos, A., Tafiadis, D., Tsapara, A., Skapinakis, P., Tzoufi, M., & Siafaka, V. (2022). Validation of the Greek version of the Affiliate Stigma Scale among mothers of children with autism spectrum disorder. *BJPsych Open, 8*(1), e30.

Papadopoulos, D. (2021). Mothers' Experiences and Challenges Raising a Child with Autism Spectrum Disorder: A Qualitative Study. *Brain Sci, 11*(3). doi:10.3390/brainsci11030309

Papoudi, D., Jørgensen, C. R., Guldberg, K., & Meadan, H. (2021). Perceptions, Experiences, and Needs of Parents of Culturally and Linguistically Diverse Children with Autism: a Scoping Review. *Review Journal of Autism and Developmental Disorders, 8*(2), 195-212. doi:10.1007/s40489-020-00210-1

Perry, E., Mandy, W., Hull, L., & Cage, E. (2022). Understanding camouflaging as a response to autism-related stigma: A social identity theory approach. *Journal of Autism and Developmental Disorders, 52*(2), 800-810.

Sankey, C., Derguy, C., Clément, C., Ilg, J., & Cappe, É. (2019). Supporting parents of a child with autism spectrum disorder: the French awakening. *Journal of Autism and Developmental Disorders, 49,* 1142-1153.

Schlebusch, L., & Dada, S. (2018). Positive and negative cognitive appraisal of the impact of children with autism spectrum disorder on the family. *Research in Autism Spectrum Disorders, 51,* 86-93.

Shanmugarajah, K., Rosenbaum, P., & Di Rezze, B. (2022). Exploring autism, culture, and immigrant experiences: Lessons from Sri Lankan Tamil mothers. *Canadian Journal of Occupational Therapy, 89*(2), 170-179.

Shilubane, H., & Mazibuko, N. (2020). Understanding autism spectrum disorder and coping mechanism by parents: An explorative study. *International journal of nursing sciences, 7*(4), 413-418.

Sidhu, H. K., & Greene, M. C. (2022). A scoping review of disparities in health and health-care service provisions experienced by adults with autism spectrum disorder. *Advances in Autism*(ahead-of-print).

Solmi, M., Song, M., Yon, D. K., Lee, S. W., Fombonne, E., Kim, M. S., . . . Keller, R. (2022). Incidence, prevalence, and global burden of autism spectrum disorder from 1990 to 2019 across 204 countries. *Molecular Psychiatry*, 1-9.

Treweek, C., Wood, C., Martin, J., & Freeth, M. (2019). Autistic people's perspectives on stereotypes: An interpretative phenomenological analysis. *Autism, 23*(3), 759-769.

Turnock, A., Langley, K., & Jones, C. R. G. (2022). Understanding Stigma in Autism: A Narrative Review and Theoretical Model. *Autism Adulthood, 4*(1), 76-91. doi:10.1089/aut.2021.0005

Wang, L., Wang, B., Wu, C., Wang, J., & Sun, M. (2023). Autism Spectrum Disorder: Neurodevelopmental Risk Factors, Biological Mechanism, and Precision Therapy. *Int J Mol Sci, 24*(3). doi:10.3390/ijms24031819

Weissheimer, G., Santana, J. M., Ruthes, V. B. T. N. M., & Mazza, V. d. A. (2020). Necessary information for the families of children with autism spectrum disorder: an integrative review. *Aquichan, 20*(2).

Willsey, H. R., Willsey, A. J., Wang, B., & State, M. W. (2022). Genomics, convergent neuroscience and progress in understanding autism spectrum disorder. *Nature Reviews Neuroscience, 23*(6), 323-341.

Yaacob, W. N. W., Yaacob, L. H., Zulkifli, M. M., & Muhamad, R. (2022). A Journey towards Resilience: Coping Strategies Adopted by Parents with Children Having Autism Spectrum Disorder in Northeast Malaysia. *International Journal of Environmental Research and Public Health, 19*(4), 2458.

