

# Stress, Anxiety and Depression in Parents of Autistic Children in Saudi Arabia



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## **Abstract**

Parents of autistic children commonly report experiencing higher levels of stress, anxiety and depression compared to parents of typically developing children and parents of children with other various developmental conditions. Considering the worldwide increase in the prevalence of autism, understanding the experiences of these parents and how they cope with their child's condition has become increasingly important. Studies exploring parental experiences caring for their autistic child have yielded inconsistent results in relation to the impact certain factors have on their mental health. Part of this inconsistency might be explained by the tendency of previous studies to measure the effect of a single factor on parental mental health as well as investigating parental stress, anxiety and depression as a single outcome variable which could compromise the potential for research to clearly isolate and understand the specific factors that contribute to each mental health construct independently. Considering that it is more likely that there are multiple contributing factors which affect parental mental health, an analysis of the interplay between key factors linked to parental mental health issues will be better able to effectively assess the experiences of parents caring for an autistic child. Moreover, despite it being well established that caring for an autistic child can have a significant impact on parents despite their cultural background, the intricacy of this impact is not yet well understood across varying cultures since the bulk of research on the mental health of parents of autistic children is typically conducted in Western countries. To date, little research has investigated factors associated with the mental health of parents of autistic children in the Middle East. As such the overarching aim of this thesis was to explore how parental stress, anxiety and depression are impacted by different factors in a participant sample from Saudi Arabia through five quantitative studies.

The first aim of this thesis was to explore the factors negatively affecting mental health in parents of autistic children in Saudi Arabia (Chapter 2 and 3). In chapter 2, the impact of child specific factors (i.e., challenging child behavior and autism symptom severity) on parental stress, anxiety and depression were explored. Results indicated that parents who rated their children as presenting with more severe autism symptomology also reported higher levels of stress, anxiety and depression. In order to gain a better understanding of the high levels of reported mental health issues in this group of parents, chapter 3 incorporated the factor of affiliate stigma to the previous factors investigated. Results from chapter 3 indicated that affiliate stigma was the only significant predictor of parental stress, anxiety and depression in this participant sample.

Although it is common for parents with autistic children to report experiencing mental health issues, not all parents report such high levels of stress, anxiety and depression. As such, the second aim of this thesis was to explore how parents of autistic children from Saudi Arabia adaptively cope with their child's condition. In chapter 4, the buffering effect of parent-specific factors (i.e., resilience and religious coping) on parental mental health was explored. Results indicated that resilience was the only significant factor predicting lower levels of stress, anxiety and depression in this participant sample. In chapter 5, the impact of perceived social support on parental mental health was also investigated in order to explore the extent of which it could protect against stress, anxiety and depression. Results indicated that perceived social support had a positive impact on parental mental health, specifically when the source of social support was from a spouse/life partner.

In Chapter 6 a more holistic approach was incorporated in order to explore the interplay between the previously investigated factors and their impact on parental mental health. The double ABC-X model was employed in this chapter for this purpose. Results from chapter 6 indicated that affiliate stigma was the only significant predictor of parental stress, anxiety and depression and that resilience and social support mediated the relationship between affiliate stigma and depression. However, only resilience was found to be a significant mediator in the relationship between stigma and anxiety.

Although there are various factors associated with the mental health of parents of autistic children in Saudi Arabia, affiliate stigma seems to play a major role. Resilience has been shown to be a key protective factors against mental health issues in this participant sample. The results from this thesis have important implications for clinical practice and future research. It is evident that there is an urgent need for Saudi Arabia to tackle the issue of mental health stigma effectively, and for healthcare and intervention providers to help parents develop their resilience skills and encourage them to seek social support to ensure the overall wellbeing of both parent and child.

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# **Introduction and Literature Review**

## **1.1 Introduction**

According to the existing literature on parental mental health associated with caring for a child diagnosed with autism, parenting an autistic child can be more challenging than parenting a typically developing child as autistic children require a more intensive level of parenting and support (Blacher & McIntyre, 2006; DePape & Lindsay, 2015; Beighton & Wills, 2017). Previous studies suggest that parents of autistic children commonly report higher levels of stress and lower levels of overall wellbeing and quality of life in comparison to parents of typically developing children (Dabrowska & Pisula, 2010; Estes et al., 2013; Hayes & Watson, 2013), and parents of children diagnosed with other developmental conditions (Dabrowska & Pisula, 2010; Wang et al., 2011; Dykens & Lambert, 2013; Estes et al., 2013). Moreover, parents of autistic children are also more likely to report higher levels of anxiety and depression (Weiss, 2002; Stein et al., 2011; Kuusikko-Gauffin et al., 2013; Falk et al., 2014) as well as other health-related issues such as physical fatigue, poor eating habits, poor sleep quality and reduced immune functioning (Stein et al., 2011; Dykens & Lambert, 2013; Giallo et al., 2013; Fairthorne et al., 2015).

Various studies exploring the underlying factors associated with parental mental health issues related to caring for an autistic child have suggested a number of possible predictors for parental stress, anxiety and depression. These include the severity of the autism symptoms (Osborne & Reed, 2009; Ingersoll & Hambrick, 2011; Rivard et al., 2014), the child's difficult behaviour (Tomanik et al., 2004; Herring et al., 2006; Lecavalier et al., 2006; Estes et al., 2013), financial concerns in terms of intervention and education cost (Sharpe & Baker, 2011; Vohra et al., 2014; Zablotzky et al., 2014; Thomas et al., 2016), being subjected to social stigma (DePape & Lindsay, 2014; Weiss et al., 2014; Smith et al., 2012; Ekas & Whitman, 2010;

Altieri & Von Kluge, 2009) and the onset of marital difficulties (Hartley et al., 2010; Pottie, Cohen, & Ingram, 2009). However, the majority of studies in this area have suggested that the primary predictive factors of parental stress, anxiety and depression are autism symptom severity, challenging child behaviour, and lack of social support. It is important to note however that not all parents caring for an autistic child report such high levels of mental health issues (Abidin, 1992; Pozo & Sarriá, 2014). A number of studies have suggested that while there are certain factors that do contribute to parental stress, anxiety and depression, these factors are also impacted by the parents' own psychological characteristics (e.g., coping strategies, individual resilience, locus of control, self-efficacy) (Boyce, Behl, Mortensen & Akers, 1991; Bristol, 1984; Hastings & Johnson, 2001). Various studies have also highlighted the importance of these parent-centered variables acting as protective factors which alleviate the experiences of stress, anxiety and depression.

Although there is somewhat of a consensus within the literature suggesting that certain factors can be regarded as significant predictors of mental health issues in parents of autistic children, a problem arises when comparing the results across these studies in terms of the inconsistency of the variables included. There are very few studies which have explored the ability of multiple variables to simultaneously predict stress, anxiety and depression in parents of autistic children (Falk et al., 2014) despite such analyses being potentially impactful in assessing and portraying more realistic parental experiences where an interplay of several variables is more likely to contribute to the reported mental health issues. Moreover, there are almost no existing studies conducted in the Middle East region which have explored a multitude of variables collectively in the same study despite research highlighting its implications. Furthermore, only a handful of studies have analysed the effect of certain variables on parental stress, anxiety and depression independently as opposed to combining these mental health issues into a single outcome variable.

Recently, studies exploring the experiences of parents of autistic children has significantly expanded and extended across different cultures. There has also been a substantial amount of evidence provided by research indicating that these parents consistently present with an overall decline in their wellbeing and report high levels of stress, anxiety and depression (Hayes & Watson, 2013). However, since little is known about the underlying factors that may potentially lead to the decline in parental mental health, it is therefore important identify and explore how these factors contribute to, or alleviate, parental stress, anxiety and depression associated with caring for an autistic child. Moreover, considering the impact cultural views have on parental mental health as well as intervention seeking behaviours (Daley, 2002; Mandell & Novak, 2009; Bernier et al., 2010), research studies with participant samples from different cultural backgrounds are essential for a more evolving and all-inclusive understanding of the varying parental experiences of caring for an autistic child. This study focused on parents of autistic children in Saudi Arabia specifically. Research on parental stress, anxiety and depression associated with caring for an autistic child in Saudi Arabia is significantly limited. This could be due to the lack of existing data on autism in the region as well as the prevalent cultural perceptions and stigma attached to mental health. Overall, this study aimed to explore which factors contribute to higher levels of stress, anxiety and depression, and which factors protect against them in this participant sample of parents of autistic children from Saudi Arabia.

### **1.1.2 Significance of the Thesis**

This thesis aimed to inform the literature on parental mental health associated with caring for an autistic child in Saudi Arabia by exploring the relationship between parental stress, anxiety, depression, challenging child behaviour, autism symptom severity, affiliate stigma, resilience, religious coping and social support. Previous studies have suggested a number of factors which could potentially act as significant predictors or buffers of mental health issues in parents of autistic children. However, only a very small number of studies have

explored how multiple variables can predict mental health issues simultaneously in parents of autistic children, with the majority of studies exploring only one or two factors. This can potentially pose an issue as each factor may be able to predict or protect against parental mental health issues in isolation but may no longer maintain significance when analysed in conjunction. The analysis of multiple variables simultaneously tends to be a more adequate means of assessing the mental health of parents of autistic children as there are likely to be a number of factors concurrently contributing to their experiences in the real world. By exploring the aforementioned variables this thesis could help us better understand the factors that contribute to parental experiences of stress, anxiety and depression and the variables that alleviate such negative mental health outcomes.

Seeing as parents are usually trained in the implementation of home-based behavioural interventions and that research has shown that increased parental involvement results in better overall outcomes for the child, parents therefore play a fundamental role in the management of their autistic child's condition. When the mental health of parents is compromised due to the challenges they face caring for their child, the implementation of interventions and the quality of support they provide for the child also becomes compromised. As such, the prevention of parental mental health issues can be more effective when the main sources of them as well as the factors that alleviate these experiences are known. The identification of these factors could potentially aid in tailoring specific interventions that improve the psychological wellbeing of parents of autistic children.

Research on autism in Saudi Arabia is still an emerging field and the research on parental experiences caring for an autistic child in Saudi Arabia is extremely limited. There is a relatively significant gap in the literature focusing on the factors associated with parental stress, anxiety and depression in the Middle East in general, and an even larger gap in studies with a participant sample from Saudi Arabia. There have been no studies to date which have

explored a considerable number of factors in unison that pertain to parental mental health issues associated with caring for an autistic child in Saudi Arabia. As such, it remains relatively unknown how parents of autistic children in Saudi Arabia perceive and cope with their child's condition. This is the first research project of its kind which has explored factors such as stress, anxiety, depression, challenging child behavior, autism symptom severity, affiliate stigma, resilience, religious coping and social support in a hard to reach participant sample from the Middle East. As such, this study could potentially shed light on the experiences of these parents and raise awareness on the struggles they face providing care for their autistic child, how it impacts their mental health and what factors mitigate these mental health issues. The cultural perceptions of autism in Saudi Arabia, namely the lack of awareness and understanding of the condition, the stigma associated with mental health in general, the lack of appropriate intervention services and the hesitancy of parents to express their views and concerns due to mental health issues being a taboo topic, may hinder the ability for research to accurately evaluate the actual scope of the issue in Saudi Arabia. Therefore, this thesis can serve to provide a more evolved and inclusive understanding of the varying parental experiences caring for an autistic child in a different part of the world.

### **1.1.3 Overview of the Thesis**

This thesis is organized into seven chapters. This chapter provides an outline of the research as well as a general literature review on the topic. The literature review provides a contextual understanding of the research setting as well as a summary of the existing literature on each of the study variables. The study in chapter 2 explored the relationship between challenging child behaviour, autism symptom severity and parental mental health. The study in chapter 3 explores the impact of affiliate stigma on parental stress, anxiety and depression. The study in chapter 4 assesses the efficacy of resilience and religious coping as protective factors against parental stress, anxiety and depression. The study in chapter 5 explores whether

social support, and especially which source of informal social support, is most associated with lower levels of stress, anxiety and depression in parents of autistic children in Saudi Arabia. The study in chapter 6 explores the interplay between each of the study variables (e.g., stress, anxiety, depression, challenging child behaviour, autism symptom severity, affiliate stigma, resilience, religious coping and social support) and assesses which variables predicts mental health issues and which variables protect against it. Chapter 7 summarizes and evaluates the main findings and their contribution to the body of knowledge along with a description of the limitations and suggestions to improve and extend future research.

#### **1.1.4 Research Question**

What are the factors affecting mental health in parents of autistic children in Saudi Arabia and how do they cope with the challenges associated with their child's condition?

#### **1.1.5 Hypotheses**

### **Chapter 2**

Hypothesis 1: Increases in levels of challenging child behaviour and autism symptom severity will be associated with higher levels of parental stress, anxiety and depression.

Hypothesis 2: There will be an overlap between challenging child behaviour and autism symptom severity.

### **Chapter 3**

Hypothesis 1: Higher levels of affiliate stigma will be associated with higher levels of parental stress, anxiety and depression.

Hypothesis 2: Parents of children with more severe autism symptoms will report higher levels of affiliate stigma.

## **Chapter 4**

Hypothesis 1: Higher levels of resilience in parents will be associated with lower levels of stress, anxiety and depression.

Hypothesis 2: Higher levels of religious coping will be associated with lower levels of parental stress, anxiety and depression.

## **Chapter 5**

Hypothesis 1: Increased levels of perceived social support will be associated with lower levels of parental stress, anxiety and depression.

Hypothesis 2: Perceived informal social support from a spouse will contribute the most to lower levels of stress, anxiety and depression.

## **Chapter 6**

Hypothesis 1 (Exploratory): Which variable/s significantly predict parental stress, anxiety and depression?

Hypothesis 2 (Exploratory): Do the variables of resilience, religious coping and social support mediate the relationship between the predictor variable and parental stress, anxiety and depression?

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## **Literature Review**

### **1.2 What is Autism?**

#### **1.2.1 Introduction**

Autism Spectrum Disorder (ASD) is commonly defined as a pervasive, complex and multifactorial neurodevelopmental disorder (APA, 2013). Autism is typically characterized by impairments in communication, social interaction along with the presence of restrictive and repetitive behavioral patterns (APA, 2013). Autism is classified as a spectrum disorder as it refers to a wide range of idiosyncratic symptoms, skills, characteristics and degrees of impairments that range from mild to severe in its core diagnostic areas (Jordan, 2003; Willis, 2006). The use of the term “condition” rather than “disorder” as a diagnostic classification for autism has been employed in recent literature. For example, according to Baron-Cohen (2017), the term “disorder” usually connotes negative associated characteristics and limits the understanding of the cognitive and biological processes associated with autism by rendering them as exclusively malfunctioning. The term “disorder” overlooks the heterogeneous nature of autism despite studies showing autistic individuals performing certain cognitive tasks significantly better in comparison to non-autistic individuals (Samson et al., 2011; Baron-Cohen, 2006). These authors argue that it is preferable to use the term Autism Spectrum Condition (ASC) as it recognizes both the strengths and impairments associated with autism. As such, in this research, autism will be referred to as Autism Spectrum Condition (ASC) as it provides a more neutral framework for understanding autism by counteracting the prevalent negative impression of it typically found in literature by encouraging a perspective that acknowledges the positive traits associated with individuals diagnosed with autism.

#### **1.2.2 Brief History of Autism**

In 1943, Dr. Leo Kanner, a physician from the John Hopkins Hospital, introduced the term “early infantile autism” through his published study “Autistic Disturbances of Affective Contact” featuring case studies of 11 children, 2 girls and 8 boys, who were referred to his

clinic through a special school. The term “Autism”, which Kanner had borrowed from Eugene Bleuler (1911), was initially used to describe the inward and self-absorbed nature of adults diagnosed with schizophrenia. However, Kanner did not regard infantile autism as a prodrome to schizophrenia as the 11 children in Kanner’s (1943) study appeared to have autism from birth. Kanner observed that these 11 children displayed similar impairments and responses to social stimuli such as being socially withdrawn and unable to form connections with others, exhibiting repetitive behaviours, having certain sensory sensitivities and an insistence on sameness and routine. Kanner also noted an atypical development of speech patterns across the cohort of children whereby they were able to learn certain nouns and rhymes but failed to learn the type of speech that is necessary for effective social communication and deduced that this language deficiency was a result of social isolation. Kanner’s characterization of autism as a distinct condition featuring an onset that is specific to infancy and early childhood developmental stages created a gradual conceptual shift wherein autism was removed from under the umbrella of schizophrenia and subsequently classified as a separate condition.

One year after Kanner’s (1943) paper, Dr. Hans Asperger published a paper titled “Autistic Psychopathy” which initially had a low readership as it was published in German during the Second World War and was not accessible by English speaking medical specialists until the 1970’s (Wing, 1981). Asperger’s (1944) paper featured 4 groups of children who exhibited patterns of behavior such as lack of empathy, intense absorption in certain special interests, poor body language and failure in the ability to form friendships. Asperger also noted that these children tended to have a high non-verbal intelligence quotient and were able to use a large vocabulary set correctly in a conversation. On the other hand, as opposed to Kanner, Asperger suggested that the condition was not recognizable before 36 months of age and that speech and language skills in early life was apparently normal. Moreover, Asperger suggested that the specific core diagnostic features for this condition consisted of communication

impairments, motor clumsiness, all-absorbing interests and social impairments, whereas Kanner specified three diagnostic criteria for the core features of autism which included the atypical development and use of speech and language, restricted and repetitive behaviours and a narrow range of interests. However, due to the high similarity between Kanner's and Asperger's set of diagnostic criteria for autism, it can therefore be suggested that they were both referring to the same condition but had shifted the focus of their investigations onto the different sub-types. Both Kanner's (1943) and Asperger's (1944) clinical studies consisted of the first comprehensive reports on symptoms and behavioural patterns related to autism. Not only did their clinical insights pave the way for future scientific research on the definition, detection and conceptualization of autism related conditions, they also facilitated the redefinition of autism as a neurodevelopmental condition as opposed to a form of schizophrenia as initially suggested by Bleuler (1911).

### **1.2.3 Etiology of Autism**

As of today, the etiology of ASC remains relatively unknown. In the first detailed description of autism by Kanner (1943), it was noted that the cohort of children in his study came from significantly intelligent families that were "strongly preoccupied with abstractions of a scientific, literacy, or artistic nature, and limited in genuine interest in people" (p. 248). He also suggested that the family members possessed obsessive traits and only a few were "warm-hearted" (p.250). Despite Kanner's observations on these parental attributes, he concluded that they could not solely explain the origins of autism as the children in his study seemed to be born with the condition. Instead, Kanner (1943) suggested the possibility of a biological predisposition for autism but also proposed that certain socio-environmental factors had a significant influence on the development of the condition. In his studies, Kanner (1952) specifically focused on parenting styles and described parents of children with ASC as emotionally cold, rejecting and obsessive. This depiction of parental characteristics would later

be coined as the term “refrigerator mothers” whereby the predominant blame for children developing ASC would be poor parenting style (Wing, 1933).

The absence of a biomedical model for ASC during the mid-forties and onwards led to the development of a psychogenic theory of autism which gained a relatively large amount of traction amongst specialists in the field of psychology (Dyches, Wilder & Obiakor, 2001). At the time, leading psychologists such as Bruno Bettelheim (1967) supported the idea that ASC was a result of cold and distant parenting styles and consequently advocated for the removal of children diagnosed with ASC from their mothers as it was suggested that the children were deprived of the chance to form effective bonding relationships (Dyches et al., 2001; Pisula, 2003; Whitman, 2004). Bettelheim proceeded to become a leading expert on autism until his death, when his research results were revealed to be significantly exaggerated (Hibbs & Jensen, 2005). His psychogenetic theory where mothers of children with ASC were labeled as “refrigerator mothers” and were regarded as the primary cause for their child’s atypical behaviour was widely accepted and went largely unchallenged by the medical establishment well into the 1960’s with its effects lingering up to the 21st century (Hibbs & Jensen, 2005; Whittaker, 2011).