Appendices

Appendix (1) Research Tool

المعلومات الديموغرافية:

معبئ الاستبيان:

الام: ☐ الاب: ☐

غير ذلك: ______________

مكان السكن:

مدينة ☐ قرية ☐ مخيم ☐

يعيش الطفل مع:

والديه (الام والاب): ☐ الام فقط: ☐ عائلة ممتدة (مثلا الجد او الجدة): ☐

معلومات عن الام: عمر الام: من 20 الى 30سنة ☐ من 31 الى 40 سنة ☐

من 41 الى 50 سنة ☐ من 51 فأعلى ☐ أكثر من 60 سنة ☐

التحصيل الأكاديمي:

أقل من ثانوي ☐ ثانوي ☐

دبلوم ☐ بكالوريوس ☐

دراسات عليا ☐

عمل الأم:

ربة منزل ☐ دوام جزئي ☐ دوام كامل ☐

معلومات عن الاب:

عمر الأب (بالسنوات):

من 20 الى 30سنة ☐ من 31 الى 40 سنة ☐

من 41 الى 50 سنة ☐ من 51 فأعلى ☐

أكثر من 60 سنة ☐

التحصيل الأكاديمي:

أقل من ثانوي ☐ ثانوي ☐

دبلوم ☐ بكالوريوس ☐

دراسات عليا ☐

عمل الأب:

لا يعمل ☐ دوام جزئي ☐ وقت كامل ☐

إجمالي عدد الأطفال في المنزل: ________

دخل الأسرة:

2000-1000 ☐

3000-2001 ☐

4000-3001 ☐

أكثر من 4001 ☐

هل يعاني أحد افراد الاسرة من اعاقة:

نعم ☐ لا ☐

إذا نعم، ما هي نوع الاعاقة: _______

معلومات عن الطفل:

عمر الطفل (بالسنوات): _______

جنس الطفل:

ذكر ☐ أنثى ☐

على أي عمر تم تشخيص الطفل؟ __________ سنوات

من قام بتشخيص الطفل؟

طبيب أطفال عام ☐ طبيب أطفال أعصاب ☐

غير ذلك _______

المستوى اللغوي للطفل:

كلمات غير لفظية ☐

كلمات مفردة ☐

جمل وليست حوارية ☐

المحادثة ☐

هل يبدي الطفل سلوكيات قهرية تؤثر على ادائه الوظيفي اليومي وتواصله مع الاخرين:

نعم ☐ لا ☐

هل يذهب الطفل الى المدرسة أو اي مؤسسة تعليمية او مؤسسة رعاية؟

نعم ☐ لا ☐

إذا نعم، كم عدد الساعات التي يقضيها الطفل في المؤسسة؟ _______

هل يلعب الطفل مع اخوته أو الاقارب او الجيران؟

نعم ☐ لا ☐

هل يواجه الطفل صعوبات في تناول الطعام؟

نعم ☐ لا ☐

هل يواجه الطفل صعوبات في النوم؟

نعم ☐ لا ☐

مقياس التكييف

الرجاء الإجابة على الأسئلة التالية مشيراً إلى أي مدى توافق أو لا توافق على كل عبارة. ضع إشارة مقابل التكرار المناسب لك:

1= أنا لم أفعل ذلك على الإطلاق

2= لقد فعلت هذا قليلا

3= لقد كنت أفعل هذا بشكل متوسط

4= لقد فعلت هذا كثيرا

	البند	أنا لم أفعل ذلك على الإطلاق	لقد فعلت هذا قليلا	لقد كنت أفعل هذا بشكل متوسط	لقد فعلت هذا كثيرا
1	**تحولت إلى العمل أو الأنشطة الأخرى لتصفية ذهني**				
2	**ركّزت جهودي على القيام بشيء حيال الوضع الذي انا فيها**				
3	**كنت أقول لنفسي "هذا ليس حقيقيا".**				
4	**استخدمت الكحول أو المخدرات لأشعر على نحو أفضل.**				
5	**حصلت على الدعم العاطفي من الآخرين.**				
6	**تخليت عن محاولة التعامل مع الموقف.**				
7	**اتخذت اجراءات في محاولة لجعل الوضع يبدو أفضل.**				
8	**كنت ارفض أن اصدق أنه ما حدث قد حدث فعلا.**				
9	**قلت أشياء حتى اتخلص او اهرب من من المشاعر غير السارة المتعلقة بالحدث.**				
10	**حصلت على المساعدة والمشورة من أشخاص آخرين.**				
11	**استخدمت الكحول أو المخدرات لتساعدني في الخروج من ذلك الموقف**				
12	**حاولت أن أرى الموقف في صورة مختلفة، لجعله يبدو أكثر إيجابية.**				

13	انتقدت نفسي.				
14	حاولت الخروج باستراتيجية حول ما يجب القيام به.				
15	حصلت على الراحة والتفهم من شخص ما.				
16	تخليت عن محاولة التأقلم مع الموقف				
17	بحثت عن شيء جيد فيما يحدث.				
18	صنعت وقلت النكات حول هذا الموضوع.				
19	فعلت أشياء لأقلل من التفكير في الموقف، مثل الذهاب إلى السينما، ومشاهدة التلفزيون والقراءة وأحلام اليقظة النوم، أو التسوق.				
20	قبلت بواقع الحقيقة أنه حدث				
21	عبرت عن مشاعري السلبية.				
22	حاولت أن أجد الراحة في ديني ومعتقداتي الروحية.				
23	حاولت الحصول على مشورة أو مساعدة من الآخرين حول ما يجب القيام به.				
24	تعلمت كيفية العيش معه.				
25	فكرت مليا في الخطوات التي يجب اتخاذها.				
26	لومت نفسي عن الأشياء التي حدثت.				
27	صليت أو لجأت الى التأمل.				
28	سخرت من هذا الموقف.				

مسح احتياجات الاسرة

في هذا الجزء نَودُّ أن نطرح عليك أسئلة حول احتياجات أسرتك فيما يتعلق بالمعلومات والدعم المطلوب لطفلك المُشخص باضطراب طيف التوحد. من فضلك اقرأ الفقرات بالأسفل وضع اشارة ✓ تحت مستوى الدعم الذي تحتاجه أنت وأسرتك في كل من المجالات التالية.

المجالات	لا حاجة إلى أي دعم	الحاجة إلى القليل من الدعم	الحاجة إلى الكثير من الدعم
المعلومات 1. كيفية نمو وتطور الأطفال المُشخصين باضطراب طيف التوحد			
2. كيفية اللعب والتحدث مع طفلي المُشخص باضطراب طيف التوحد			
3. كيفية تعليم طفلي المُشخص باضطراب طيف التوحد			
4. كيفية التعامل مع سلوك طفلي المُشخص باضطراب طيف التوحد			
5. معلومات حول أي حالة أو إعاقة قد تكون موجودة لدى طفلي المُشخص باضطراب طيف التوحد			
6. معلومات حول الخدمات المتوفرة حالياً لطفلي المُشخص باضطراب طيف التوحد			
7. معلومات عن الخدمات التي يمكن أن يتلقاها طفلي المُشخص باضطراب طيف التوحد في المستقبل			
الدعم الأسري والاجتماعي 1. التحدث مع فرد من أسرتي حول ما يقلقني			
2. وجود أصدقاء أتحدث إليهم			
3. إيجاد المزيد من الوقت لنفسي			
4. مساعدة زوجي/ زوجتي تقبل أي حالة قد يصاب بها طفلنا المُشخص باضطراب طيف التوحد			
5. مساعدة أسرتنا مناقشة المشاكل والوصول إلى حلول			