In contest of the common acceptance of the psychogenic theory of autism, Bernard Rimland (1964) proposed an etiology for ASC that is predominantly biologically based. His research suggested that most parents of autistic children were not exclusively detached or cold, the children diagnosed with ASC did not have siblings with the same condition, the ratio of boys diagnosed with ASC is higher than that of girls, high levels of ASC co-occurrence was found in twins and that a link between symptoms consistent with ASC and organic brain dysfunction was evident (Whitman, 2004). Consequently, Rimland’s (1964) biological based etiology assisted in the shift and evolution of the focus of research on autism.

In recent years, with autism becoming a rapidly growing developmental condition, a significantly large amount of research has been dedicated to determining the etiology of ASC with various hypotheses being presented in attempt to further understand the biological, psychological and social correlates of the condition (Whittaker, 2011). Several studies have suggested that the socioeconomic status, education and occupation of a parent could potentially be regarded as a correlate or a risk factor for the development of ASC in a child (King, 2011). Although earlier research in the field of parental social characteristics and autism have indicated a consistent association between levels of parental education and socioeconomic status with the development of ASC (Finegan & Quarrington, 1979), current studies on the matter did not find any statistical significance relating ASC to parental socioeconomic status, thus rendering the literature on parental social characteristics and ASC considerably inconclusive (Croen, Grether, & Selvin, 2002; Larsson et al., 2005; Palmer et al., 2005; King, 2011).

Other studies with a predominant focus on the biological etiology of ASC have explored conditions associated with obstetric, prenatal and perinatal complications as potential risk factors for the development of autism (King, 2011; Ben-Itzhak, Ben-Shachar, & Zachor, 2013). These include birth order (Durkin et al., 2008), gestational age (Hultman & Sparen, 2004; Larsson et al., 2005), multiple births (Croen, Grether, & Selvin, 2002), fetal distress (Glasson et al., 2004), low birth weight (Eaton et al., 2001) and advanced parental age (King, 2009). However, there are noticeable inconsistencies across these studies which could compromise the extent to which parental biological factors are deemed significant in terms of a child developing ASC (Kolevzon, Gross, & Reichenberg, 2007). Moreover, according to the largest twin study to date (Liu, Zerubavel, & Bearman, 2010), there is significant evidence to show that ASC is a condition that is subject to substantial heritability. Although results from the aforementioned study support the notions put forth by previous studies focusing on

biological risk factors pertaining to autism, research on molecular genetics have not yet identified a conclusive genetic cause or definite biological marker for the majority of ASC cases (Abrahams & Geschwin, 2008).

Studies investigating possible environmental risk factors associated with the development of ASC have suggested that parental exposure to environmental toxicants could be regarded as a potential causation factor. Currently, there are two hundred chemicals that are likely to cause neuro-toxic symptoms in adults and five chemicals which contain components known to potentially contribute to the development of ASC and other neurodevelopmental disorders in children (Grandjean & Landrigan, 2006). This may suggest that certain environmental risk factors could be implicated in the development of ASC. However, according to Lubin (2015), there is a great uncertainty on the direct link between parental environmental toxicant exposure and ASC due to the limited number of existing empirical ecological studies on the role of environmental risk factors associated with the development of ASC in children.

As the etiology of ASC remains largely inconclusive and considerably unknown, the diagnosis of ASC is regarded as somewhat complicated (King, 2011). According to Fombonne (2003) and Strauss et al. (2015), ASC is one of the most common neurodevelopmental conditions in children, with a high probable heritability rate (Rutter, 2000) and can therefore be considered as a major public health concern (Isaksen et al., 2013). Moreover, Strauss et al. (2015) suggested that the identification of certain medical and genetic issues linked to ASC in around 20% of patients has recently been made possible due to the implementation of contemporary neuroimaging methods. Although some studies suggest that causal genetic factors linked to ASC remain considerably complicated to assert (Seitler, 2010), results from the study by Strauss et al. (2015) shows considerable evidence highlighting aberrant changes in neuronal networks linked to the interplay of genetic and environmental factors.



#### **1.2.4 Autism Prevalence**

There has been an ongoing debate in recent literature on whether the prevalence of ASC is increasing amongst the general population worldwide (Chakrabarti & Fombonne, 2001, 2005; Herbert, Sharp, & Gaudiano, 2002; Nicholas et al., 2008; Tidmarsh & Volkmar, 2003; Willemsen-Swinkels & Buitelaar, 2002; Williams, Mellis, & Peat, 2005; Wing & Potter, 2002). Previous studies exploring the epidemiology of ASC estimated that the prevalence of individuals diagnosed with a form of ASC was less than 10 in 10,000 (Chakrabarti & Fombonne, 2001; Sevin, Knight, & Braud, 2007; Willemsen-Swinkels & Buitelaar, 2002; Wing & Potter, 2002). However, there is substantial evidence suggesting a global rise in the prevalence of individuals being diagnosed with ASC (Blumberg et al., 2013; Neggers, 2014; Blumberg et al., 2013; Matson & Alison, 2011; Tsai, 2014) with one of the most recent reviews exploring epidemiological surveys on ASC estimating a global median prevalence rate of 62/10,000 worldwide (Elsabbagh et al., 2012).

According to Baxter et al. (2015), there is an estimate of fifty-two million individuals diagnosed with ASC around the world, which indicates a mean occurrence of 7.6/1000 or a single case of ASC in every 132 individuals. For example, the estimated prevalence of individuals diagnosed with ASC in the United States is 1 in every 68 (CDC, 2017), while the rate of ASC diagnosis in Canada is estimated at 1 in every 147 individuals (Norris, Pare & Starky, 2006). In Europe, the prevalence of ASC ranges from an estimate of 1 in every 150 individuals in France (Van Bakel et al., 2015), 38 in every 10,000 individuals in Germany (Bachmann et al., 2016) and 1 in every 100 individuals in the UK (NHS, 2016). Moreover, ASC prevalence estimates in Asia range from 23 in every 10,000 individuals in China (Wan et al., 2013), 161 in every 10,000 in Japan (Honda et al., 2005) and 263 in every 10,000 in South Korea (Kim et al., 2011). On the other hand, there is very limited official statistical data, if any,

on the prevalence of ASC in areas around the world such as South America, Africa and the Middle East.

The constant evolution of the diagnostic criteria for ASC is one of the most frequently cited factors attributed to the reported prevalence increase of the condition (Croen, Grether, Hoogstrate, & Selvin, 2002; Fombonne, 2002, 2005; Honda et al., 2005; Lingam et al., 2003; Waldman, Nicholson, Adilov, & Williams, 2008; Williams et al., 2005; Wing & Potter, 2002). The increased prevalence rates are also attributed to the improved ASC assessment methods, the broad range of symptoms associated with the condition, the increase in parental awareness on symptoms associated with ASC and the improved rate of diagnosis from healthcare professionals (Ruble & Brown, 2003; Daniels & Mandell, 2013). Since it has been reported that the estimated occurrences of ASC have risen by almost 78% in recent years (Neggers, 2014), the various attempts at estimating official figures on the prevalence of ASC on a global level are faced with a significant number of challenges including the lack of readily available diagnostic tools and support services in some regions which could potentially lead to a reduction in the recognized numbers of individuals diagnosed with ASC. According to Elsabbagh et al. (2012), the low prevalence rate of ASC reported by developing countries in the recent worldwide epidemiological survey is likely to reflect factors such as inaccessibility to diagnostic tools and services, lack of ASC awareness and other cultural factors as opposed to a general global difference in the incidences of ASC.

Although ASC occurs across all cultures (APA, 2013) and is prevalent in all societies regardless of a country's socioeconomic status (Dyches et al., 2004), ASC prevalence research has been predominantly conducted in developed countries whereas information on ASC in developing countries is significantly scarce (Samadi et al., 2011). In support of the study by Elsabbagh et al. (2012), research by Abubakar (2016) confirmed that some of the reasons as to why the prevalence rates of ASC in developing countries is usually reported as significantly

lower than those in developed countries are attributed to the low levels of awareness in comparison to developed countries, the lack of diagnostic tools which results in the lack of reliable prevalence rate data, and various cultural factors. Since the low reported prevalence rates of ASC in developing countries does not depict a true representation of actual situation (Al-Farsi et al., 2011) there is a great need for an international coordination of efforts to direct the research focus on ASC towards various other countries and cultures besides the developed ones.

### **1.2.5 Cultural Perceptions of Autism**

Despite the ample amount of research conducted on the various facets of ASC, studies on the influence of cultural contexts in terms of the diagnosis, presentation of symptoms and treatment of ASC is somewhat lacking (Jegatheesan, Miller, & Fowler, 2010; Welterlin & LaRue, 2007; Broder-Fingert et al., 2017; Pierce et al., 2014; West et al., 2016; Wong et al., 2014, 2015). According to Daley (2002), little attention has been paid to understanding ASC through a cultural perspective due to the bulk of research on ASC overemphasizing its neurobiological aspects and neglecting the social meanings of the condition in specific cultural populations. Therefore, cross-cultural comparative studies are essential for inclusive understanding of ASC considering the impact cultural views have on parental reports of ASC, help-seeking behaviours, the management of ASC symptoms and the degree to which health professionals and researchers in different cultures follow the international diagnostic criteria (Daley, 2002; Mandell & Novak, 2009; Bernier et al., 2010).

Culture, as defined by Singer (1971) is “a pattern of learned, group related perceptions, including both verbal and nonverbal language, attitudes, values, belief systems, disbelief systems, and behaviours that is accepted and expected by an identity group” (p. 6). In essence, the way in which an individual selects, evaluates and organizes stimuli from the external environment is through an internal process of perception that is generally influenced by the

individual's idiosyncratic beliefs, values and attitudes (Weru, 2005). As such, health, illness and disability can also be seen as cultural concepts (Gabel, 2004; Hatton, 2004; Lindsay, Pather & Strand, 2006) due to the extent in which cultural contexts can shape how an individual perceives, experiences and manages these concepts (Furnham et al., 1999; Narayan, 2002; Gupta & Singhal, 2004; Mandell & Novak, 2005). Despite the core characteristic of ASC being universal, some researchers suggest that the identification, expression and symptomology reporting of ASC may be subject to subtle cultural influences (Freeth et al., 2013; Norbury & Sparks, 2013). For example, certain culture-specific norms and stigmas may mask or emphasize the relative differences between ASC traits and typically developing behaviours (Freeth et al., 2013; Norbury & Sparks, 2013; Caron et al., 2012; Freeth et al., 2014; Daley, 2002). Moreover, the fact that the diagnosis of ASC is still based exclusively upon parental reports and clinical observations of unusual behaviours and continual impairments in social communication (Shattuck, 2006; Wing & Potter, 2002; Strauss et al., 2015), the decisions a parent or healthcare provider makes about the diagnosis and treatment of ASC is directly influenced by their cultural background as it shapes their beliefs about disabilities in general (Griffen, Peters & Smith, 2007).

According to studies by Tincani, Travers and Boutot (2000) and Donovan (2013), there is evidence to show that the cultural background of a parent has a noticeable impact on how they interpret and accept their child's disability, their beliefs on the cause of the disability itself, their reactions to the diagnosis and their ultimate future expectations for their child. For example, results from a study by Bishop, Richler, Cain, and Lord (2007) indicated that, in the United States, African American mothers tended to report lower levels of perceived negative impact of having a child diagnosed with ASC as opposed to Caucasian mothers. Moreover, reports by mothers in the United States from Colombian and Mexican cultures indicated that they strongly believed in genetic and environmental factors as a main cause for their child being

diagnosed with ASC, while parents from a Native American culture, such as the Navajo tribe, regard any person with a disability as a teacher of the clan who possesses the unique gift of a sixth sense and is accordingly not allowed to receive any form of intervention as it may interfere with the messages they are meant to deliver to the tribe (Rogers-Adkinson, Ochoa, & Delgado, 2003).

Another example on the varying cultural perceptions of disability is a study by Rogers-Adkinson et al. (2003) on parents from South America. This study suggests that there is a tendency for some societies, such as the Puerto Rican society, to blame mothers for having children with any form of disability as it is seen as a consequence of religious sins committed by the mother (Rogers-Adkinson et al., 2003). However, in other Haitian and Latin American cultures, any form of disability is viewed as a result of the family being cursed by an enemy (Groce & Zola, 1993; Rogers-Adkinson et al., 2003). According to Seung (2013), parents from Asian cultures tend to be significantly sensitive to the perceptions of others and worry that their child's disability may bring shame to the family. Consequently, Asian parents of children diagnosed with a developmental condition tend to limit their social contact with extended family members to avoid pressure resulting from their child being ostracized for having a disability. For example, mothers from a South Korean culture tended to report higher stress levels as opposed to European mothers as they expressed feelings of being trapped due to society refusing to accept their child's disability without passing judgement (Shin, 2002). In other regions in Asia, certain societies in India for example, regard a child's disability as a form of punishment for sins that were committed by the parent or the child in their past life (Groce & Zola, 1993), while in Pakistan, a large number of members in the society believe that a child's developmental condition is simply the "will of God" and it is therefore the family's duty to take care of the child, for which God would surely reward them (Mirza et al., 2009).

Another example on the different cultural understandings of disability is seen in a study by Al-Busaidi (2010) which notes that the majority of people in the Middle East refuse to seek mental health assistance on their own accord as it is commonly seen as a sign of weakness. In the past, individuals with a disability were regarded as shameful and burdensome in Arab societies (Al-Lawati, 2011). Hence, in Arab countries, specifically in the Gulf Cooperation Council (GCC), namely, Saudi Arabia, Kuwait, the United Arab Emirates, Qatar, Bahrain, and Oman, hiding individuals with a mental health condition from the rest of society had become common (Al-Thani, 2006; Al-Hilwanai et al., 2008). Similar to the cultural perceptions of disability in Pakistan (Mirza, 2009), individuals from Arab cultures view developmental disability as a result of the “will of God” but tended to keep persons with disabilities away from society due to the fear of social stigma (Al-Hilawani et al, 2008).

Since cultures around the world have varied perceptions towards mental health, including developmental conditions such as ASC, it is particularly important to explore how ASC is understood and managed by parents in population samples from cultures that are somewhat understudied. For example, the limited research on ASC in the Arab region has led to a number of significant issues in terms of understanding ASC in the Arab context. Firstly, the prevalence of ASC in the majority of Arab countries is difficult to determine as there is no official statistical prevalence rate (Al-Salehi et al., 2009; Taha & Hussein, 2014). For example, in Saudi Arabia, it has been reported that 2 in every 1000 individuals were estimated to have ASC in the year 2002 (Alnemary et al., 2016), however it has been suggested that there is a larger number of individuals with ASC which have not yet been diagnosed due to an array of cultural factors specific to Saudi Arabia (Alnemary, Aldhalaan, Simon-Cereijido, & Alnemary, 2017). Secondly, the limited amount of research focusing on the experiences of parents of autistic children in Arab countries such as Saudi Arabia, hinders the ability of ASC specialists

and researchers from other countries in gaining a comprehensive understanding and a true representation of the parental experiences of raising an autistic child in the Arab region.

In order for parents of autistic children to be able to achieve the best possible outcomes for themselves and their child through adequate intervention methods, it is necessary for research to acknowledge both the universal biological aspects of ASC as well as the cultural aspects and perceptions that influence parental and societal attitudes towards autism.

### **1.3 Research Context (Saudi Arabia)**

#### **1.3.1 Brief Overview of Saudi Arabia**

Situated in the southwest of the Arabian Peninsula, Saudi Arabia is the largest country in the Middle East, occupying 80% of the region (Almazroui, Islam, Jones, Athar, & Rahman, 2012) and spanning over approximately 2,250,000 square kilometers (CDSI, 2012). Saudi Arabia shares its borders with several countries in the Middle East region and most of its western border with the Red Sea. Saudi Arabia borders Kuwait, Jordan and Iraq at the North, Oman and Yemen at the South and the United Arab Emirates, Qatar and Bahrain on the East (Alquraini, 2010). Saudi Arabia was established in 1932 with Riyadh as its capital city (CIA, 2014). The country has a total population of over 33 million people (GAS, 2019).

In recent decades, Saudi Arabia has been experiencing a remarkable degree of cultural and social change, specifically due to the economic growth brought about through the production and trade of oil, which the government has invested into the economy as part of its dedication to modernize the nation. Considerable economic investments have been made alongside extensive efforts to reform the social, educational and transportation systems, as well as the health care and communications sector in an effort to boost infrastructure and raise the standard of living (Alnemary, Aldhalaan, Simon-Cereijido, & Alnemary, 2016; Madi, 2014). Notable improvements in the overall quality of life for its citizens have been observed as a

result of this undertaking. Additionally, the government has endeavored to preserve and protect Saudi Arabian culture and traditions amidst these changes (Madi, 2014). In essence, Saudi Arabia can be viewed as a developing country that is strongly influenced by its history and culture yet adamant on making progress to afford its citizens with the highest standard of what the contemporary world has to offer.

### **1.3.2 The Social and Cultural Context of Saudi Arabia**

The Saudi Arabian culture is generally conservative and is largely marked by the influence of Islamic traditions through its adherence to Islamic law (Alqahtani, 2012). Since Saudi Arabia is an Islamic Arab country, it is reasonable to assume that Islamic traditions and principles have substantial influence on a significant number of aspects in the culture, including the day-to-day activities of most members of the Saudi Arabian society (Almutairi & McCarthy, 2012). The teachings of the Quran (Islamic holy book) and the Hadith (The prophet's life teachings) notably shape the social environment of Saudi Arabia (Alquraini, 2010; Wynbrandt, 2010) and have a profound impact on establishing society's norms, responsibilities, rules, rights and social principles (Al-Saggaf, 2004, Aseri, 2015). Therefore, the extent to which the religion of Islam has pervaded the Saudi Arabian culture could imply that Islam in itself is the central governing culture in the country (Donnan, 2001).

Literature on the Saudi Arabian culture notes that the traditions and values of the country, which are in line with the Islamic religion, are still considered relatively stricter in comparison to other Arab countries in the Middle East region (Ezzi, Teal, & Izzo, 2014; Robertson et al., 2001). The predominant importance of religion in Saudi Arabia stems from the fact that it is the birthplace of the religion of Islam and is home to the two holiest Islamic sites, the Holy Mosque in the city of Makkah and the Prophet Muhammad's Mosque in the city of Madinah. Thus, Saudi Arabia is regarded as the main spiritual center for Muslims worldwide who visit the country every year in order to perform pilgrimage at these holy sites



(Abdulwahab, 2015). Moreover, Saudi Arabia being the location of these two Islamic holy sites, has substantial influence on the self-perceptions of Saudi Arabian culture and identity, which unequivocally aims to maintain a society based on the Islamic teachings of the Quran and Hadith (Baki, 2004).