المجالات	**لا حاجة إلى أي دعم**	**الحاجة إلى القليل من الدعم**	**الحاجة إلى الكثير من الدعم**
6. مساعدة أسرتنا دعم بعضها البعض خلال الأوقات الصعبة			
7. تحديد من يقوم بالأعمال المنزلية ورعاية الأطفال وغيرها من المهام الأسرية			
8. اتخاذ القرارات بشأن الأنشطة الترفيهية العائلية والقيام بها			
الدعم المالي 1. دفع تكاليف مثل الطعام، السكن، الرعاية الطبية، الملابس، أو المواصلات			
2. الحصول على أي معدات خاصة يحتاجها طفلي			
3. دفع تكاليف العلاج أو الرعاية النهارية أو الخدمات الأخرى التي يحتاجها طفلي			
4. الاستشارات أو المساعدة في الحصول على عمل			
5. دفع تكاليف خدمة مجالسة الأطفال أو خدمة الرعاية المؤقتة			
6. دفع ثمن الألعاب التي يحتاجها طفلي			
الشرح للأخرين 1. شرح حالة طفلي لوالديّ او والديّ زوجي/زوجتي			
2. شرح حالة طفلي لأخوته أو أخواتة			
3 . معرفة كيفية الرد على الأسئلة المتعلقة بطفلي المشخص بالتوحد من قبل الأصدقاء أو الجيران أو الغرباء.			
4. شرح حالة طفلي لأطفال اخرين			
5. العثور على مواد قراءة حول أسر أخرى لديها طفل مُشخص باضطراب طيف التوحد مثل طفلي			
رعاية الطفل 1. إيجاد جلساء أطفال أو مقدمي خدمات الرعاية المؤقتة من لديهم الرغبة والقدرة على رعاية طفلي المُشخص باضطراب طيف التوحد			

المجالات	لا حاجة إلى أي دعم	الحاجة إلى القليل من الدعم	الحاجة إلى الكثير من الدعم
2. إيجاد برنامج رعاية يومي أو روضة لطفلي المُشخص باضطراب طيف التوحد			
3. الحصول على الرعاية المناسبة لطفلي في المسجد أو الكنيسة أو المعبد أثناء تأدية الطقوس الدينية			
دعم من قبل الاخصائيين 1. الاجتماع مع إمام، كاهن، او حاخام			
2. الاجتماع مع مستشار (أخصائي نفسي، اجتماعي، طبيب نفسي)			
3.الحصول على المزيد من الوقت للتحدث مع معلم أو معالج طفلي			
خدمات المجتمع 1.الإلتقاء والتحدث مع أهالي أطفال مُشخصين باضطراب طيف التوحد تماثل حالتهم حالة طفلي			
2. إيجاد طبيب يفهمني ويفهم احتياجات طفلي			
3. إيجاد طبيب الأسنان الذي سوف يتابع طفلي			

مقياس الوصمة الذاتية لدى الوالدين.

	ابدا	نادرا	احيانا	غالبا	تقريبا كل الوقت
1-أنا لست والدًا جيدًا بما فيه الكفاية					
2-طريقة تربيتي لطفلي ساهمت في مشكلته					
3- انا والد جيد بغض النظر عما يقوله الاخرون					
4- اشعر بالذنب لان طفلي يواجه مشاكل					
5- أشعر بالخجل من المشاكل التي يواجهها طفلي.					
6- طفلي يواجه مشكله بسببي					
7- ليس خطأي ان طفلي يواجه مشكلة					
8- اشعر بالحرج لكوني والداً لطفل يواجه مشاكل					
9- انا أفضل والد ممكن أن أكونه					
10- أنا واعي كوني والد لطفل يواجه مشاكل					
11- أستحق أن ألام على المشاكل التي يواجهها ابني					

Appendix (2) IRP Approval

Arab American University- Palestine
Deanship of Scientific Research
IRB committee
Tel: 04-241-8888, ext 1196
E-mail: irb.aaup@aaup.edu

الجامعة العربية الامريكية- فلسطين
عمادة البحث العلمي
لجنة أخلاقيات البحث العلمي
تلفون: 04-241-8888 ext 1196
البريد الالكتروني: irb.aaup@aaup.edu

IRB Approval Letter

Study Title: Investigating the Coping Strategies and the Needs of Parents of Children with ASD Applied During Confrontation with Community Stigma in the West Bank.