Despite Islam chiefly influencing the core belief system of the members of the Saudi Arabian society, according to Al-Ghamdi (2012), it is generally known that Bedouin (Arabian nomads) tribal traditions, customs and values also play a considerable role in shaping the Saudi Arabian culture. Accordingly, one of the primary aspects of Saudi Arabian culture is the central importance of family in the social structure of the tribe or family (Al-Awaji, 1989). Moreover, tribal culture usually places a strong emphasis on kinship solidarity and patrilineal bloodlines whereby the clans are generally organized around male relatives that do everything they can to assist each other in order to gain advantage in society through nepotism (Long, 1997; 2005; Bowen, 2008). Due to tribal ties being of great significance in the Saudi Arabian society, individuals with tribal backgrounds still possess a sense of pride regarding their heritage and tribal customs. According to Khan and Varshney (2013), despite Islamic teachings emphasizing the importance of equality and discouraging discrimination based on class and socioeconomic status (Syed & Ali, 2010), the majority of the current literature on Saudi Arabian culture predominantly reflects the values and traditions originating in Bedouin tribal culture.

Recently, the Saudi Arabian society has been changing and evolving due to the rise in consumerism as a result of oil wealth and the influence of globalization and the Western world through social media (Bechtold, 2012). Despite these changes affecting the nature of social life in Saudi Arabia, members of its society still remain strongly connected to their tribal identities, families and religion (Aseri, 2015). Therefore, the remarkable degree to which the Saudi Arabian culture is interwoven with the Islamic faith and tribal customs is expected to influence

the way in which members of society perceive and approach other members of society, including individuals with mental health conditions or developmental conditions such as autism.

### **1.3.3 Autism in Saudi Arabia**

According to Groce and Zola (1993), disability and mental health conditions are considered as human constants and are prevalent in all cultures across the world, however, the perceptions and implications of mental health conditions varies significantly across cultures and across time. A cross-cultural study on parental perceptions regarding ASC conducted by Dyches et al. (2004) found that “members of various cultures may appraise the stressor of autism differently, and these appraisals may be considered to be negative or positive” (p. 219). Thus, a culture’s understanding and approach to disabilities and mental health conditions plays a major role in influencing a family’s or society’s attitudes towards the individual diagnosed with ASC and may also potentially determine the country’s level of resource and investment expenditure on effective intervention methods, empirical research on the epidemiology of ASC and the necessary appropriate cultural adaptations of ASC screening and diagnostic tools.

At present, there is no confirmed data or precise figures of ASC cases in Saudi Arabia (Alnemary, Aldhalaan, Simon-Cerejido, 2017; Eid et al., 2017; Alnemary, 2016). Despite the unavailability of official statistical data on the prevalence of autism in Saudi Arabia, several anecdotal reports suggest an apparent increase in the incidences of ASC throughout the country. For example, a study by Al-Salehi et. al (2009) approximates 40,000 cases of ASC in the year 2009 when the population number was 26.66 million. However, seeing as the population number in Saudi Arabia has increased to 32.94 million (GAS, 2019), it can be suggested that the actual number of individuals with ASC, in addition to the undiagnosed cases, is currently higher than the figures presented in previous anecdotal reports.

The low estimated prevalence rate and the lack of official statistical data on ASC in Saudi Arabia can be attributed to several factors. Firstly, in Saudi Arabia, the access to well developed and adequate diagnosis services and centers is improving but is still somewhat limited (Alqahtani, 2012; Al-Salehi, Al-Hifthy, & Ghaziuddin, 2009; Almasoud, 2010; Alquraini, 2010) and the degree to which existing services utilize and effectively implement evidence-based practices is unknown (Mostafa, 2011, Eid et al., 2017). Secondly, the knowledge on and understanding of ASC amongst members of the Saudi Arabian society is also limited (Al-Farsi et al., 2011; Mostafa, 2011). This could potentially lead to the inability for parents or others caring for an autistic individual to identify the signs and symptoms unique to ASC which may subsequently influence the degree to which they seek appropriate diagnosis or intervention. For example, according to Daley (2004), child development norms are significantly shaped by culture and can often have a direct impact on symptom recognition, especially since ASC diagnosis rates largely rely on parental reports which may be influenced by cultural differences regarding what symptoms or behaviors are considered problematic.

A study conducted by Al-Aoufi, Al-Zyoud, and Shahminan (2012) explored how disability is generally understood in Islamic societies. This research showed that despite Islamic traditions and the Quran regarding disabilities as a natural part of the human condition (Bazna & Hatab, 2005; Waldman et al., 2010), a dichotomy of perception exists within most Islamic societies such as Saudi Arabia, where some individuals believe that a disability is a divine gift and others believe it is a curse. Considering the importance of the role religious belief plays on the overall perception and understanding of mental health in the Saudi Arabian society, a large number of mental health conditions, various forms of physical disabilities as well as developmental conditions such as ASC are commonly explained and understood with reference to religious and cultural beliefs unique to Saudi Arabia (Alqahtani & Salmon, 2008). Generally, the Islamic point of view on any form of disability is that it is an extension of faith

and belief in God (Bazna & Hatab, 2005). A key aspect in Saudi Arabian culture, which is derived from Islamic teachings is 'Fatalism'. Fatalism is the theory that any event that occurs in an individual's life, be it positive or negative, is a result of the will of God. This suggests that a person cannot alter or take charge of their destiny as it promotes the idea of acceptance and resignation of the unfamiliar or unanticipated through divine trust and faith (Haniffa & Hudaib, 2007; Hamady, 1960). As such, some members of the Saudi Arabian society believe that any form of disability can be seen as the need to be fatalistic, thus rendering the care required for a child with ASC for example, as a test of faith (Alqahtani, 2012).

On the other hand, according to a study by Alqahtani (2012) on the perceptions of ASC in Saudi Arabia, a significant number of parents of autistic children attributed their child's condition to an array of medical, psychological, cultural and religious reasons. For example, some parents believed that vaccinations, vitamin deficiency and examination during pregnancy is what caused their child to develop ASC. Others proposed that negative events during pregnancy or early childhood such as trauma, car accidents or the death of a close relative was the reason behind their child being diagnosed with autism. Additionally, some parents believed that their child's condition was a result of black magic or "evil eye". According to Alqahtani and Salmon (2008), evil eye is a force which "is emanating from another person, or rather from the bad soul, which inhabits that person" (p. 311) and affects anything it comes in contact with negatively (Madi, 2014). In contrast, a study by Jegatheesan, Miller, & Fowler (2010) reported that the majority of families from a culture influenced by the religion of Islam believed that an autistic child was a gift from God and was granted to the family as a reward for their unwavering faith. These families adamantly believed that they would receive divine support from God in all their endeavors as a result of bearing an autistic child. Consequently, any form of diagnosis or intervention for that child was delayed in an attempt to avoid challenging the will of God. Specifically, in Saudi Arabia, Alqahtani's (2012) study showed that parents of

autistic children opted for a variety of treatments for their child. Some parents chose to treat and manage their child's autism symptoms through informal cultural intervention methods such as prayer or local herbal treatments, while others chose forms of intervention such as hyperbaric oxygen therapy or strict nutritional programs. Moreover, a qualitative study by Al-Salehi et al. (2009) found that 68% of the children diagnosed with ASC were simply being medicated and sedated as opposed to engaging in therapeutic interventions. Furthermore, studies by Al-Ayadhi et al. (2013) and Hussein et al. (2011) also reported that parents of autistic children in their studies chose to manage their child's symptoms through cultural, religious or medical means as opposed to behavioural or educational ones. Evidence from these studies suggests that a relatively significant number of parents of autistic children in Saudi Arabia still hold on to outdated beliefs and cultural superstitions about autism which in turn, affects the way in which they manage their child's behavior and the intervention methods they utilize.

Due to the overall poor awareness on ASC in Saudi Arabia (Al-Salehi et al., 2009), there is a tendency for autistic children to be prevented from social interaction by their parents due to the sense of shame and guilt the parents may feel about their child's condition (Al-Jadid, 2013, Alquraini, 2010). For example, the study by Alqahtani (2012) had a considerably high non-response rate despite the assurance of participant anonymity. Alqahtani (2012) suggests that this could be due to the fact that people in Saudi Arabia often feel uncomfortable discussing mental health issues and are encouraged to avoid it altogether by friends and relatives since it is considered a taboo topic according to tribal traditions. Moreover, there is still a stigma associated with individuals diagnosed with ASC in Saudi Arabia as a relatively large sector of the Saudi Arabian society are poorly informed on the nature of the condition. Consequently, parents of autistic children hesitate to ask for help, seek advice or intervention for their children due to the fear of the cultural stigma associated with mental health issues (Alqahtani, 2012; Al-Ayadhi, & Bashir, 2014; Sulaimani, 2018). Since stigma towards mental health conditions

contributes to the delay in intervention, diagnosis and acceptance of autism, a significant number of parents and families with autistic children face high levels of distress for this reason (Kermode, Bowen, Arole, Pathare & Jorm, 2009; Weiss, Ramakrishna & Somma, 2006).

In Saudi Arabia, there is a significant lack in the number of qualified specialists and diagnosticians in the field of ASC to meet the estimated incidences of ASC cases in the population. According to Gray (2002), caring for a child diagnosed with ASC is notably more challenging than caring for a typically developing child. Therefore, the availability and provision of professionals specialized ASC services are crucial, and the lack of such services poses a great deal of stress on parents. Qualitative studies conducted on parental perceptions of ASC in Saudi Arabia (e.g., Al-Salehi et al., 2009; Alqahtani, 2012; Al-Ayadhi et al., 2013; Hussein et al., 2011), show that hardly any autistic children received appropriate and effective intervention. This could potentially impact parental mental health negatively and lead to high levels of stress, anxiety and depression which, in turn, can also affect the child negatively. The cultural perceptions of ASC in Saudi Arabia, namely the lack of awareness and understanding of the condition, the stigma associated with it, the lack of appropriate intervention services and the hesitancy of parents of autistic children to readily express their views and concerns, may hinder the ability for research to accurately assess and evaluate the actual scope of the issue in Saudi Arabia.

## **1.4 Parental Stress, Anxiety and Depression**

### **1.4.1 Parental Stress**

Studies on parental experiences caring for an autistic child has consistently presented evidence showing parents reporting high levels of stress (Al-Kandari et al., 2017; Lai, Goh, Oei, & Sung, 2015; McAuliffe, Cordier, Vaz, Thomas, & Falkmer, 2017; Thoits, 1995; Tway, Connolly, & Novak, 2007), with a relatively significant number of these parents reporting

stress levels that fall within the clinical range (Oelofsen & Richardson, 2006; Webster et al., 2008). Stress was first defined by Selye (1980) as the psychological and physiological reaction that occurs, usually in stages, in order to adapt to a stressful situation. Lazarus and Folkman's (1985) theoretical concept of stress suggests that stress is an idiosyncratic and subjective process which manifests as a result of an interaction between the individual and their environment. When an individual perceives that a stressor in their environment is overwhelming their resources, they employ a coping mechanism in order to restore functioning. However, in the case where the employed coping mechanism falls short of meeting the demand, the outcome is stress. This process of stress consists of four components: (1) the stressor or external event, (2) the cognitive appraisal of the event, (3) the coping mechanism used to alleviate the event caused by the stressor and (4) the psychological and physiological consequential effects of the stress reaction (Lazarus, 1993). Thus, an individual's perception of stress stems from their appraisal on whether or not an event caused by a stressor exceeds their ability to adaptively cope with the situation (Lazarus & Folkman, 1985; Rice, 1999). From this perspective, it can be suggested that parental stress usually arises when a parent is unable to restore adequate functioning using adaptive coping strategies subsequent to being exposed to a certain stressor (Hayes & Watson, 2013).

In particular, parental stress is defined in a number of ways throughout the literature. For example, according to Raphael et al. (2010), parental stress is defined as an imbalance between a parent's perception of a certain parenting demand and the availability of resources to that parent. Moreover, according to Sepa, Frodi and Ludvigsson (2004), parental stress is a condition where a discrepancy arises when parental perceptions are conflicting with actual situational demands and the availability of personal resources. Furthermore, parental stress is also considered as a reflection of a parent's ability to self-adjust within a family unit (Saisto et al., 2008) or a reflection in a parent's poor ability to manage parental tasks such as child

behaviour management or functional parent-child interactions (Putnick et al., 2010). In addition, according to Abidin's (1992) ecological and systemic approach to family relations, parental stress is usually a result of certain characteristics that are present in the child (behavioural problems) and the parent (perceived availability of resources and personal competence). Accordingly, a parent's perceptions or beliefs can act as potential mediators between events caused by a stressor and the level of parental stress. Since there is, to some extent, a form of congruence throughout the literature on the core aspects of parental stress, it can be suggested that the cognitive appraisal of an event caused by a stressor along with the utilization of a coping mechanism are the main factors by which parental stress can be conceptualized. Given the importance of the mentioned evaluative processes when it comes to understanding parental stress, it has been proposed that parental stress is not necessarily directly linked to caring for an autistic child as the stress levels experienced significantly depend on the parent's evaluative processes (Pastor et al., 2015).

Nevertheless, although the majority of studies on parental stress show that parents of autistic children report higher levels of chronic stress than parents of typically developing children (DePape & Lindsay, 2014; Weiss et al., 2014; Smith et al., 2012; Ekas & Whitman, 2010; Altieri & Von Kluge, 2009; Schieve et al., 2007), the potential predictors of parental stress throughout the literature, be it specific to a parent's self-perception or the child's externalized behaviour, remains largely inconclusive. For example, a meta-analysis conducted by Hayes and Watson (2013) on parental stress associated with caring for an autistic child as well as children with other developmental conditions reported a large effect size in parents of autistic children indicating that these parents tend to report higher levels of stress. However, Hayes and Watson (2013) did caution that the large effect size was yielded by comparing families with a child diagnosed with ASC and families with a child diagnosed with Down Syndrome. Quintessentially, according to the aforementioned meta-analysis parental stress is



a significant variable associated with a child's behaviour (Deater-Deckard, 1998) as parents who report higher levels of stress tend to perceive their children as difficult and often exhibit ineffective and dysfunctional parenting skills which, in turn, negatively affect the wellbeing of the child (Abidin, 1992; Östberg & Hagekull, 2000).

Some studies suggest that the most significant predictor of parental stress is challenging child behaviour. For example, Griffith, Hastings, Nash and Hill (2010) conducted a study on adaptive and difficult behaviours in children diagnosed with ASC, Down syndrome and mixed etiology intellectual disabilities. The participants (N=57) were grouped according to their age, gender and communication skills. Results from the study showed that the parents of the autistic children reported the highest levels of stress as they rated their child as more likely to present with self-injurious behavior and lower social competency compared to the other groups of children. According to Davis and Carter (2008), elevated levels of stress reported by parents are highly correlated with child behavioural problems. In support of this notion, a study conducted by Lecavelier, Leone and Wiltz (2006) exploring parental stress associated with caring for a child with a developmental condition (N=293), found that challenging behaviours were strongly associated with stress and results were considerably stable over the one year interval in which participants were being rated. This implies that challenging child behaviour could be regarded as a potential predictor of parental stress.

Another factor suggested in literature that may act as a potential predictor of parental stress is stigma. Parents of autistic children sometimes experience stress as a result of the negative reactions and judgments they receive from family, friends and society in general (Pisula, 2011). According to Gray (1993), although ASC has no defining atypical physical features which easily identify autistic children unlike other disorders such as Down syndrome, ASC does however involve "extremely disruptive social behaviours" (p. 103) which can result in others reacting insensitively towards the child and parent for being unable to manage the

situation. Additionally, a study conducted in China by Mak and Kwok (2010) focusing on the internalization of stigma amongst parents of children with developmental conditions (N=188), found that the internalization of stigma in parents was severe. However, despite the number of participants, the study design was cross-sectional and therefore no causal inferences could be made. Another study focusing on parental experiences of stigmatization conducted by Farrugia (2009) found that parents tended to report higher levels of perceived stigmatization accompanied by loss of friendships. However, this qualitative study was limited in its participant sample as the number of participants interviewed were totaled at twelve. To date, there have been very few studies focusing specifically on the issue of parental stress and stigma related to ASC in particular, however, various researchers agree that parents of children diagnosed with a disability or a mental health condition, in general, often encounter stigma (Bonis, 2016; Brei, Schwarz, & Klein-Tasman, 2015; DePape, & Lindsay, 2015; Kinnear et al., 2016). According to Gray (2002), it is important to understand that parents of autistic children themselves similarly face forms of stigmatization as well due to their child's condition.

Some studies on the predictors of parental stress associated with caring for an autistic child suggest that high levels of parental stress are strongly and positively linked to the child's ASC symptom severity (Konstantareas & Papageorgiou, 2006; Lyons et al., 2010; Moh & Magiati, 2012). These studies argue that when comparing stress levels between parents of autistic children and parents of typically developing children, ASC symptom severity is the primary predictor of parental mental health issues. A study conducted by Duarte et al. (2005) comparing parental stress levels between parents of autistic children and parents of non-autistic children (N=62), found that despite the parent's and child's age acting as a contributory factor to some extent, the main variable correlating with elevated levels of parental stress was ASC symptom severity. However, the participants in this study were recruited from centers where parents seek professional support services for their children, thus they are not reflective of the

overall general population of parents of autistic children, who in some cases may not request assistance from specialized services.

Currently, there is no consensus within the literature as to which specific factor or factors act as a significant contributor to elevated levels or reported parental stress. While some studies suggest that the severity of ASC symptoms is the strongest predictor of parental stress, others suggest that challenging behaviours displayed by the child is the primary predictor for parental stress, and others posit that stigma experienced by parents of autistic children is one of the main factors contributing to parental stress. Despite the lack of agreement within the literature on the main predictive factors of parental stress associated with caring for an autistic child, it has been well established that high levels of parental stress have a significantly negative influence on parenting skills and can have a negative consequential effect on the wellbeing of the child (Anthony et al., 2005; Bonds, Gondoli, Sturge-Apple, & Salem, 2002; Hastings & Beck, 2004).

#### **1.4.2 Parental Anxiety**

Anxiety is generally defined as a psychological state that is characterized by worried thoughts, feelings of tension, somatic changes and recurring intrusive thoughts or concerns (APA, 2013). Anxiety can either manifest as persistent and prolonged daily symptoms that negatively impact an individual's quality of life or manifest in brief spurts accompanied by stressful sporadic panic attacks (Rynn & Brawman-Mintzer, 2004). Anxiety can often present with wide-ranging symptoms that vary in frequency, number and intensity, depending on the individual. Cognitive symptoms related to anxiety may include recurrent thoughts and fears about anticipated threats or dangers, as well as problems with concentration (Robinson et al., 2013). Behavioural symptoms linked to anxiety may include withdrawal from certain social engagements, changes in sleeping patterns, changes in appetite and increased motor tension (Barker, 2003). Emotional symptoms associated with anxiety may include irritability,

restlessness, nightmares and feelings of apprehension or dread (Smith, 2008). Physical symptoms of anxiety may include elevated heart rate, headaches, sweating, gastrointestinal issues, shortness of breath and muscle tension (Testa et al., 2013). Generally, when experiencing anxiety, an individual may feel worried, uneasy and seem unfocused or overreact to a situation or an event that is subjectively perceived as menacing (Bouras & Holt, 2007).

There are several studies that have shown that parents caring for an autistic child tend to report high levels of anxiety (Weiss, 2002; Davis & Carter, 2008; Eisenhower et al., 2005; Hastings, 2003; Lainhart, 1999; Piven et al., 1991; Smalley, McCracken, & Tanguay, 1995). Some studies comparing anxiety levels amongst parents of autistic children and parents of typically developing children, as well as children with other developmental conditions, have also shown that parents of autistic children are more likely report higher levels of anxiety in comparison to control groups (Gong et al., 2015; Hamlyn-Wright, Draghi-Lorenz & Ellis, 2007; Padden & James, 2017; Bitsika & Sharpley, 2004; Brobst, Clopton, & Hendrick, 2009; Silva & Schalock, 2012; Zablotsky, Bradshaw, & Stuart, 2013). Considering that autistic children tend to exhibit atypical communication skills, restricted repetitive behaviours as well as aberrant social interactions (APA, 2013), the likelihood of these symptoms increasing childcare demands and consequently impacting parental mental health negatively is considerably high (Hayes & Watson, 2013; Mugno, Ruta, D'Arrigo & Mazzone, 2007). Notably, a meta-analysis conducted by Yirmiya and Shaked (2005) exploring studies on parental experiences caring for an autistic child found that these parents consistently reported greater incidences of psychopathological symptoms such as depression and anxiety compared to parents of typically developing children. Seeing as parental mental health in general has a significant and consequent effect on a child's wellbeing (Kahn et al., 2004), it is important to understand and highlight the various mental health issues, such as anxiety, that may manifest

in parents caring for an autistic child, including the possible predictors which could exacerbate the mental health issues they might experience.

Despite several large survey studies indicating that parents of children diagnosed with ASC consistently report high levels of stress, anxiety and depression (Gray, 1993, 2002; Koegel et al., 1992; Montes & Halterman, 2008; Schieve, Blumberg, Rice, Visser, & Boyle, 2008; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2013), there has been limited research focusing solely on parental anxiety and its specific potential predictors. For example, a study by Piven et al. (1991) exploring psychopathology amongst parents of autistic children and parents of children diagnosed with Down syndrome found that 23.5% of the parents of children with ASC reported at least one anxiety disorder episode, panic attack or phobic disorder. Piven et al. (1991) also went on to state that parents of autistic children were more likely to be at risk of developing a form of life-long anxiety disorder as opposed to parents of children with Down syndrome. Another comparative study conducted by Pocinho and Fernandes (2017) exploring parental stress, anxiety and depression amongst parents of children diagnosed with ASC, intellectual deficits and parents of typically developing children (N=871) found that parents of children diagnosed with a developmental condition reported significantly higher anxiety levels as opposed to parents of typically developing children. However, their research stated that parental anxiety was not associated with the specific developmental condition diagnosed, therefore they did not highlight the differences in levels of reported parental anxiety within the experimental group of parents of children diagnosed with a developmental condition. Moreover, a recent case-control study conducted by Alfarsi et al. (2016) spanning eight months which examined stress, anxiety and depression in parents of autistic children and parents of typically developing children from Saudi Arabia's neighboring country Oman, indicated that parents of children diagnosed with ASC reported higher levels of anxiety compared to parents of typically developing children. However, the study by Alfarsi et al. (2016) did not discuss

any potential predictors for the outcome of parental anxiety. Furthermore, studies by Bitsika and Sharpley (2004) and Micali, Chakrabarti and Fombonne (2004) on parental distress associated with caring for a child diagnosed with a developmental condition also showed that parents and caregivers of autistic children reported high levels of anxiety. Although the study by Bitsika and Sharpley (2004) indicated that 60% to 80% of parents of children diagnosed with ASC reported severe levels of anxiety, the study was limited in its generalizability as it focused on a participant sample from a single city in Australia. Moreover, the study by Micali, Chakrabarti and Fombonne (2004) was also limited in its generalizability due to a small sample size and did not discuss any potential predictors that may lead to parents experiencing anxiety associated with caring for their autistic child.

To date, there is a dearth in studies focusing specifically on parental anxiety and its potential predictors or protective factors. However, there are some studies that suggest that challenging child behaviours specific to autistic children may predict, to some extent, parental stress and anxiety (Hastings, 2003; Hastings et al., 2005). Such findings imply that, in line with literature (Tomanik et al., 2004; Herring et al., 2006; Lecavalier et al., 2006; Osborne & Reed, 2009; Estes et al., 2013), challenging behaviour displayed by a child may significantly increase parental stress, thus creating an environment that is more conducive to experiences of associated parental anxiety. However, studies exploring the underlying mechanisms of this dynamic are notably scarce and the specific potential predictors of parental anxiety linked to caring for an autistic child remain or the factors that may mitigate it are somewhat overlooked and largely inconclusive.

#### **1.4.3 Parental Depression**

For the purpose of this study, depression is defined as feelings of sadness that are generally characterizing by anhedonia, self-disparaging thoughts, lack of interest and motivation, pessimism about the future and feeling that life has no value (Lovibond &

Lovibond, 1995). Various studies on parental mental health associated with caring for an autistic child have indicated that parents of children with ASC are more likely to develop mental health issues such as depression in comparison to parents of non-autistic children (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Hastings et al., 2005; Yirmiya & Shaked, 2005). A meta-analysis of 18 studies focusing on depression in parents of children diagnosed with a pervasive developmental disorder (PDD) and parents of typically developing children indicated that parents of children with a PDD have shown to be at a significantly higher risk for developing depressive symptoms (Singer, 2006). Similarly, a more recent systematic literature review conducted by Karst and Van Hecke (2012) highlighted that parents of autistic children tend to report an overall decrease in parental mental health and wellbeing as well as a variety of psychological symptoms, including depression.

Within the past decade, research focusing on parental mental health associated with caring for a child diagnosed with ASC has sought to gain a better understanding of the heightened risk of depression amongst these parents. However, there is a lack of congruity within the literature on the factors that may potentially predict or protect against parental depression associated with caring for an autistic child. While some studies suggest that the challenging behavior exhibited by an autistic child is the primary predictor of parental depression (Osborne & Reed, 2009; Seltzer et al., 2001), other studies suggest that the severity of the child's ASC symptoms is a factor that is more likely to contribute to the development of parental depression (Yirmiya & Shaked, 2005). Additionally, there are a few studies which suggest that the elevated levels of stress consistently reported by parents of autistic children puts them at particular risk for psychological distress, thus potentially leading to the development of psychopathologies such as depression (Abbeduto et al., 2004, Bromley et al., 2004).

Several studies on parental depression have found that depression was directly linked to high levels of stress which is brought on by challenging child behavior and the severity of the child's symptoms (Benson, 2006). This notion is particularly important as studies have consistently shown that parental depression is a strong correlate of parental stress (Gelfand et al., 1992; Abbeduto et al., 2004, Bromley et al., 2004; Maxted et al., 2005). Parents of autistic children who struggle with their own emotional difficulties or suffer from existing psychopathologies such as depression may resort to maladaptive coping mechanisms which in turn, leads them to feeling increased levels of stress by their child's challenging behavior. Thus, it is essential to distinguish between the contributions to parental depression made by parental stress and the contribution to parental stress made by parental depression while taking factors associated with the child's externalized behavior into consideration.

For example, a study by Davis and Carter (2008) on parental experiences caring for an autistic child indicated that the majority of parents reported high levels of stress while 33% of mothers and 17% of fathers fell within the clinical range of depression. Although, the number of participants in this study was relatively small (N=54), correlational analyses revealed that there was no significant association between parental depression and challenging child behavior. Consequently, Davis and Carter (2008) suggest that the high levels of stress reported by parents may lead to cognitions and emotions linked to depression and depressive symptoms. Moreover, a cross-sectional study conducted by Azeem et al. (2013), assessing psychopathology levels in parents of children diagnosed with an intellectual disability (N=198) found that 89% of parents met the DSM-IV criteria for depression. Similarly, a study by Bitsika and Sharpley (2004) found that nearly two thirds of parents of autistic children reported clinical levels of depression. Furthermore, results from a control-comparison study by Micali, Chakrabarti and Fombonne (2004) on parental mental health and PDD using a semi-structured



questionnaire devised by the authors, showed that depression was more prevalent in parents of children with PDD as opposed to parents of typically developing children.

Despite studies indicating that a significant number of parents of autistic children fall within the clinical range of depression or may be at risk of developing depression, there are some issues that need to be addressed when comparing data between these studies. Firstly, there is an inconsistency throughout the studies on the definition of depression, whereby some studies have used standardized measures for depression while others have required an official diagnosis from a clinician. Secondly, although the majority of studies have used standardized scales for measuring depression, some studies have relied on self-report measures in general health questionnaires and questionnaires developed by the authors. The lack of conformity in terms of the instruments and measures used to measure levels of depression in parents of autistic children as well as the inconsistent definitions of depression may be the underlying factor attributed to the lack of agreement within the literature on the nature of parental depression and its predictors.

Although previous studies have highlighted the high levels of reported parental stress, anxiety and depression, it is apparent that there is a lack in conformity in terms of the choice of variables included as well as the definitions of mental health outcomes across studies. Despite a large number of studies on parental experiences caring for an autistic child focusing on parental stress, there is a lack in both qualitative and quantitative data exploring the nature of parental anxiety and depression as well as the predictive or protective role of the factors associated with it. Importantly, the majority of studies on parental mental health related to caring for an autistic child have combined and investigated parental stress, anxiety and depression as a single outcome variable which could compromise the potential for research to clearly isolate and understand the specific variables that may contribute to each mental health outcome independently. Considering that it is more likely that there are multiple contributing

factors which affect parental mental health outside a research setting, a comparative analysis of the predictor and outcome variables linked to parental mental health issues will be better able to adequately assess the experiences of parents caring for an autistic child.

## **1.5 Challenging Child Behaviour, Autism Symptom Severity and Affiliate Stigma**

### **1.5.1 Challenging Child Behaviour**

Recently, much attention from the developmental conditions research community has been focused on exploring the mental health issues reported by parents of children with developmental conditions and the challenging child behaviour associated with it. Previous studies on this topic have demonstrated that parents of autistic children were the most likely to report high levels of mental health issues in comparison to parents of children with other conditions and parents of typically developing children (Dabrowska & Pisula, 2010; Estes et al., 2013; Hayes & Watson, 2013; Wang et al., 2011; Dykens & Lambert, 2013). Across the existing research in this field, it has been commonly suggested that the main factor leading to the development of stress, anxiety and depression in parents of autistic children is the child's unpredictable and inappropriate behaviour. (Donenberg & Baker, 1993; Seltzer et al., 2001; Tomanik et al., 2004; Herring et al., 2006; Lecavalier et al., 2006; Osborne & Reed, 2009; Estes et al., 2013). To a certain extent, studies have consistently emphasized the existing link between high levels of parental stress, anxiety and depression and ASC-specific symptoms. These include repetitive behaviours (Gabriels et al., 2005), poor social skills (Davis & Carter, 2008; Kasari & Sigman, 1997), the lack of communication skills (Bebko, Konstantareas & Springer, 1987; Tomanik, Harris & Hawkins, 2004) and ASC symptom severity in general (Estes et al., 2009; Hastings & Johnson, 2001; Hoffman, et al., 2008; Ingersoll & Hambrick, 2010). Despite this, research has also indicated that parental mental health issues have also been heavily linked to other child related factors that are not ASC-symptom specific such as

the presence of challenging child behaviours in general (Davis & Carter, 2008; Estes et al., 2009; Hastings et al., 2005) which include irritability, aggression and noncompliance.

Literature on child behavioural issues generally classify challenging behaviour into two categories labelled as internalizing and externalizing behaviours. Internalizing behaviours are usually defined as actions displayed by the child that are inwardly directed and tend to be challenging to directly observe and assess. These include behaviours such as anxiety, withdrawn and depressive traits and other somatic symptoms. On the other hand, externalizing behaviours are usually defined in literature as actions exhibited by the child that are outwardly directed, such as tantrums, aggression and other types of destructive behaviours. Despite research demonstrating the high levels of parental stress, anxiety and depression are related to managing both the internalizing and externalizing challenging behaviours associated with children with ASC (Freeman, Perry, & Factor, 1991; Hastings et al., 2006; Lecavalier et al., 2006; Rao & Beidel, 2009; Weiss & Lunsy, 2011), the aforementioned challenging behaviours are also commonly observed and recorded in other childhood disorders and are not specifically unique to autistic children. A small number of studies have attempted to develop a differential behavioural profile between children diagnosed with ASC and children diagnosed with other behavioural conditions such as Attention Deficit Hyperactivity Disorder (ADHD), Conduct Disorder (CD) and other learning disorders (Donenberg & Baker, 1993; Dumas, Wolf, Fisman, & Culligan, 1991; Efstratopoulou, Janssen, & Simons, 2012). Results from such studies suggest that externalizing difficult behaviours were more present in children diagnosed with ADHD and CD while internalizing difficult behaviours were more commonly identified in children diagnosed with ASC (Efstratopoulou et al., 2012). Moreover, some of these studies indicated that repetitive and ritualistic behaviours associated with ASC showed the highest correlation related to parental mental health issues, while other studies have reported no correlation between the two (Davis & Carter, 2008; Lecavalier et al., 2006; Tehee et al., 2009).

This lack of consistency within the literature could be due to the absence of uniformed classification in terms of ASC specific behaviors, specifically to what constitutes externalizing and internalizing ASC behaviours. Irrespectively, although high levels of reported parental stress, anxiety and depression remain consistently linked to challenging child behaviours that are present in a range of varying childhood disorders, parents of autistic children continue to report markedly high levels of mental health issues compared to other control groups.

While research shows that parents of children with ASC have been found to report high levels of stress, anxiety and depression which tend to fall within the clinical range (Eisenhower, Baker, & Blacher, 2005; Estes et al., 2009; Jang, Dixon, Tarbox, & Granpeesheh, 2011; Kozlowski & Matson, 2012), research also suggests that the relationship between challenging child behaviour and parental mental health issues seems to be a reciprocal and bi-directional one. Thus, an increase in challenging child behaviours displayed by the child leads to an increase in parental mental health issues which consequently exacerbates the child's challenging behaviour (Baker et al., 2003; Pesonen et al., 2008; Neece et al., 2012). Such findings highlight the importance of exploring and analyzing the factors that may potentially lead to the increase in parental mental health issues and caution future research to avoid merely assuming that an ASC diagnosis is an adequate and sufficient factor that predicts parental stress, anxiety and depression (Herring et al., 2006).

A recent meta-analysis conducted by Biswas, Moghaddam and Tickle (2015) on studies focusing on parental mental health provided further support to the significant correlation between parental stress and challenging child behaviour commonly demonstrated within the literature. Moreover, various other studies, focusing on the relationship between parental stress, anxiety and depression and challenging child behaviour, specifically in parents of children diagnosed with ASC, have also identified a significant correlation between these two factors (Paynter et al., 2013; McStay et al., 2014). This significant relationship can also be seen in a

number of qualitative studies where parents of autistic children have expressed how their child's challenging behaviour has been somewhat disruptive to their family life and is a source of their stress, anxiety and depression to some extent (Ludlow et al., 2012). For example, results from a study by Mcstay et al. (2014) indicated that the child's age, verbal ability and ASC symptom severity were not associated with parental mental health issues, however, challenging child behaviour was in fact significantly associated with parental stress in mothers of autistic children between the ages of 6 and 18. Similarly, a study by Gardiner and Iarocci (2015) also indicated that challenging child behaviour was significantly linked to parental mental health issues despite controlling for the variables of ASC symptom severity, child's gender, socioeconomic status and the child's age. Such findings imply that challenging child behaviour can be considered as a potential predictor of parental stress, anxiety and depression despite other research highlighting ASC symptom severity and other factors as a key components in predicting parental mental health issues instead.

Another seminal example supporting the notion of challenging child behaviour being directly linked to elevated levels of reported parental stress, anxiety and depression in parents of children with ASC, is a study by Lecavalier, Leone and Wiltz (2005) where results from parents of autistic children (N=293) demonstrated a strong correlation between parental stress and challenging child behaviour. However, it is important to note that these results are somewhat difficult to generalize as they were mostly correlational and there was also a lack of agreement between the participants in this study on the extent and definition of challenging child behaviour. Moreover, a study conducted by Civick (2008) which required parents of autistic children to rate their child's externalizing behaviour, determined that the externalizing challenging behaviours displayed by the child positively predicted increased levels of stress and decreased levels of wellbeing. Similarly, a study by Fiske (2009) on mothers (N=67) and fathers (N=39) of autistic children also produced similar results. Furthermore, a comparative

study by Abbudeto et al. (2004) exploring parental mental health in parents of children with ASC, Down syndrome and fragile X syndrome found that the most prominent and consistent predictor of maternal stress, anxiety and depression was the extent of the child's challenging behaviour.

Although there is an agreement on the idea of challenging child behaviour being a major contributor to parental stress, anxiety and depression within the literature, there is currently a lack of consensus as to which specific behavioural factor or factors can be attributed to increased levels of parental mental health issues in parents of children diagnosed with ASC. While some studies suggest that the severity of the challenging behaviours is the most prominent predictor (Abbeduto et al., 2004), other studies suggest that the impairments in social interaction and communication are the main contributing factors to parental stress (Konstantareas & Papageorgiou, 2006; Allen, Bowles, & Weber, 2013). Additionally, other studies such as the one conducted by Plant and Sanders (2007) posit that the most significant contributor to negative parental mental health outcomes is the inability of a parent to complete a care-giving task while the child is displaying challenging behaviours.

While a large number of the studies on parental mental health associated with caring for an autistic child have indicated a strong positive correlation between stress, anxiety and depression and challenging child behaviour, a difficult issue may arise in terms of the behaviours being explored in these studies overlapping with the severity of ASC symptoms (Lyons et al., 2010). Thus, it is important for research to set clear operational definitions, comprehensive behavioural categories and to uniformly employ standardized measurement tools in order to gain a clearer understanding of the specific factors related to challenging child behaviours that may negatively affect parental mental health while avoiding potential overlaps between the variables being measured.

### **1.5.2 Autism Symptom Severity**

Despite research identifying a variety of different variables associated with caring for an autistic child which could entail a decline in parental mental health, the majority of research conducted in this field has strictly been focused on three predictive factors, which are the child's challenging behaviour, perceived social support and autism symptom severity. As such, a considerable number of authors have argued that autism symptom severity is the primary predictor of stress, anxiety and depression in parents caring for an autistic child (e.g., Duarte et al. 2005; Hastings and Johnson 2001; Hastings et al. 2005; Brobst et al., 2009; Hoffman et al., 2009; Lecavalier, Leone, & Wiltz, 2006; Lyons, Leon, Phelps, & Dunleavy, 2010; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2013; Konstantareas & Papageorgiou, 2006; Wang et al., 2013; Osborne & Reed, 2009; Zaidman-Zait et al., 2014).

Parents of autistic children, including those who are considered to be at Level 1 autism and do not exhibit specifically challenging behaviours, oftentimes report that their child's behaviour makes them feel stressed, particularly when they occur in a public setting (Tomanik, Harris & Hawkins, 2004). More specifically, research on parental mental health has identified two core diagnostic traits of ASC to be the most problematic for parents, these include restricted and repetitive behaviors (Richardson, 2010) and social communication impairments (Bebko et al., 1987). Whilst autism is generally defined as a neurodevelopmental disorder which is characterized by the presence of restricted and repetitive behaviours as well as impairments in social communication (APA, 2013), autism is also a condition which is heterogeneous and encompasses adults and children with symptoms that vary in severity, different co-occurring difficulties, comorbidity of other disorders and idiosyncratic corresponding needs for support.