Submitted by: ESRA TAISEER OTHMAN QADDAN

Date received: 6th May 2023

Date reviewed: 4th June 2023

Date approved: 16th June 2023

Your Study titled "**Investigating the Coping Strategies and the Needs of Parents of Children with ASD Applied During Confrontation with Community Stigma in the West Bank.**" With archived number 2023/A/102/N was reviewed by the Arab American University IRB committee and was approved on 16th June 2023

Reham Khalaf-Nazzal, MD, PhD
IRB committee chairman
Arab American University of Palestine

General Conditions:

1. Valid for 6 months from date of approval.
2. It is important to inform the committee with any modification of the approved study protocol.
3. The committee appreciates a copy of the research when accomplished.

لجنة أخلاقيات البحث العلمي في الجامعة العربية الامريكية

IRB at Arab American University

Appendix (3) Hospital Approval “Non-GOV”

Arab American University
Faculty of Graduate Studies
الجامعــة العربيــة الأمريكيــة
كلية الدراسات العليا

2023/8/21

الى من يهمه الأمر

تسهيل مهمة بحثية

تحية طيبة وبعد،

تُهديكم كلية الدراسات العُليا في الجامعة العربية الأمريكية أطيب التحيات، وبالإشارة الى الموضوع أعلاه، تشهد كلية الدراسات العُليا في الجامعة أن الطالبة **اسراء تيسير عثمان قعدان** والتي تحمل الرقم الجامعي 202113450هي طالبة ماجستير في برنامج العلاج الوظيفي وتعمل على أُطروحة الماجستير الخاصة بها بعنوان:

" دراسة الإستراتيجيات والاحتياجات لأهالي أولاد فلسطينيين ذوي اضطراب طيف التوحد في مواجهة وصمة العار المجتمعية في الضفة الغربية" تحت إشراف الدكتورة سنا أبو الذهب. نأمل من حضرتكم الإيعاز لمن يلزم لمساعدتها للحصول على المعلومات اللازمة للدراسة، علماً أن المعلومات ستستخدم لغاية البحث فقط وسيتم التعامل معها بغاية السرية، وقد أُعطيت هذه الرسالة بناءً على طلبها.

وتفضلوا بقبول فائق الاحترام

عميد كلية الدراسات العليا

د. نوار قطب

كلية الدراسات العليا
FACULTY OF GRADUATE STUDIES

Page 1 of 2

Jenin Tel: +970-4-2418888 Ext.:1471,1472 Fax: +970-4-2510810 P.O. Box:240
Ramallah Tel: +970-2-2941999 Fax: +970-2-2941979 Abu Qash - Near Alrehan
E-mail: FGS@aaup.edu ; PGS@aaup.edu Website: www.aaup.edu

Appendix (4) Participant Information Sheet

Arab American University
Scientific Research Deanship
Ethical Review Committee

الجامعة العربية الأمريكية
عمادة البحث العلمي
لجنة اخلاقيات البحث العلمي

ورقة معلومات المشارك

عنوان الدراسة:
دراسة الإستراتيجيات والإحتياجات لأهالي أولاد فلسطينيين ذوي اضطراب طيف التوحد في مواجهة وصمة العار المجتمعية في الضفة الغربية.

ندعوكم للمشاركة في دراسة بحثية. قبل أن تقرر ما إذا كنت ستشارك ، تحتاج إلى فهم سبب إجراء البحث وما الذي سيتضمنه. يرجى أخذ الوقت الكافي لقراءة المعلومات التالية بعناية ؛ تحدث مع الآخرين عن الدراسة إذا كنت ترغب في ذلك.