When conducting research on parental mental health associated with caring for an autistic child, especially with a focus on the child's autism symptom severity level, it is important to take into consideration the following potential issues. Firstly, the definitions of

symptom severity may differ depending on the type of measurement used in any given study. Since the autism severity indicators in the varying measurement tools employed in research may consist of a total score, caregiver rating, professional or clinical judgement and level of needed support, the outcome of how severity is measured may lack overall uniformity across studies. Moreover, there are a number of sources which could contribute to the rating of autism severity such as emotional difficulties, behavioural challenges, adaptive functioning, core ASC symptoms, learning difficulties and poor parental mental health. Secondly, consideration should be given to the possibility of how the rater measuring autism symptom severity conceptualizes severity. According to Zablotsky, Bramlett, & Blumberg (2015), the concept of severity can be understood differently by different raters, therefore, conflicting differences may exist between the severity index which is determined by the measurement tool, clinical or professional judgment and the parents' perception of autism symptom severity.

Despite there being a lack of consensus when it comes to the conceptualization and the definition of severity within the literature, it is crucial to gain a clearer and more comprehensive understanding of the variables which influence autism symptom severity. Specifically, parental perceptions of severity itself is essential to understand as these perceptions could potentially guide and direct treatment and intervention decisions as well as other help-seeking methods (Mire, Gealy, Kubiszyn, Burrige, & Goin-Kochel, 2015). Additionally, it is important to highlight the lack of research conducted on the different perceptions of severity which may vary cross-culturally. The different interpretations of symptoms, disorders and intervention methods which exist across various cultures may also help drive research on parental stress, anxiety and depression associated with a child's autism symptom severity levels towards a more accurate and extensive understanding of this association.

When it comes to exploring the link between parental stress, anxiety and depression and autism symptom severity, factors such as the child's age, linguistic impairments, existing



comorbid disorders, level of intellectual functioning and the presence of challenging behaviours should be considered as they could potentially influence the rating of severity. Firstly, when it comes to age, parents have a tendency to rate younger children as presenting with more severe ASC symptoms in comparison to adolescents, since ASC symptoms tend to be more apparent in children of a younger age. Research conducted by Esbensen, Mailick Seltzer, Lam and Bodfish (2009) has shown that one of the core symptoms of ASC, restricted and repetitive behaviours, present less frequently and less severely in adults diagnosed with ASC as opposed to children. Thus, older children who exhibit milder restricted and repetitive behaviours may appear to have less functional impairments and are therefore rated lower on the autism symptom severity measures by parents. On the other hand, other studies conducted on the link between parental mental health autism symptom severity have indicated that the severity of ASC symptoms is typically stable across time, rendering the factor of the child's age unreliable as an independent factor which could account for ASC symptom severity levels (Gotham, Pickles & Lord, 2012). Secondly, it has also been suggested by research that the level of intellectual functioning in children diagnosed with ASC has been shown to influence the ASC severity rating (Gotham et al., 2012). A study conducted by Hartley, Schaidle and Burnson (2014) has shown that parents of children diagnosed with ASC as well as a concurrent intellectual functioning impairment were more likely to report greater overall autism symptom severity levels, more frequent displays of challenging behaviour as well as more ASC symptoms as opposed to parents of children diagnosed with ASC alone. Moreover, lower scores on measures exploring adaptive behaviours as well as general deficits in theory of mind have also been shown to predict higher ASC severity rates (Gotham et al., 2012; Hoogenhout & Malcolm-Smith, 2017). Additionally, research conducted by Esbensen et al. (2009) has shown that intellectual functioning may moderate the relationship between core symptoms of ASC and the child's age. However, there is a need for future research to further explore the

different variables that may moderate or mediate the various factors that could affect the ratings of autism symptom severity. Finally, it has also been suggested by research that the child's gender may also have an influence on a parent's perception of their child's symptom severity. According to Hattier, Matson, Tureck and Horovitz (2011), males diagnosed with ASC tend to present with more frequent and severe restricted behaviours in comparison to females diagnosed with ASC. On the other hand, research by Frazier, Georgiades, Bishop and Hardan (2014) has shown that females diagnosed with ASC tend to exhibit more challenging behaviour and are more likely to have concurrent intellectual disabilities. As such some research studies indicated that parents of females diagnosed with ASC tend to report higher levels of stress, anxiety and depression in comparison to parents of males diagnosed with ASC (Zamora, Harley, Green, Smith, & Kipke, 2014). However, no concrete conclusions can be extrapolated from such studies with regards to the child's gender and its link to the perception of autism symptom severity considering the historical emphasis on the male-biased diagnostic criteria which was prevalent in previous literature (Haney, 2016; Wilson et al., 2016). Nevertheless, a child's gender may still potentially impact parental perceptions of autism symptom severity to some extent due to the inherent culture-specific gender socialization norms for playing, social communication and social interaction (Goldman, 2013), the salience of deficits in social communication (Lai et al., 2011) as well as the presentation of existing comorbidity (Begeer et al., 2013).

There are a number of existing studies within the literature on parental stress, anxiety and depression associated with caring for an autistic child which have found a positive correlation between autism symptom severity and parental mental health issues (e.g., (Liwag, 1989; Foronda, 2000; Nikmat et al., 2008; Charnsil and Bathia, 2010; Yeo and Lu, 2012; Athari et al., 2013; Wisessathorn et al., 2013; Lai et al., 2015; Ilias et al., 2016). For example, a study conducted by Kissel and Nelson (2016) examining the link between parental stress and autism

symptom severity (N=64), found that parents of children which presented with more severe autistic behaviours were more likely to report higher levels of stress as opposed to parents of children who displayed less severe autistic behaviours and parents of typically developing children. Although this study found that parents of children who displayed more severe autistic behaviours were the only group who fell into the clinically significant range of parental stress, it is also important to note that the participant sample in this study predominantly consisted of middle class Caucasian married mothers which could potentially limit the generalization of the results. Another example examining the link between parental mental health and autism symptom severity is a study conducted by Duarte et al. (2005) which showed that the primary factor predicting stress in mothers of autistic children (N=62) was autism symptom severity, despite the study showing that variables such as the parent's and child's age were also contributory factors to the high parental stress outcome. Moreover, a study of (N=141) parents of autistic children by Hastings and Johnson (2001) also indicated a significant correlation between parental stress and autism symptom severity. However, in both studies by Duarte et al. (2005) and Hastings and Johnson (2001), the participants that were recruited were limited to parents seeking specialized support services for their children and are therefore not necessarily reflective of the general population of parents of autistic children who may have not sought any professional form of assistance. In contrast, studies on the predictive factors determining parental stress, anxiety and depression in parents of autistic children which consist of participants recruited directly from the community as opposed to participants from a clinical sample found that autism symptom severity was not predictive of parental stress (Hastings et al., 2005). Similarly, a study by Davis and Carter (2008) indicated that the core symptoms of ASC such as deficits in social communication and repetitive and restricted behaviours were not predictive of parental stress either.

When it comes to research exploring the link between autism symptom severity and parental mental health, there is an evident amount of inconsistency in the findings presented in the studies. Whilst a large number of studies indicate a positive correlation between the severity of ASC symptoms and parental stress, anxiety and depression (e.g., Benson, 2006; Bromley et al., 2004; Davis & Carter, 2008; Hastings & Johnson, 2001; Konstantareas & Homatidis, 1998), other studies have shown that the link between parental stress and levels of autism symptom severity are either weak or insignificant (Hastings et al., 2005; Manning et al., 2011; Morgan, 1988). Interestingly, results from the studies showing no apparent link between autism symptom severity and parental stress contradict the idea that higher levels of symptom severity pertaining to a greater need for dependency on parents and caregivers may consequently elevate the levels of parental stress, anxiety and depression due to the great caring demands placed on parents by children who are in need for a more intensive level of parenting (Blacher & McIntyre, 2006; DePape & Lindsay, 2015), behaviour management strategies, time and resources (Beighton & Wills, 2017).

The current debate within the literature concerned with parental mental health and autism symptom severity regarding the source of parental mental health issues focuses on the difficulty in isolating the specific behaviours related to ASC symptoms and the overall challenging externalized behaviours of children which tend to overlap to some extent. Considering the diversity of autism symptomology, it is somewhat challenging to clearly understand where parental stress, anxiety and depression originates from. Currently, it remains unclear whether the predictive factors of parental mental health issues stem from the core symptoms of ASC or the associated challenging externalized behaviors typically presented in children diagnosed with ASC and children diagnosed with ASC and other comorbid conditions (Lyons et al., 2010).

An understudied domain within the current literature on parental stress, anxiety and depression and its link to autism symptom severity is the possibility that certain sociocultural factors may influence and account for the differences in parental perceptions of ASC severity (Norbury & Sparks, 2013). For example, there are some cases where the autism symptom severity tool may perceive the symptomology as more severe than the perception of severity held by the parent. Additionally, families from an extreme disadvantaged economic background whose primary concern is adequate housing, family safety, access to nutrition and disease prevention may not regard ASC symptoms as a priority, thus perceiving ASC symptomology as less severe. Moreover, when it comes to measuring the core ASC symptoms and their severity, it is important to note that pragmatic language and communication skills are also susceptible to cultural variation which makes it difficult to accurately measure using standardized tests and procedures (Norbury & Sparks, 2013). Furthermore, research by Taylor Dyches, Wilder, Sudweeks, Obiakor and Algozzine (2004) has suggested that families from varying ethnic or racial backgrounds may also perceive the severity of ASC symptoms differently as they may experience subjectively varying levels of stress, anxiety and depression. For example, some studies have shown that parents from a non-Caucasian background are more likely to perceive fewer negative impacts of caring for a child diagnosed with an intellectual disability or ASC as opposed to Caucasian parents (Ferguson, 2001; Valentine, McDermott, & Anderson, 1998). Similarly, studies have found that parents from a Hispanic background tend to report fewer developmental concerns as well as ASC symptoms despite clinicians and autism specialists perceiving the symptoms to be more severe (Blacher, Cohen, & Azad, 2014; Pereira Ponde & Rousseau, 2012). Finally, in terms of cultural considerations, when it comes to research conducted on ASC symptom severity and parental mental health issues it is necessary to consider the existing difference in social expectations of behaviour prevalent in different cultures which could potentially affect parental perceptions of ASC symptom severity. For

example, in many Asian cultures, the amount of eye contact expected between adults and children may be different than what is considered as typical in other cultures. Considering the amount of eye contact made by the child being an indicative factor of the diagnostic process of ASC, parents of children diagnosed with ASC from Asian backgrounds may perceive and rate their child's ASC symptom severity level differently on standardized screening tools due to the existing cultural variations (Dyches, Wilder, Algozzine, & Obiakor, 2007; Norbury & Sparks, 2013; Perepa, 2013; Wilder, Dyches, Obiakor, & Algozzine, 2004). Moreover, some Asian cultures expect less verbal communication between children and adults which could also in turn affect the way in which parents rate the severity of their child's symptoms especially in the domain for language and communication development which can sometimes be impaired in children diagnosed with ASC (Daley, 2004; Liu, 2005). According to Dyches et al. (2007), this cultural variation in what is considered as expected communication between children and adults may also account for findings in research suggesting that parents from some Asian backgrounds tend to perceive ASC characteristics such as echolalia and repetitive questioning as more challenging in comparison to parents from other cultural backgrounds. Furthermore, parents from some African backgrounds may perceive their child's ASC symptom severity differently, especially in the domain of nonverbal communication considering the variation in the appropriateness of pointing towards people and objects (Perepa, 2014).

In conclusion, although some research suggests that autism symptom severity levels can predict parental mental health issues, other research suggests that the link between those two factors are insignificant. In addition, the overlap between behaviours which fall under ASC symptomology and general challenging child behaviour can be somewhat hard to distinguish and therefore poses a challenge when it comes to attempting to isolate the potentiality for each variable to predict parental stress, anxiety and depression. Moreover, various cultural and familial factors can also influence the way in which ASC symptom severity is rated. Given the

current state of research on parental mental health associated with caring for an autistic child, it is so far unclear whether parental stress, anxiety and depression stem from the parent's subjective perception of the child's symptoms, the child's challenging externalized behaviour or the severity of the core ASC symptoms.

### **1.5.3 Affiliate Stigma**

Recently, the impact of stigma upon the mental health of parents of children with ASC has been receiving increased recognition. According to a recent review, parents of autistic children often report encountering various forms of stigmatization related to their child's condition (Mitter et al., 2019). Consequently, these parents tend to experience high levels of stress, anxiety and depression associated with the experience of stigma (Crabtree, 2007; Green, 2007; Gray, 2002; Papadopoulos et al., 2018). Stigma is defined as a set of prejudicial attitudes and discriminatory behaviours upheld by one group against another (Corrigan et al., 2000). According to Goffman (1963), stigma is a relationship between "attribute and stereotype" (p.4) as well as a component which reflects notions of discredit and disgrace that could distinguish and exclude a certain individual from others. According to Jones et al. (1998), stigma occurs when what has been termed as a "mark" (a descriptor that includes a variety of what society may regard as deviant conditions) becomes linked to the identity of an individual via an attributional process which discredits that specific individual leaving them subject to stigmatization.

In terms of ASC, the presence of challenging behaviours along with the absence of an obvious physical 'mark' makes ASC an invisible disorder (Gray, 1993). The display of such behavioural challenges is often regarded by society as a result of poor parenting. As a result, parents of autistic children often become subject to societal stigma. As such, stigma not only affects autistic individuals, but it can also extend to and affect their family members and caregivers (Mitter et al., 2019). Stigma related to autism that extends to parents and caregivers

is known as ‘courtesy stigma’ whereby individuals closely affiliated with an individual with a stigmatic ‘mark’ are subjected to negative reactions from society as well (Abojabel et al., 2016; Koshorke et al., 2014; Zhou et al., 2018). In terms of ASC, this includes members of society blaming parents for the onset of autism and the expectation that they should be ashamed about their lack of competency and ability to manage their child’s behaviour (Milacic-Vildojevic et al., 2012). This can, in turn, lead to the social rejection of parents of autistic children (Gray, 1993; Corrigan et al., 2006). Additionally, due to the repeated exposure to courtesy stigma, parents of autistic children may develop “affiliate stigma” (Mak & Cheung, 2008) whereby society’s negative reactions towards the autistic child and their parent becomes accepted and internalized by the parent. These parents often subsequently integrate these stereotypes into their own sense of identity and core beliefs (Papadopoulos, 2016). Also, the self-stigmatization of these parents leads them to becoming more vulnerable to experiencing mental health issues such as stress, anxiety and depression (Mak & Cheung, 2008; Corrigan & Watson, 2002) and impedes their ability to cope with adversity (Jahoda & Markova 2004; Meyers et al., 2009).

Studies on the psychological impact of stigma have consistently shown negative associations between stigma and mental health (Linl & Phelan, 2006). It has been well documented that consistent exposure to stigma is associated to higher levels of mental health issues and lower life satisfaction (Clark et al., 1999; Paradies, 2006; Pascoe & Sutin, 2015; Williams et al., 2003). Various studies have found affiliate stigma to be a significant predictor of poor mental health among mothers of children with developmental conditions (Chiu et al., 2013; Banga et al., 2016; Dalky et al., 2017; Kim-Wan et al., 2016; Kwok et al., 2014; Magana et al., 2007; Mikami et al., 2014), however, a study by Werner and Schulman (2013) indicated that parents of autistic children were found to be the most affected by affiliate stigma compared to parents of children with other developmental conditions. Parents who experience affiliate stigma often react by concealing their situation from others, withdrawing from social relations



and engagements and sometimes alienating themselves from their child (Mak & Cheung, 2008; Mak et al., 2011; Grover et al., 2017). According to Lowell and Wetherell (2018), the internalization of stigma leads to feelings of rejection, devaluation, shame and low self-esteem which can result in the reduction of parental caregiving behaviours, thus compromising the wellbeing of the child.

A study conducted by Gray (2002) found that parents of autistic children reported symptoms of anxiety and depression, with over a third of these parents receiving psychotherapy and medication. Gray (2002) interpreted that this was mostly due to public stigma felt by the parents as well as their experience of courtesy stigma from extended family members. Another study conducted by Kinnear et al. (2015) on the effect of autism stigma (N=502) found that parents of autistic children who were exposed to stigma reported poor mental health and expressed a strain on their relationship with their child. Moreover, a recent systematic review conducted by Papadopolous et al. (2019) on 1142 studies looking at existing empirical evidence associated with autism stigma and its effect on parents found a significant link between experiences of stigma and poor mental health, specifically autism stigma being linked to parental depression (Crabtree 2007; Gray 2002; Dababnah and Parish 2013; Chan and Lam 2017, 2018; Ting et al. 2018) and parental anxiety (Gray 2002; Chan and Lam 2017).

Although supporting a child with ASC can have a significant impact on parents despite their cultural background (Rose 2014; Vanegas & Abdelrahim 2016), the nature of this impact is still not well understood across varying cultures due to the bulk of research on the parental mental health being typically conducted in Western countries (Elsabbagh et al., 2012, Daley, 2002). For example, there are a very limited number of studies exploring autism stigma and parental wellbeing with a sample from an Arabian culture (e.g., Al-Farsi et al. 2016; Almansour et al. 2013; Dababnah & Bulson 2015). Nonetheless, these studies have indicated that parents of children with ASC from an Arabian cultural background tend to experience additional

stressors when caring for their child due to cultural perceptions of ASC as well as mental health issues in general being considered a taboo topic. Research by Papadopoulos, Foster and Caldwell (2013) found that collectivist cultures were more likely to stigmatize individuals who deviate from the social norms compared to individualistic cultures. Seeing as Middle Eastern cultures such as the Saudi Arabian culture is categorized as be a collectivist culture, the impact of affiliate stigma on parents of autistic children with could therefore be particularly relevant in understanding their overall experiences of caring for an autistic child.

## **1.6 Resilience, Religious Coping and Social Support**

### **1.6.1 Resilience**

An extensive amount of research on parental mental health related to caring for a child with ASC indicates that parents consistently report high levels of stress, anxiety and depression (Schieve, Blumberg, Rice, Visser, & Boyle, 2008; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2013), however not all parents caring for an autistic child report such high levels of mental health issues (Abidin, 1992; Ekas, Lickenbrock, & Whitman, 2010; Pozo & Sarriá, 2014). A number of studies have suggested that while a child's characteristics do contribute to elevated parental stress, anxiety and depression, these factors are also impacted by the parents' psychological characteristics (e.g., coping strategies, individual resilience, locus of control) as opposed to demographic variables such as education and socioeconomic level and marital status (Boyce, Behl, Mortensen, & Akers, 1991; Bristol, 1984; Hastings & Johnson, 2001). Despite the limited investigation into the factors specifically associated with parental characteristics and their influence on mental health, such research highlights the importance understanding some of these factors as they may act as protective agents against stress, anxiety and depression. For example, studies have found that parents of children diagnosed with ASC who are highly resilient are more likely to report lower levels of stress, anxiety and depression and are more competent at managing the challenges of caring for their child (Hayes & Watson,

2013; Bekhet, Johnson, & Zauszniewski, 2012). Since resilience has recently emerged as a growing field of interest in research on parents of autistic children, it is important to explore resilience and its positive impact on parental mental health.

The general definition of resilience is an individual's capacity to navigate through life regardless of adverse conditions and misfortune. According to Ungar (2004), resilience can be explained as a sense of competence when facing significant challenges against adaptation and development. In terms of caring for a child with ASC, studies suggest that when a parent of an autistic child rises above the expected challenges of providing support in their daily lives while continuing to engage in healthy adaptation processes, they can be considered as resilient (Harris & Glasberg, 2003). Seeing as resilience is generally defined as a process of successful adaptation to and recovery from a significant life challenge (Whitehead, et al., 2015), the link between psychological wellbeing and resilience has been described as "compelling" (Gill & Harris, 1991, p. 131) as it has been found to have a buffering effect on mental health issues including anxiety and depression. (Fredrickson & Joiner, 2002).

For example, a study conducted by Bitsika et al (2013) looking at factors related to the personal characteristics of parents of autistic children found resilience to be a protective factor against parental stress, anxiety and depression. This study suggested that despite the challenges associated with parenting an autistic child being associated with severe levels of anxiety and depression, reports of resilience successfully buffered the relationships. Another study conducted by Whitehead et al. (2015) which also confirmed the link between resilience and psychological wellbeing of mothers of children diagnosed with ASC found mothers who had high resilience also scored highly on the wellness scale in comparison to mothers who engaged in avoidant strategies such as self-blame and disengagement which led to increased levels of anxiety, stress and depression.

According to Fergus and Zimmerman (2005), the absence of symptomology associated with distress can be characterized as resilience and parents of autistic children who are classified as resilient are better able to cope with the stressful demands of caregiving while maintaining their wellbeing as well as the wellbeing of their child. Despite the recent traction within the relevant literature towards studies focusing on family resilience in families of children with developmental conditions, resilience especially in parents of children with ASC remains somewhat understudied (Carter et al., 2009; Siman-Tov & Kaniel, 2011; Tobing & Glenwick, 2006; Kuhn & Carter, 2006; Ekas & Whitman, 2010). It is also important to note that identifying factors such as potential protective factors such as resilience in parents of autistic children is essential as it could be regarded as a factor that enables parents to effectively cope when faced with the various challenges of providing care and support for their autistic child.

The majority of studies on parental mental health and resilience in parents of children diagnosed with ASC are conducted using a participant sample from Western countries (Bekhet et al., 2012; McConnell et al., 2014; Leone et al., 2016). The ability of resilience to acts as a protective factor has yet to be explored in Saudi Arabia. Seeing as culture is likely to shape how parents of children with ASC perceive their child's condition, there is also a possibility that these cultural factors also play a role in how these parents cope and how it affects their level of resilience (Ghosh & Magana, 2009; Cridland et al., 2014; Xue et al., 2014). Thus, exploring how resilience in parents of autistic children from Saudi Arabia impacts their levels of stress, anxiety and depression is needed in order to address the gap in the literature.

### **1.6.2 Religious Coping**

According to some studies, religious coping can be considered as a protective factor against parental stress, anxiety and depression. Studies have shown that religious coping is a form of adaptive coping that alleviates parental mental health issues in parents of children with

developmental conditions (Kim & Esquivel, 2011; Pargament, Tarakeshwar, Ellison, & Wulff, 2001) and acts as a buffer against stressors such as challenging child behaviour (Friedrich et al., 1988). Although some studies suggest that religious coping lowers the rates of reported mental health issues in parents of children with ASC, this field of research remains largely understudied despite it being a vital part of daily life across many cultures.

Although religion tends to get overlooked in mental health research, it does however play an important role in the lives of many people as a coping tool (Loewenthal, 2000; Moreira-Almeida, Lotufo Neto, & Koenig, 2006). Religious coping is commonly defined as a process of using tools that are associated with religion in order to adjust to challenging situations (Avent Harris et al., 2019; Pargament et al., 1998). Previous studies have indicated that religious coping is correlated with lower psychopathology (Abdel-Khalek, 2009; Abdel-Khalek & Lester, 2007; Bullock, Nadeau, & Renaud, 2012; Meltzer, Dogra, Vostanis, & Ford, 2011; Pearce, Little, & Perez, 2003; Robbins & Francis, 2009; Scales Rostosky, Danner, & Riggle, 2008; Schludermann, Schludermann, & Huynh, 2003). For example, a study conducted by Ai, Peterson and Huang (2003) exploring how religious coping can predict positive mental health outcomes has shown that religious coping significantly predicted optimism. Although such studies demonstrate the ability of religious coping to alleviate stress, a more comprehensive understanding of how people engage in religious coping to deal with stressors across varying cultures is needed.

According to a small number of studies, parents of children with ASC regularly use religious coping in their everyday life to help deal with their child's condition (Ault et al., 2013, Ekas et al., 2009; Gallagher et al., 2015). For example, studies show that some parents of autistic children use religious coping to overcome experiences of stigma and other stressors associated with caring for their child (Ekas et al., 2009; Richardson & Stoneman, 2015; White, 2009). Other qualitative studies have also indicated that parents of autistic children described

religious coping as a method by which they can accept and derive meaning of their child's diagnosis, as a way of providing support for their own mental health and as way to improve their overall quality of family life (Ault et al., 2013; Carter & Boehm, 2019; White, 2009; Ting and Chuah, 2010; Tait and Mundia, 2012; Resurreccion, 2013; Wahyuni, 2013; Santoso et al., 2015; Chong and Kua, 2016; Ilias et al., 2016). In summary, according to the aforementioned studies, religious coping can potentially act as a protective factor against daily stressors for parents of children with ASC (Koenig, McCullough, & Larson, 2001) and also provide parents with a positive framework by which they can interpret their child's condition (Jegatheesan, Miller & Fowler, 2010). Therefore, the buffering effect of religious coping against stress, anxiety and depression across varying cultural groups is an important topic to explore in order to better understand the way in which different groups of parents perceive their child's developmental condition and how they personally manage the difficulties associated with caring for their child (Dyches, Wilder, Sudweeks, Obiakor & Algozzine, 2004; Skinner, Correa, Skinner & Bailey, 2001).

While religion can be regarded as one of the various cultural values in different societies, in Saudi Arabia, religion is considered as the most dominant influential factor affecting all life matters by most of the members of society. Therefore, the significance of religion can be seen in the diagnosis and treatment of an autistic child as well as in the wellbeing of the parents (Alqunaibet, 2019). To date, there has only been one study which has explored how parents of children with ASC in Saudi Arabia use religion as a coping mechanism (Alqunaibet, 2019). An awareness of the culturally specific mechanisms of coping related to the experience of caring for an autistic child within Saudi Arabia is therefore necessary when it comes to an attempt to explore the various ways in which parents perceive and cope with their child's condition and how they manage to deal with the daily stressors associated with their child.

### **1.6.3 Social Support**

Research has found that parents of children diagnosed with ASC who perceive to have higher levels of social support are less likely to report stress, anxiety and depression (Dunn et al., 2001; Ramisch, 2010; Sanders & Morgan, 1997; Siman-Tov & Kaniel, 2011; Stuart & McGrew, 2009). Social support is commonly defined as a multidimensional construct that is comprised of the psychological, instrumental, emotional and physical support that an individual receives from others whereby the receiver feels cared for and supported (Cobb, 1976; Boyd, 2002; Dunst, Trivette, & Cross, 1986). Throughout the literature, social support is generally broken down into two categories: Formal and informal support. Formal support is defined as the support an individual receives from professional organizations, community resources or governmental agencies. However, informal support is generally defined as the support an individual receives from family, friends, partners and other informal groups (Sarason et al., 1983). It has been well documented that both forms of social support increase the overall wellbeing of parents of autistic children (Pottie et al., 2009), however, numerous studies have indicated that parents who are more likely to report lower levels of stress, anxiety and depression are the parents who also report high levels of informal social support as opposed to formal social support (Hastings & Johnson, 2001; Boyd, 2002; Bishop et al., 2007; Ekas, et al., 2010).

Most of the literature on social support suggests that perceived social support is the key factor that alleviates stress and mediates the relationship between a significant life-stressor and poor mental health (Haber, Cohen, Lucas, & Baltes, 2007; Lin & Margolin, 2014; Norris & Kaniasty, 1996; Wesley, Zelikovsky, & Schwartz, 2013; Russell & Cutrona, 1991; Dour et al., 2014). For example, a study conducted by Gray and Holden (1992) found that mothers of autistic children who reported higher levels of perceived social support also reported lower levels of anger, anxiety and depression. In qualitative studies, parents of autistic children often

report relying on social support as a way to reduce their experiences of stress and as a means to cope with symptoms of depression and anxiety (Tunali & Power, 2002; Weiss, 2002; Benson, 2006; Luther, Canham, & Cureton, 2005; Siklos & Kerns, 2006). Moreover, social support is the most frequently reported factor described by parents of children with ASC that helps them cope with daily stressors associated with caring for their child (Meadan, Halle, & Ebata, 2010; Luther, Canham, & Cureton, 2005). Another example of the importance of social support for parents of autistic children is a study by Luther, Canham, and Cureton (2005) which found that parents of autistic children are more likely to be in need for informal social support compared to parents of non-autistic children as these parents report that they consistently rely on friends and family as opposed to their neighbors.

Previous studies have reported that different cultural factors can potentially affect how parents of children with ASC cope with caring for their child as well as the type of assistance they seek. For example, many parents of children with developmental conditions from the Middle East refuse to seek formal social support as they tend to regard it as a sign of weakness (Zhang & Bennett, 2003). Studies on parents of autistic children from the Middle East indicates that the Arabian society in general holds negative perceptions towards individuals with disabilities compared to individuals from Western societies, thus Arab parents are less likely to accept their child's diagnosis or seek any form of social support (Al Khateeb et al., 2014; Al Thani, 2006; Gharaibeh, 2009; Haboush, 2007; Sharifzadeh, 2011; Turmusani, 2003). In the case of Saudi Arabia, cultural dimensions of autism are generally unexplored and there is a gap in evidence-based literature on this topic (Alallawi, Hastings & Gray, 2020). Only a handful of studies have been conducted on social support in Saudi Arabia (e.g., Ebrahim & Alothman, 2021; Hassanein, Adawi, & Johnson, 2021; Khusaifan & El-Keshky, 2020; Gehan & Moawad, 2012). These studies have all found that informal social support was the only utilized factor for



coping in parents of autistic children in Saudi Arabia. However, these studies did not specify the source of informal support they considered most effective.

Seeing as previous studies have suggested that parent's perception of autism and how they provide support for their child are significantly influenced by their cultural background (Gona, Newton, Rimba, Mapenzi, Kihara, Van de Vijver, et al., 2015; Mandell & Novak, 2005; Mire, Gealy, Kubiszyn, Burrridge, & Goin-Kochel, 2015; Ponde & Rousseau, 2013), it is important to explore social support amongst an understudied population sample such as Saudi Arabia in order to gain a better understanding on how parents from other parts of the world cope with the stressors associated with caring for their child. Such studies can also inform professionals in the field on the cultural variations in terms of social support as well provide them with the basis to further develop culturally appropriate interventions for parents of autistic children in Saudi Arabia.

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## **Chapter 2: Parental Stress, Anxiety and Depression Associated with Autism Symptom Severity and Challenging Child Behaviour in Saudi Arabia**

### **Abstract**

**Objective:** Studies suggest that parents of autistic children report high levels of stress, anxiety and depression attributable to their child's autism symptom severity and challenging behaviour. This in turn affects the overall wellbeing of both parent and child. This study aims to explore the relationship between stress, anxiety, depression, challenging behaviour and autism symptom severity.

**Method:** 128 participants from Saudi Arabia were recruited via opportunity sampling to complete an online survey. The survey consisted of the Depression, Anxiety and Stress Scale (DASS- 21), the Child's Challenging Behavior Scale (CCBS) and the Gilliam Autism Rating Scale (GARS-3).

**Results:** Results indicated a significant association between challenging child behaviour, stress, anxiety and autism symptom severity. Regression analyses indicated that autism symptom severity was the only significant predictor of parental stress, anxiety and depression.

**Conclusion:** There appears to be an overlap between autism symptom severity and challenging child behaviour. While challenging behaviour was strongly associated with stress, anxiety and depression, autism symptom severity showed to be the key factor explaining high levels of parental mental health issues.

*Key Words:* Autism, Stress, Anxiety, Depression, Saudi Arabia

### **Introduction**

Autism is commonly recognized as a pervasive, complex and multifactorial neurodevelopmental disorder (DSM-5, 2013). autism is typically characterized by impairments in communication, social interaction along with the presence of restrictive and repetitive behavioural patterns (APA, 2013). Individuals diagnosed with ASC, especially children, often experience a set of complex and idiosyncratic array of behavioural, emotional and social challenges that cause substantial and continual concerns for parents. Consequently, parents of autistic children are potentially at a higher risk of developing stress disorders and mental health issues, including anxiety disorders and depression (Hastings, 2003; Tomanik et al., 2004; Lecavalier et al., 2006). Oftentimes, autistic children also diagnosed with other comorbid disorders such as Attention Deficit Hyperactive Disorder (ADHD), various seizure disorders,

metabolic disorders, gastrointestinal disorders and sleep disorders (Bauman, 2010). The chronic nature and pervasiveness of ASC along with the impairments associated with it and the possibility of existing comorbid disorders can also further impact parents negatively by compromising their wellbeing and increasing their levels of stress, anxiety and depression, thus resulting in further challenges associated with parenting as a greater need for a more intricate support system for the child is usually required.

Parenting a child diagnosed with ASC can be more challenging than parenting a typically developing child as autistic children require a more intensive level of parenting (Blacher & McIntyre, 2006), behaviour management as well as more financial resources (Beighton & Wills, 2017). Previous studies suggest that parents of autistic children commonly report higher levels of stress, anxiety and depression compared to parents of typically developing children (Hayes & Watson, 2013) and parents of children diagnosed with other developmental conditions (Estes et al., 2013; Dabrowska & Pisula, 2010; Hayes & Watson, 2013; Wang et al., 2011; Dykens & Lambert, 2013). Various studies have suggested a number of possible factors which may account for the high levels of reported parental mental health issues associated with caring for an autistic child diagnosed. These include the severity of ASC symptoms (Osborne & Reed, 2009; Rivard et al., 2014; Duarte et al., 2005, Hastings & Johnson 2001), the child's challenging behaviour (Tomanik et al., 2004; Lecavalier et al., 2006; Fiske 2009; Gray 2003), financial issues in terms of intervention and education cost (Sharpe & Baker, 2011; Thomas et al., 2016) and being subjected to social stigma (DePape & Lindsay 2014; Weiss et al. 2014; Farrugia, 2009). However, there is little consensus within the literature focusing on parental mental health associated with caring for an autistic child as to which specific factor, or group of factors, act as a significant contributor to these elevated levels of reported mental health issues. Despite this lack of agreement within the literature, it has however been well documented that increased levels of parental stress, anxiety and depression

have a significantly negative influence on parenting skills which can consequently have a negative effect on the child's mental health and wellbeing (Anthony et al., 2005; Hastings & Beck, 2004).

Across the existing research in this field, it has been commonly suggested that the main factor leading to the development of stress, anxiety and depression in parents of children with ASC is the child's unpredictable and inappropriate behaviour. (Donenberg & Baker, 1993; Seltzer et al., 2001; Tomanik et al., 2004; Herring et al., 2006; Lecavalier et al., 2006; Osborne and Reed, 2009; Estes et al., 2013). To a certain extent, studies have consistently emphasized the existing link between high levels of parental mental health problems and ASC-specific symptoms. These include repetitive behaviours (Gabriels et al., 2005), poor social skills (Davis & Carter, 2008; Kasari & Sigman, 1997), lack of communication skills (Bebko, Konstantareas & Springer, 1987; Tomanik et al., 2004) and ASC symptom severity in general (Estes et al., 2013; Hastings & Johnson, 2001; Ingersoll & Hambrick, 2010). On the other hand, some studies have also indicated that high levels of reported parental stress, anxiety and depression have also been heavily linked to other child related factors that are not ASC-symptom specific, such as the presence of challenging child behaviours in general (Davis & Carter, 2008; Estes et al., 2009; Hastings et al., 2005) which include irritability, self-injurious behaviour, aggression and noncompliance.

The most recent meta-analysis which was conducted by Hayes and Watson (2013) on parental stress associated with caring for an autistic child and children diagnosed with other conditions and disabilities reported a large effect size in parents of autistic children. Their study indicated that parents of children diagnosed with ASC tend to report higher levels of stress. Additionally, a study conducted by Lecavelier, Leone and Wiltz (2006) exploring parental stress in parents of autistic children found that child behaviour problems were strongly associated with stress and that the results were considerably stable over the one-year interval

in which participants were being rated. In support of this, a study conducted by Griffith, Hastings, Nash and Hill (2010) on behavioural issues in children diagnosed with ASC, Down syndrome and intellectual disabilities found that the parents of the children diagnosed with ASC reported the highest levels of stress as they were more likely to rate their child displaying self-injurious behaviour and lower social competency in comparison to the other groups of children.

While research has shown that parents of children with ASC have been found to report high levels of stress, anxiety and depression which tend to fall within the clinical range (Eisenhower, Baker, & Blacher, 2005; Estes et al., 2009; Jang, Dixon, Tarbox, & Granpeesheh, 2011; Kozlowski & Matson, 2012), research also suggests that the relationship between challenging child behaviour and parental mental health issues is a bi-directional one. Thus, an increase in challenging child behaviours displayed by the child leads to an increase in parental stress, anxiety and depression which accordingly intensifies the child's challenging behaviour (Pesonen et al., 2008; Neece et al., 2013). Such findings highlight the importance of exploring and analyzing the underlying factors that may potentially lead to the increase in parental mental health issues and caution future research to avoid merely assuming that an ASC diagnosis is an adequate factor that predicts parental stress, anxiety and depression (Herring et al., 2006).

There are a number of existing studies within the literature on parental mental health associated with caring for an autistic child which have found a positive correlation between ASC symptom severity and parental mental health issues (e.g., (Nikmat et al., 2008; Charnsil & Bathia, 2010; Yeo & Lu, 2012; Athari et al., 2013; Wisessathorn et al., 2013; Ilias et al., 2016). For example, a study conducted by Kissel and Nelson (2016) investigating the link between parental stress and autism symptom severity found that parents of children who presented with more severe autistic behaviours tended to report higher levels of stress as opposed to parents of children who displayed less severe autistic behaviours. Another study

examining the association between parental mental health issues and ASC symptom severity is a study conducted by Duarte et al. (2005) which indicated that the primary variable predicting stress in mothers of autistic children was ASC symptom severity. Moreover, a study by Hastings and Johnson (2001) also indicated a significant correlation between parental stress and ASC symptom severity. However, in both studies by Duarte et al. (2005) and Hastings and Johnson (2001), the participants that were recruited were limited to parents seeking formal social support services for their children and are therefore not necessarily reflective of the general population of parents of autistic children who may have not sought any professional form of assistance. In contrast, other studies have found no significant link between parental stress and autism symptom severity (Estes et al., 2009; Ben-Sasson et al., 2013; Giovagnoli et al., 2015). For example, a study on the factors determining parental stress in parents of autistic children which consisted of participants recruited directly from the community, as opposed to participants recruited from a clinical sample, found that autism symptom severity was not linked to parental stress (Hastings et al., 2006). Similarly, a study by Davis and Carter (2008) indicated that the core symptoms of autism such as deficits in social communication and repetitive and restricted behaviours did not significantly predict of parental stress either.

Importantly, a large number of studies on parental experiences caring for a child with ASC focuses predominantly on parental stress. Currently, there is a dearth in both qualitative and quantitative data exploring the nature of parental anxiety and depression as negative parental mental health outcome and the variables associated with them. Also, the majority of studies on parental mental health related to caring for a child with ASC have combined and investigated parental stress, anxiety and depression as a single outcome variable which could compromise the potential for research to clearly isolate and understand the specific variables that may contribute to each mental health construct independently (Falk et al., 2014). Considering that it is more likely that there are multiple contributing factors which affect

parental mental health, an analysis of several factors linked to parental mental health issues will be better able to effectively assess the experiences of parents caring for an autistic child.