اسألنا إذا كان هناك أي شيء غير واضح أو إذا كنت ترغب في مزيد من المعلومات. خذ وقتك لتقرر ما إذا كنت ترغب في المشاركة أم لا

1- ما هو الغرض من هذه الدراسة؟
للتحقيق في آثار واحتياجات كونك أبًا لأطفال مصابين بالتوحد ، وتأثيرات الوصمة الاجتماعية على الصحة العقلية للوالد ورفاهيته.

2- لماذا هذه الدراسة مهمة؟
هذه الدراسة المقترحة لها آثار كبيرة على فهم تأثيرات وصمة العار على آباء الأطفال المصابين بالتوحد وتحديد استراتيجيات المواجهة الفعالة المشتركة المطبقة في التعامل مع هذه الآثار. ستساعد هذه المعرفة ممارسي العلاج النفسي والمهنيين الآخرين على فهم هذه المشكلة بعمق والتخطيط للتدخلات الفعالة وتطبيق استراتيجيات أكثر فاعلية مع أولياء الأمور.

3- ما هو الإجراء الذي يتم اختباره؟ (إذا كان قابلا للتطبيق)
ستقوم الباحثة بالاتصال بمراكز التأهيل المختلفة في الضفة الغربية للأطفال المصابين بالتوحد ، وطلب الإذن بالتواصل مع أولياء أمورهم (عينة الدراسة). سيُطلب من الوالدين التوقيع على موافقة مستنيرة للمشاركة في هذه الدراسة. بعد ذلك ، سيُطلب من أولياء الأمور ملء استمارة الدراسة بشكل فردي بإشراف الباحث.

4- لماذا تمت دعوتي للمشاركة في هذه الدراسة؟
لأنني أحد المشاركين الأساسيين في الدراسة وفقًا لمعايير التضمين: والد لطفل مصاب باضطراب طيف التوحد.

5- من لا يجب أن يشارك في الدراسة؟
والدي الأطفال الذين لا يعانون من اضطراب طيف التوحد. نظرًا لأن الهدف الرئيسي للدراسة هو استكشاف استراتيجيات التكيف واحتياجات أولياء الأمور الذين لديهم أطفال يعانون من اضطراب طيف التوحد، فإن والدي الأطفال الذين لا يعانون من هذا الاضطراب ليسوا الجمهور المستهدف للدراسة. يجب أن يكون المشاركون في الدراسة هم أولياء الأمور الذين لديهم تجربة مباشرة في التعامل مع التحديات التي يواجهها الأطفال المصابين بطيف التوحد أثناء التعامل مع المجتمع في الضفة الغربية.

6- هل يمكنني رفض المشاركة في الدراسة؟
نعم ، المشاركة في هذه الدراسة تطوعية.

7- ماذا سيحدث لي إذا شاركت؟
لا ، ضرر محتمل

8- إلى متى سأشارك في هذه الدراسة؟
4 اشهر.

9- ما هي العيوب والمخاطر المحتملة؟
لا يوجد خطر.

10- ما هي الفوائد المحتملة بالنسبة لي؟
زيادة الوعي باحتياجات الأطفال المصابين بالتوحد.

11- من سيتمكن من الوصول إلى سجلاتي الطبية وبيانات البحث؟
أنا والمشرف.

12- هل ستبقى سجلاتي / بياناتي سرية؟
نعم ، البيانات والملفات سرية.

13- ماذا سيحدث لأية عينات أعطيها؟ (إذا كان قابلا للتطبيق)
غير قابل للتطبيق.

-14 ماذا سيحدث إذا لم أرغب في مواصلة الدراسة؟
لا شيئ.

-15 ماذا سيحدث لنتائج الدراسة البحثية؟
سيتم نشر النتيجة.