While there has been an ample amount of research conducted on the various facets of ASC, little attention has been paid to the cultural implications of parental experiences caring for an autistic child (Daley, 2002; Mandell & Novak, 2005; Bernier et al. 2010). Since cultures around the world have varied perceptions towards mental health, including developmental disabilities such as ASC, it is particularly important to explore how ASC is understood and managed by parents in population samples from cultures that are somewhat understudied. As such, this study aimed to explore parental mental health associated with caring for an autistic child in Saudi Arabia.

The limited research on ASC in the Middle East, especially Saudi Arabia, has led to a number of significant issues in terms of understanding parental experiences associated with autism in the Arab context. These issues include the lack of statistical data on the incidence of ASC cases (Al-Salehi et al., 2009; Hussein et al., 2014), the very limited number of previous studies which explore multiple factors that are associated with parental mental health and ASC (Al-Salehi et al., 2009; Al-Ayadhi et al., 2013; Hussein et al., 2013) and the cultural stigma attached to mental health conditions (Alqahtani, 2012). These issues all hinder the ability of autism specialists and researchers from other countries from gaining a comprehensive understanding and a true representation of the parental experiences of raising a child with autism in the Arab region. Moreover, in order for parents of children with ASC to achieve the best possible outcomes for themselves and their children through adequate intervention methods, it is necessary for research to acknowledge both the universal biological aspects of ASC as well as the unique cultural aspects and perceptions that influence parental and societal attitudes towards autism.

As there are currently no existing studies exploring the underlying factors that may be associated with parental mental health issues such as stress, anxiety and depression as separate outcome variables a participant sample from Saudi Arabia, this study aims to explore how challenging child behaviour and ASC symptom severity affect parental stress, anxiety and depression in in parents of autistic children from Saudi Arabia. This is important as such studies can be regarded as being potentially impactful in assessing and portraying a more realistic experience of parents of children with ASC from different cultural contexts where an interplay of several variables is more likely to contribute to their mental health issues. Based on findings from previous literature on the factors associated with mental health issues in parents of children with ASC, it was hypothesized in this study that higher levels of reported challenging child behaviour will be positively associated with increased stress, anxiety and depression (e.g., Hayes & Watson, 2013; Wang et al., 2011; Dykens & Lambert, 2013). Moreover, this study hypothesized that higher levels of ASC symptom severity will be positively associated with increased stress, anxiety and depression (e.g., Duarte et al. 2005; Hastings & Johnson 2001; Hastings et al. 2005; Brobst et al., 2009; Hoffman et al., 2009; Lecavalier, Leone, & Wiltz, 2006). Furthermore, in line with a small number of studies which have investigated the overlap of some factors pertaining to stress, anxiety and depression in parents of autistic children, this study hypothesized that there will be an association between challenging child behaviour and ASC symptom severity (Lyons et al., 2010).

## **Method**

### **Participants**

An opportunity sample consisting of 128 parents from Saudi Arabia with at least one child with ASC completed this online survey exploring the relationship between challenging child behaviour, ASC symptom severity and stress, anxiety and depression. Participants'

details are shown in (Table.2.1). The sample criteria for this study were restricted to parents of children under the age of eighteen with ASC from Saudi Arabia.

## **Measures**

The online survey employed in this study consisted of a short demographic questionnaire as well as an Arabic translated version of three psychometric scales aimed at exploring the relationship between challenging child behaviour, autism symptom severity and parental stress, anxiety and depression. At the time of this study being conducted, an evaluated Arabic version of the (CCB and GARS-3) were not available and therefore the English version of the scales (Bourke-Taylor, Law, Howie & Pallant, 2013; Gilliam, 2014) were translated and validated. The translation of the two scales involved a forward-backward translation process between English and Arabic by two other independent native Arabic speakers and the translated versions of the scales were evaluated in terms of validity and reliability. A validated Arabic translation of Depression, Anxiety and Stress Scale (DASS-21; Lovibond & Lovibond, 1995; Moussa, Lovibond & Laube, 2001) was already available and indicated adequate validity and consistency (Ali et al., 2017).

*Demographic Questionnaire* Information in terms of the parent's and child's age, the parent's and child's gender were collected to outline the sample characteristics. Information on the parent's nationality was also collected in order to ensure that the participant fitted into the inclusion criteria for this study.

*The Depression Anxiety Stress Scale* (DASS-21; Lovibond & Lovibond, 1995) is a 21 item self-report scale that measures stress, anxiety and depression and was developed for use in non-psychiatric populations (Lovibond & Lovibond, 1995). This scale is not intended for a clinical diagnosis of any participant, but only employed in this study in order to detect symptoms of stress, anxiety and depression. The DASS-21 was chosen because it is relatively short with



questions that are direct and easily understood. Also, the DASS-21 is able to adequately discriminate between the three constructs of stress, anxiety and depression. The DASS-21 consist of three 7-item subscales, each measuring one of the constructs of stress, anxiety and depression on a 4-point Likert scale ranging from (0 = never, 1 = sometimes, 2 = often, 3 = always) and for scoring purposes, each score is multiplied by 2 to enable interpretation across all measures (Lovibond & Lovibond, 1995). The subscale for depression included questions 3,5,10,13,16,17,21 which assessed dysphoria, hopelessness, self-deprecation, anhedonia, lack of interest, devaluation and inertia. The subscale for anxiety included questions 2,4,7,9,15,19,20 which assessed subjective and situational anxiety, physical effects of a panic attack and autonomic arousal. The subscale for stress included questions 1,6,8,11,12,14,18 which assessed agitation, irritability, difficulty relaxing, impatience, nervous arousal and over-reactivity. The cut-off points for the stress subscale on the DASS-21 are 0-14 (normal), 15-18 (mild), 19-25 (moderate), 26-33 (severe), and > 34 (severe). As for the anxiety subscales the cut-off points are as 0-7 (normal), 8-9 (mild), 10-14 (moderate), 15-19 (severe) and >20 (extremely severe). For the depression subscale, the cut-off points are 0-9 (normal), 10-13 (mild), 14-20 (moderate), 21-27 (severe) and >28 (extremely severe) (Lovibond & Lovibond, 1995). The DASS-21 has been shown to be internally consistent and stable with a Cronbach's alpha =.85 (Henry & Crawford, 2005; Osman et al., 2012) and has been widely used in a large number of studies measuring stress, anxiety and depression. The DASS-21 has also been shown to have reasonable levels of validity compared to other similar self-report tools with a correlation of .49 to the Hospital Anxiety and Depression Scale (Musa, Ramli, Abdullah, & Sarkarsi, 2011) and a correlation of above .70 to the Beck Depression Inventory (Lovibond & Lovibond, 1995; Sahebi, Asghari, & Salari, 2004) and .49 for the Hospital Anxiety and Depression Scale (Musa, Ramli, Abdullah, & Sarkarsi, 2011). In this current study, the Arabic translated version of the DASS-21 (Moussa, Lovibond & Laube, 2001) was used and reliability

testing for this version reported a Cronbach's Alpha of  $=.84$ . Moreover, Cronbach's Alpha was calculated for the internal consistency of each subscale: Depression  $=.76$ , Anxiety  $=.80$  and Stress  $=.79$  in order to statistically analyze each mental health outcome of the DASS-21 as individual variables.

*The Child's Challenging Behaviour Scale* (CCBS-Version 2; Bourke-Taylor, Law, Howie & Pallant, 2013) is a 9-item scale for parents to report the difficult behaviours exhibited by their child who is diagnosed with a disability. This scale is often used in studies assessing parental mental health associated with caring for a child with disability (Bourke-Taylor, Law, Howie & Pallant, 2013). Parents are instructed to rate each item on the scale corresponding to a specific behaviour demonstrated by their children which they agree with using a four-point Likert rating scale (1 = strongly agree, 2 = agree, 3 = disagree, 4 = strongly disagree). The score ranges between 9 and 36, with higher scores representing more challenging child's behavior (Bourke-Taylor et al., 2017). The CCBS-Version 2 was initially developed by Bourke-Taylor, Howie and Law (2010) using a mixed method instrument design whereby qualitative and quantitative data was collected from (N=152) mothers of school aged children diagnosed with a disability. The psychometric evaluation of the scale indicated excellent internal consistency with a Cronbach's alpha value of  $.89$ . Since there was no existing Arabic version of the CCBS-Version 2, the original scale (Bourke-Taylor, Law, Howie & Pallant, 2013) was translated into Arabic using a forward-backward translation process. In this current study, reliability testing of the CCBS-Version 2 reported a Cronbach's Alpha of  $=.74$ .

*The Gilliam's Autism Rating Scale* (GARS-3; Gilliam, 2014) is a 58-item scale developed to identify persons with ASC and assess the severity of their symptoms. In 2014, the GARS-3 was recreated in order to reflect the most current perspectives on ASC in the (DSM-5). The scale consists of items describing the characteristic behaviors of individuals with ASC. The items are separated into 6 subscales: Restrictive and Repetitive Behaviors, Social Interaction,

Social Communication, Emotional Responses, Cognitive Style, and Maladaptive Speech. These subscales have been empirically determined to be valid for identifying and assessing the symptom severity of children with ASC. Items on the scale are scored on a 4-point Likert type scale. Responses include (1 = not at all like the individual, 2 = not much like the individual, 3 = somewhat like the individual, 4 = very much like the individual). The scores of each subscale are then combined in order to provide a total score known as the Autism Index. Following the Autism Index score calculation, a corresponding severity level can then be identified. The GARS-3 provides 4 levels of probability of having ASD: level 0 with an Autism Index  $\leq 54$ , “unlikely;” level 1 with an Autism Index between 55 and 70, requiring “minimal support;” level 2 with an Autism Index between 71 and 100, “very likely” and requiring substantial support; level 3 with an Autism Index  $\geq 101$ , “very likely,” and requiring very substantial support (Gilliam, 2014). The internal consistency reliability coefficients for GARS-3 exceed .85 and the Autism Indexes exceed .93. The GARS-3 test-retest reliability coefficients exceed .80 for subscales and .90 for the Autism Indexes and the interrater reliability intraclass coefficients exceed .80 and 0.84 for the Autism Indexes. Moreover, correlations of the GARS-3 scores with other widely used diagnostic tests for ASC are large or very large in magnitude (Gilliam, 2014). The GARS-3 measure was developed and normed on over 1,800 individuals diagnosed with ASC between the ages 3 to 22 in the United States and has been frequently used in research concerned with Autism symptom severity levels. Since there was no existing Arabic version of the GARS-3, the original scale (Gilliam, 2014) was translated into Arabic using a forward-backward translation process. In this current study, reliability testing of the GARS-3 reported a Cronbach’s Alpha of  $\approx .91$ .

## **Procedure**

Ethical approval to conduct this research project was obtained from the University of Lincoln Committee, U.K. The survey was created online using the Qualtrics software and a

survey distribution link was sent out to two ASC specific support groups for mothers in Saudi Arabia and two ASC learning centers and one ASC charity organization. All participants were taken to an information page which provided an overview of the study and explained that participation in this study is voluntary, and methods of data withdrawal were made clear. Participants were then directed to a tick-box consent form prior to the survey and no personal information was collected in order to guarantee data protection and anonymity. Participants were also taken to a debrief page upon completion of the survey which contained useful links on how to access local support in Saudi Arabia should they need it as well as the researcher's, supervisors' and university's contact details should they require more information about the study or wish to have their data withdrawn.

## **Data Analysis**

Data for each participant was scored for all measures in this study, giving a total DASS-21 (Lovibond & Lovibond, 1995) score as well as one for each subscale for stress, anxiety and depression separately. A total CCBS (Bourke-Taylor, Law, Howie & Pallant, 2013) score for challenging child behaviour was also calculated as well as a total score for GARS-3 (Gilliam, 2014) in order to determine the ASC symptom severity level. The examination of the raw dataset prior to analyzing the data showed 6.8% of responses containing missing item values. Multiple imputation was used to estimate the average missing values to ensure that all responses would be included in the study. The process of analyzing the data combined standard statistical methods as well as correlational analyses using IBM SPSS 25 for Windows (IBM Corporation, Armonk, NY, USA).

## **Results**

The total sample number for this study was (N=128) and standard descriptive calculations were conducted for the demographics of the study (Table.2.1). All participants in

this study were female. Results indicate that 76% of the children were male and 24% were female. As for the education level of the participants, 4% reported no educational qualification, 24% reported having a high-school degree, 23% reported some university but no degree, 41% reported having a bachelor's degree, 6% reported having a postgraduate degree and 2% reported having a vocational diploma. Descriptive statistics for the variables explored in this study were also calculated and are displayed in (Table.2.2).

The results for the outcome variables of stress, anxiety and depression were normally distributed. The results for stress indicated a mean of 24.63 (SD=9.19) with a minimum score of 4 and a maximum score of 40. The values of the stress scores show that 59.0% of participants experienced severe/extremely severe levels of stress associated with caring for a child with ASC. The anxiety scores show a mean of 21.43 (SD=10.05) with a minimum score of 2 and a maximum score of 43. The results of the anxiety scores indicate that 76.1% of participants experienced severe/extremely severe levels of anxiety associated with caring for a child with ASC. The results for the variable of depression showed a mean of 19.34 (SD=8.90) with a minimum score of 4 and a maximum score of 38. The depression scores indicate that 52.1% of participants experienced severe/extremely severe levels of depression associated with caring for a child with ASC.

The results for challenging child behaviour indicated a mean of 25.94 (SD=5.09) with a minimum score of 17 and a maximum score of 36. The values of the challenging behaviour scores show that 91.5% of participants rated their child's behaviour as challenging. The autism symptom severity scores show a mean of 2.23 (SD=.42) with a minimum score of 2 and a maximum score of 3. The results of the autism symptom severity scores indicate that 77.3% of participants have a child with Level 2 Autism (requiring substantial support) and 22.7% of parents reported that their child would be considered as having Level 3 Autism (requiring very

substantial support). There were no reports of Level 1 Autism (requiring minimal support) in this present study.

**Table 2.1**

*Descriptive statistics for demographic questions*

	N	MEAN	SD	MIN	MAX
Age of Child	128	8.15	3.00	4.00	17.00
Age of Mother	128	35.80	6.50	24.00	55.00

**Table 2. 2**

*Descriptive statistics for stress, anxiety, depression, challenging child behaviour and autism symptom severity*

	N	MEAN	SD	MIN	MAX
Stress	128	24.63	9.19	4.00	40.00
Anxiety	128	21.43	10.04	2.00	43.00
Depression	128	19.34	8.90	4.00	38.00
Challenging Child Behaviour	128	25.94	5.09	17.00	36.00
Autism Symptom Severity	128	2.23	.42	2.00	3.00

Stress, Anxiety and Depression, *Depression, Anxiety and Stress Scale: DASS- 21*; Challenging Child Behaviour, *Child's Challenging Behavior – CCBS (Version 2)*; Autism Symptom Severity, *Gilliam Autism Rating Scale- Third Edition GARS-3*

A bivariate correlation was conducted to examine the relationship between all the study variables (Table.2.3). Pearson's Correlation results showed a moderate positive significant correlation between the outcome variable of stress and challenging child behaviour ( $r = .50$ ,  $N = 128$ ,  $p < .001$ ) indicating that an increase in challenging child behaviour is linked to an increase in stress. The results also indicated a weak positive significant correlation between stress and ASC symptom severity ( $r = .34$ ,  $N = 128$ ,  $p < .001$ ). Additionally, the variable of stress

had a moderate positive significant correlation with both of the other outcome variables of anxiety ( $r = .63$ ,  $N = 103$ ,  $p < .001$ ) and depression ( $r = .60$ ,  $N = 103$ ,  $p < .001$ ) indicating that an increase in stress is associated with an increase in anxiety and depression.

Correlational analyses also showed a weak positive significant correlation between the outcome variable of depression and challenging child behaviour ( $r = .44$ ,  $N = 128$ ,  $p < .001$ ). Similarly, there was a weak positive significant correlation between depression and ASC symptom severity ( $r = .30$ ,  $N = 128$ ,  $p < .001$ ). There was also a weak positive significant correlation between the two variables of challenging child behaviour and ASC symptom severity ( $r = .42$ ,  $N = 128$ ,  $p < .001$ ). Pearson's Correlation results showed a weak positive significant correlation between anxiety and challenging child behaviour ( $r = .41$ ,  $N = 128$ ,  $p < .001$ ) suggesting that an increase in challenging child behaviour pertains to an increase in anxiety. Moreover, there was a weak positive significant correlation between anxiety and ASC symptom severity ( $r = .35$ ,  $N = 128$ ,  $p < .001$ ) which shows that an increase in the severity of ASC symptoms increases the level of anxiety. Furthermore, results also indicate a strong positive significant correlation between anxiety and depression ( $r = .62$ ,  $N = 128$ ,  $p < .001$ ) suggesting that an increase in anxiety is associated with an increase in depression.

**Table 2.3**

*Correlations between stress, anxiety, depression, challenging child behaviour and autism symptom severity*

	Stress	Anxiety	Depression	Challenging Child Behaviour	Autism Symptom Severity
Stress	1.00				
Anxiety	.63**	1.00			
Depression	.60**	.62**	1.00		
Challenging Child Behaviour	.50**	.41**	.44**	1.00	

Autism Symptom Severity	.34**	.50**	.30**	.42**	1.00
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Stress, Anxiety and Depression, *Depression, Anxiety and Stress Scale: DASS- 21*; Challenging Child Behaviour, *Child's Challenging Behavior – CCBS (Version 2)*; Autism Symptom Severity, *Gilliam Autism Rating Scale- Third Edition GARS-3*

Significance - \*\* $p < 0.01$ , \* $p < 0.05$

In order to explore the contribution that challenging child behaviour and ASC symptom severity had on the outcome variables of stress, anxiety and depression, three linear regressions were conducted. The first regression analysis was conducted between the potential predictor variables of challenging child behaviour, autism symptom severity and the outcome variable of stress. The model explained 27.5% of the variance and was significant ( $F(2,125) = 23.00$ ,  $p < .001$ ). Regression analysis indicated that ASC symptom severity was the only predictor of parental stress ( $\beta = .21$ ,  $p < .001$ ). Secondly, another regression analysis was conducted to determine whether higher levels of parental anxiety were predicted by higher levels of challenging child behaviour or ASC symptom severity. The model explained 30.9% of the variance and was significant ( $F(2,125) = 29.40$ ,  $p < .001$ ). Regression results indicated that ASC symptom severity was the only significant predictor of higher levels of anxiety in parents of children with ASC ( $\beta = .33$ ,  $p < .001$ ). Finally, a regression analysis was conducted in order to determine whether higher levels of parental depression was predicted by challenging child behaviour or ASC symptom severity. The model explained 19.3% of the variance and was significant ( $F(2,125) = 16.20$ ,  $p < .001$ ). Regression results indicated that ASC symptom severity was the only significant predictor of higher levels of reported depression in parents of children with ASC ( $\beta = .38$ ,  $p < .001$ ).

## Discussion

The principle aim of this study was to explore whether challenging child behaviour and ASC symptom severity are associated with parental mental health problems, specifically:



stress, anxiety and depression in parents of autistic children from Saudi Arabia. Four key findings emerged from this study. Firstly, the majority of participants in this study reported extremely high levels of stress, anxiety and depression, well above the population mean. Secondly, as predicted, a significant association between challenging child behaviour and ASC symptom severity was found, which gives credence to previous studies that suggest the presence of an overlap between these two factors (Lyons et al., 2010). Thirdly, as predicted, ASC symptom severity was strongly associated with parental stress, anxiety and depression. Fourthly, as expected, challenging child behaviour was significantly associated to parental stress, anxiety and depression, however, challenging child behaviour did not predict any of the parental mental health outcomes.