-16 هل سأحصل على تعويض عن المشاركة في هذه الدراسة؟
لا

-17 بمن يجب علي الاتصال إذا كانت لدي أسئلة / مشاكل إضافية أثناء الدراسة؟
تفاصيل الاتصال بالباحث:
طالبة الماجستير في العلاج الوظيفي اسراء قعدان.
Esraa-qaddan@hotmail.com

0569733137

-18 بمن يجب علي الاتصال إذا كنت غير راضٍ عن كيفية إجراء الدراسة؟
الباحث : الدكتورة سناء ابو ذهب .

لجنة المراجعة الأخلاقية
عمادة البحث العلمي
الجامعة العربية الأمريكية - فلسطين (AAUP)
البريد الإلكتروني: src@aaup.edu

دراسة الإستراتيجيات والاحتياجات لأهالي أولاد فلسطينيين ذوي اضطراب طيف التوحد في مواجهة وصمة العار المجتمعية في الضفة الغربية

اسراء قعدان

د. سناء أبو ذهب

د. هشام كعبية

د. دعاء الواوي

ملخص

تهدف هذه الدراسة إلى استكشاف استراتيجيات التكيف واحتياجات أولياء أمور الأطفال المصابين باضطراب طيف التوحد (ASD) في الضفة الغربية، مع التركيز بشكل خاص على وصمة العار المجتمعية. وبما أن أولياء الأمور يواجهون تحديات وضغوطًا فريدة نتيجة إصابة أطفالهم بالتوحد، تسعى هذه الدراسة إلى تسليط الضوء على الاستراتيجيات التكيفية الإيجابية والسلبية التي يستخدمها الآباء في مواجهة هذه التحديات والضغوط.

اعتمدت الدراسة على منهج وصفي وتصميم مقطعي، حيث شملت العينة 100 من أولياء أمور الأطفال المصابين باضطراب طيف التوحد، من خلال استخدام استبيانات منظمة. أظهرت النتائج أن الآباء يعتمدون بشكل رئيسي على استراتيجيات التكيف الإيجابية مثل القبول، والدين، وطلب الدعم العاطفي. في المقابل، كانت الاستراتيجيات السلبية مثل تعاطي المواد والإنكار نادرة الاستخدام.

كما أبرزت النتائج أهمية الدعم الأسري والمجتمعي، والمساعدة المالية، وإمكانية الوصول إلى المعلومات المتعلقة باضطراب طيف التوحد. وبيّنت الدراسة أيضًا أن وصمة العار المجتمعية تُعد حاجزًا كبيرًا يمنع الآباء من طلب الدعم ويزيد من مستوى الضغط النفسي لديهم. ومع ذلك، أكدت النتائج أن الآباء أظهروا قوة داخلية ورفضوا إلقاء اللوم على أنفسهم، مما يدل على قدرتهم على الحفاظ على ثقتهم في مهاراتهم الوالدية رغم الضغوط المجتمعية.

استنادًا إلى نتائج الدراسة، قدّم الباحث عددًا من التوصيات. أولاً، شدد على أهمية إجراء المزيد من الدراسات التي تركز على احتياجات أولياء أمور الأطفال المصابين باضطراب طيف التوحد. كما أكد على ضرورة

رفع مستوى الوعي المجتمعي حول هذا الاضطراب، وتزويد أولياء الأمور بالمعلومات والمعرفة اللازمة التي تسهم في تقليل الفجوة بين الأطفال المصابين بالتوحد والعالم من حولهم. بالإضافة إلى ذلك، أوصى الباحث بتمكين أولياء الأمور ماليًا، وتوفير منح دراسية، وتأمين صحي، وتعليم خاص، وأنواع مختلفة من العلاجات للأطفال المصابين باضطراب طيف التوحد، الأمر الذي من شأنه أن يسهم بشكل كبير في تقليل الضغوط ومواجهة التحديات.

الكلمات المفتاحية :اضطراب طيف التوحد، استراتيجيات التكيف، وصمة العار المجتمعية، احتياجات الوالدين، الضفة الغربية.