The results support the findings from a relatively significant number of previous studies indicating that parents of children with ASC often report high levels of stress, anxiety and depression (e.g., Dabrowska & Pisula, 2010; Estes et al., 2013; Hayes & Watson, 2013; Wang et al., 2011; Dykens & Lambert, 2013; Weiss, 2002; Stein et al., 2011; Kuusikko-Gauffin et al., 2013; Falk et al., 2014). The results also, to some extent, support previous studies suggesting that challenging child behaviour and ASC symptom severity are associated with parental stress, anxiety and depression (Tomanik et al., 2004; Osborne & Reed, 2009; Estes et al., 2013; DePape & Lindsay 2014; Weiss et al. 2006). However, the combination of findings in this study allude to other potential factors at play considering that challenging child behavior did not predict any of the parental mental health issues explored in this study (i.e., stress, anxiety, depression).

This study aimed to explore the impact challenging child behaviour had on levels of stress, anxiety and depression in parents of autistic children in Saudi Arabia. The majority of the mothers that took part in this study reported high levels of challenging child behaviour with results well above the cut-off score. This finding is consistent with previous studies that

suggests that a relatively large number of children diagnosed with ASC tend to exhibit clinically significant difficult behaviors that are usually long lasting and are developed at an earlier age in comparison to typically developing children (Roberts, Mazzucchelli, Taylor & Reid; 2003, Rzepecka et al. 2011). The presence of challenging behaviors exhibited by autistic children can have a substantially negative impact on parental wellbeing as behavioural issues tend be demanding and include the need for implementing specific and unique routines, aversions to certain stimuli, managing various inappropriate behaviour in public and preventing self-harm behaviour (APA, 2013). In support of this, a study by Keller and Fox (2009) found that children with ASC were reported to exhibit more frequent and intense behavioural problems (e.g., issues during mealtimes, aggression, sleep disturbances and temper tantrums) as opposed to the children that did not meet the autism diagnostic criteria, which subsequently resulted in parents of autistic children reporting higher levels of psychological distress.

Results from this study have shown a strong relationship between challenging child behaviour and parental stress, anxiety and depression suggesting that an increase in challenging child behaviour is associated with an increase in parental mental health issues. These findings are consistent with a multitude of previous studies which have shown that child behaviour problems were strongly associated with stress, anxiety and depression in parents (Lecavelier, Leone & Wiltz, 2006; Gabriels et al., 2005; Davis & Carter, 2008). However, the results from this study did not show challenging child behaviour to be a significant predictor of parental mental health issues despite the correlation results.

Another aim in this study was to explore the impact ASC symptom severity had on levels of stress, anxiety and depression in parents of autistic children in Saudi Arabia. In line with a considerable number of authors who have argued that ASC symptom severity is the primary predictor of stress, anxiety and depression in parents caring for a child diagnosed with ASC (e.g., Duarte et al. 2005; Hastings & Johnson 2001; Hastings et al. 2005; Brobst et al.,

2009; Hoffman et al., 2009; Lecavalier, Leone, & Wiltz, 2006; Lyons et al., 2010; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2013; Konstantareas & Papageorgiou, 2006; Wang et al., 2013; Osborne & Reed, 2009; Zaidman-Zait et al., 2014), results from this study have also found a significant association between ASC symptom severity and parental mental health issues. In contrast to the hypothesis, challenging child behaviour did not predict higher levels of parental stress, anxiety or depression. However, it can be suggested that there might be a number of other protective factors (e.g., social support, resilience, self-efficacy, mindfulness) which could be acting as a buffer against parental stress and depression which need to be explored in future research.

This study has shown that there is a strong association between parental mental health issues and both ASC symptom severity. However, after further investigating these associations, it appeared that the relationship between ASC symptom severity and parental mental health issues was the only one to remain significant. Despite this, some studies suggest that child behaviour problems specific to children diagnosed with ASC may predict, to some extent, parental stress and anxiety (Hastings, 2003; Hastings et al., 2005). Such findings imply that, in line with literature (Tomanik et al., 2004; Herring et al., 2006; Lecavalier et al., 2006; Osborne & Reed, 2009; Estes et al., 2013), challenging child behaviour may significantly increase parental stress, thus creating an environment that is more conducive to experiences of associated parental anxiety. However, studies exploring the underlying mechanisms of this dynamic are very limited and factors associated with parental anxiety specifically linked to caring for a child with ASC remain overlooked and largely inconclusive.

In line with literature, this study hypothesized the presence of an association between both challenging child behaviour and ASC symptom severity. Results indicated a strong relationship between challenging child behaviour and ASC symptom severity which supports some studies that have previously suggested the existence of an overlap between these two

factors (Lyons et al., 2010, Matson et al., 2008). To a certain extent, studies have consistently emphasized the existing link between high levels of parental stress, anxiety and depression and ASC-specific symptoms. These include repetitive behaviours, poor social skills, lack of communication skills, and ASC symptom severity in general (Estes et al., 2009; Hastings & Johnson, 2001; Hoffman, et al., 2008; Ingersoll & Hambrick, 2010). However, other studies have also indicated that high levels of stress, anxiety and depression have also been heavily linked to other child related factors that are not ASC-symptom specific such as the presence of challenging child behaviour in general that are also commonly observed and recorded in other childhood disorders and are not specifically unique to children with ASC. The positive association seen in the results of this study between challenging child behaviour and ASC symptom severity could be indicative of an overlap between behavioral profiles. Some studies have attempted to develop a differential behavioural profile between children diagnosed with ASC and children diagnosed with other behavioural disorders such as Attention Deficit Hyperactivity Disorder (ADHD), Conduct Disorder (CD) and other learning disorders (Donenberg & Baker, 1993; Dumas, Wolf, Fisman, & Culligan, 1991; Efstratopoulou et al., 2012) however there is still some difficulty in isolating the specific behaviours related to ASC symptoms and the overall difficult externalized behaviours of children which tend to overlap to some extent (Lyons et al., 2010, Matson et al., 2008).

Considering the impact cultural views have on reported parental mental health as well as intervention seeking behaviours (Daley, 2002; Mandell & Novak, 2009; Bernier et al. 2010), research studies with participant samples from differing cultural backgrounds are essential for a more evolving and all-inclusive understanding of the varying parental experiences of caring for a child with ASC. This study focused on parents of autistic children from Saudi Arabia. Research on parental stress, anxiety and depression associated with caring for an autistic child in Saudi Arabia is significantly limited. This could be due to the lack of existing data on ASC

in the region as well as the prevalent cultural perceptions of mental health in Saudi Arabia. Firstly, across Saudi Arabia, there is a lack of awareness and understanding of ASC in general (Al-Salehi et al., 2009). Secondly, there is an issue of social stigma associated with mental health conditions which causes a reluctance for people to seek professional assistance. Thirdly, there is a lack of effective intervention services for both parent and child which are tailored to the specific cultural context of Saudi Arabia. Lastly, it is important to highlight the hesitancy of parents of children diagnosed with ASC to readily express their views and concerns due to mental health issues being considered a taboo topic. Consequently, the ability for research to accurately assess and evaluate the actual scope of the issue in that particular region is somewhat hindered.

There are several limitations to note in this study. Firstly, the measures in this study are self-report measures which could be prone to social desirability biases and participants who are experiencing high levels of stress, anxiety and depression could perceive their child's behaviour or ASC symptom severity as more problematic (Bennett et al., 2012; Beurkens et al., 2013). Moreover, quantitative data using a 5-likert-scale can only provide close-ended information and does not explain why participants chose their responses (Creswell & Clark, 2007) Secondly, due to the size of the sample and the geographical specificity and the overrepresentation of gender in the participant sample, the results are limited in their generalizability and the lacking in sample size may be due to the recruitment method or indirect method of communication. In order to address some of the cultural concerns regarding the discussion of mental health, this study utilized the anonymized survey method, whereby parents of children with ASC will be more likely to take part in the study with less hesitation. Although employing online surveys are convenient and can be easily accessed, it is a possibility that the participants were limited to those with access to the internet who are either technologically competent or socio-economically advantaged. Thirdly, due to the correlational

nature of the present study, no causal inferences or explanations can be made with regards to the variables affecting stress, anxiety and depression. Finally, factors including Saudi Arabia's cultural attitudes towards mental health in general and ASC specifically should be considered. Nevertheless, results from this current study could serve as a stepping-stone by contributing to the limited existing quantitative research on parental stress, anxiety and depression in Saudi Arabia and also contribute to the development of effective intervention methods and coping mechanisms that are culturally relevant for parents of children with ASC.

Considering the continual increase in the prevalence of ASC worldwide (Blumberg et al., 2012; Neggers, 2014; Sun & Alison, 2010; Tsai, 2014), it is expected that the prevalence of parents who must cope with the stressors of caring for a child with ASC is likely to continue to increase accordingly. Despite literature indicating that parents of children with ASC experience a wide range of chronic stressors, they oftentimes differ in their perception and responses to the challenges associated with caring for their child. Therefore, it is important for future research to further explore how challenging child behaviour and ASC symptom severity influence parental mental as a lack of clear understanding of these factors could deem the support given to these parents ineffective. Future research should also explore this relationship using longitudinal research methods as well as a larger sample size and potentially employ more sophisticated modelling procedures as a means to investigate more complex transactional models that consist of potential predictor and mediating variables that influence the high rates of reported parental stress, anxiety and depression.

### **Conclusion**

This study aimed to address the following issue. Parents of autistic children face a variety of unique challenges and experience higher levels of mental health issues in comparison to parents of typically developing children and parents of children with different disorders. An attempt was made in this study to understand the underlying factors that potentially influence

the high prevalence of stress, anxiety and depression in this parental group and to explore whether stress, anxiety and depression are associated with similar factors commonly suggested by previous literature conducted in Western countries in parents from a different cultural background, specially from Saudi Arabia. This study revealed that although challenging child behaviour and ASC symptom severity impacted levels of parental mental health to some extent, only ASC symptom severity predicted higher levels of parental stress, anxiety and depression.

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## Chapter 3: Autism, Affiliate Stigma and Parental Mental Health in Saudi Arabia

### Abstract

**Objective:** Studies suggest that parents of autistic children report high levels of stress, anxiety and depression as a result of the stigma they experience associated with having an autistic child. This experience of affiliate stigma is often internalized resulting in high psychological distress and has a negative effect on the overall wellbeing of the parent and child as well as the likelihood of seeking intervention. The aim of this study is to explore the relationship between parental stress, anxiety, depression, affiliate stigma and autism symptom severity.

**Method:** 128 participants from Saudi Arabia were recruited via opportunity sampling to complete an online survey. The survey consisted of demographic questions, The Depression, Anxiety and Stress Scale (DASS- 21), The Affiliate Stigma Scale (ASS) and The Gilliam Autism Rating Scale (GARS-3).

**Results:** Correlational analyses indicated a significant positive association between affiliate stigma and stress, anxiety, depression and autism symptom severity. Results also showed a significant positive correlation between autism symptom severity stress, anxiety and depression. Regression analysis indicated that the only significant predictor of parental mental health issues was affiliate stigma.

**Conclusion:** Affiliate stigma is a key factor in predicting high levels of stress, anxiety and depression in parents of autistic children in Saudi Arabia. Results imply that there is an urgent need for intervention providers to develop methods that tackle affiliate stigma effectively.

*Key Words:* Autism, Stress, Anxiety, Depression, Affiliate Stigma, Saudi Arabia

### Introduction

Autism is classified as a complex and pervasive multifactorial neurodevelopmental disorder (Diagnostic and Statistical Manual of Mental Disorders (DSM-5), 2013) that is generally characterized by impairments in communication, and social interaction as well as the presence of restrictive and repetitive behavioural patterns (APA, 2013). Children diagnosed with ASC tend to experience a complex and idiosyncratic array of emotional, behavioural and social difficulties that cause considerable and continual concerns for parents. Consequently, parents of autistic children tend to be at a higher risk of developing stress disorders, anxiety disorders and depression (Hastings, 2003; Tomanik et al., 2004; Lecavalier et al., 2006). Usually, autistic children are also diagnosed with other comorbid disorders (e.g., Attention Deficit Hyperactive Disorder (ADHD), sleep disorders, seizure disorders, metabolic disorders

and gastrointestinal disorders) (Bauman, 2010). The amalgamation of the possibility of existing comorbid disorders along with the chronic nature of ASC and its impairments can sometimes impact parents negatively by compromising their mental health and increasing their levels of stress, anxiety and depression. Consequently, poor mental health in parents results in further challenges associated with parenting an autistic child as a greater need for a more intricate wellbeing and support system for the child is typically needed.

Caring for an autistic child can usually be more challenging than caring for a typically developing child as autistic children tend to require a more parental support (Blacher & McIntyre, 2006), more behavioural management strategies as well as more financial resources (Beighton & Wills, 2017). According to literature, parents of autistic children are more likely to report higher levels of stress, anxiety and depression compared to parents of typically developing children (Hayes & Watson, 2013) and parents of children diagnosed with various other developmental conditions (Estes et al., 2013; Dabrowska & Pisula, 2010; Hayes & Watson, 2013). Several studies have suggested a number of potential factors which may contribute to the high levels of reported parental stress, anxiety and depression associated with caring for an autistic child. These include the child's challenging behaviours (Tomanik et al., 2004; Lecavalier et al., 2006; Fiske 2009; Gray, 2003), the severity of ASC symptoms (Osborne & Reed, 2009; Rivard et al., 2014; Duarte et al., 2005, Hastings & Johnson, 2001) and being subjected to social stigma (DePape & Lindsay 2014; Weiss et al. 2014; Farrugia, 2009). However, there is little consensus within the literature as to which particular factor, or combination of factors, significantly contribute to the consistently high levels of reported mental health issues. Despite this lack of agreement within the literature, it has however been well established that poor parental mental health has a significantly negative influence on parenting skills which can consequently negatively affect the child's mental health and overall development (Anthony et al., 2005).

Recently, the impact of stigma upon the mental health of parents of children with ASC has been receiving increasing recognition. According to a recent review, parents of autistic children often report encountering various forms of stigmatization related to their child's condition (Mitter et al., 2019). Consequently, these parents tend to experience mental health issues due to the stigma they experience (Crabtree, 2007; Green, 2007; Gray, 2002; Papadopoulos et al., 2018). Stigma is typically defined as a set of prejudicial attitudes and discriminatory behaviours upheld by one group against a discredited subgroup (Corrigan et al., 2000). According to Goffman (1963), stigma is a relationship between attribute and stereotype as well as a component reflecting notions of discredit and disgrace which could potentially distinguish and exclude a certain individual from others. According to Jones et al. (1998), stigma occurs when what has been termed as a “mark” becomes associated with the identity of an individual via an attributional process which discredits that specific individual rendering them subject to stigmatization.

In terms of autism, the presence of behavioural issues with the absence of an obvious physical “mark” makes ASC an invisible disorder (Gray, 1993). The display of such behavioural issues is often perceived by society as a result of poor parenting. Consequently, parents of autistic children often become subject to societal stigma. Therefore, stigma not only affects individuals with autism, but it can also affect their family members and caregivers (Mitter et al., 2019). Stigma related to autism that extends to parents and caregivers is known as ‘courtesy stigma’ whereby individuals closely affiliated with an individual with a stigmatic “mark” are subjected to negative reactions from the public as well (Abojabel et al., 2016; Koshorke et al., 2014; Zhou et al., 2018). With regards to autism, this includes members of society blaming parents for the onset of autism and the expectation that they should be ashamed of their lack of competence and ability to control their child's behaviour (Milacic-Vildojevic et al., 2012). This can then potentially lead to the social rejection of parents of children with



ASC (Gray, 1993; Corrigan et al., 2006). Moreover, as a result of repeated exposure to courtesy stigma, parents of children with ASC may develop “affiliate stigma” (Mak & Cheung, 2008) whereby the public’s negative reactions towards the child with ASC and their parent becomes accepted and internalized by the parent subsequently integrating these stereotypes into their own sense of identity (Papadopoulos, 2016). Furthermore, the self-stigmatization of these parents leads them to becoming more vulnerable to experiencing mental health issues such as stress, anxiety and depression (Mak & Cheung, 2008; Corrigan & Watson, 2002) and hinders their ability to cope with adversity or face the challenges associated with caring for their child (Jahoda & Markova 2004; Meyers et al., 2009).

Studies on the psychological impact of stigma have consistently presented significantly negative associations between stigma and mental health (Linl & Phelan, 2006). It has been well established in previous studies that consistent exposure to any form of stigma is linked to higher levels of stress, anxiety, depression, lower life satisfaction and overall mental health problems (Clark et al., 1999; Paradies, 2006; Pascoe & Sutin, 2015; Williams et al., 2003). A large number of studies have found affiliate stigma to be a significant correlate of poor mental health among parents of children with developmental conditions (Chiu et al., 2013; Banga et al., 2016; Dalky et al., 2017; Kim-Wan et al., 2016; Kwok et al., 2014; Magana et al., 2007; Mikami et al., 2014), however, according to Werner and Schulman (2013), parents of autistic children were found to be the most negatively impacted by affiliate stigma compared to parents of children with other developmental disorders. Parents who experience affiliate stigma often react by concealing their situation from others, withdrawing from social relations and engagements and sometimes alienating themselves from their child (Mak & Cheung, 2008; Mak et al., 2011; Grover et al., 2017). According to Lowell and Wetherell (2018), the internalization of stigma leads to feelings of rejection, devaluation, shame and low self-esteem which can consequently reduce positive parenting behaviours, thus compromising the

wellbeing of the child. Previous research suggests that experiences of stigma is severe and relatively prevalent among parents of autistic children (Gray, 1993; Farrugia, 2009; Mak and Kwok, 2010; Wong et al., 2016) and has been recently identified as a significant predictor of poor mental health in parents of autistic children specifically (Mitter et al., 2012; Cantwell et al., 2015; Chan and Lam, 2017; Chou et al., 2009; Green, 2003; Mak and Kwok, 2010; Wong et al., 2016).

For example, a study conducted by Gray (2002) found that parents of autistic children reported high levels of anxiety and depression, with over a third of these parents receiving psychotherapy and medication in order to cope. Gray (2002) interpreted that this was mostly due to negative public stigma felt by the parents as well as their experience of courtesy stigma from extended family members whereby the parent's child raising skills were constantly criticized. Another study conducted by Kinnear et al. (2015) on the effect of autism stigma found that parents of autistic children who were exposed to stigma reported poor mental health and expressed a strain on their relationship with their child. Moreover, a recent systematic review conducted by Papadopolous et al. (2019) looking at studies on parents of autistic children and stigma found a significant link between parental experiences of stigma and poor mental health, specifically autism stigma being linked to parental depression (e.g., Crabtree, 2007; Gray, 2002; Dababnah & Parish, 2013; Chan & Lam, 2017, 2018; Ting et al., 2018), reports of parental anxiety (Gray, 2002; Chan & Lam, 2017), psychological distress (Gray, 2002; Wong et al., 2016; Broady et al., 2018; Mak & Kwok, 2010; Werner & Shulman, 2013; Dababnah & Parish, 2013) and general poor mental health (Dehvani et al., 2011). Notably, a significant link between parental stress, anxiety, depression and stigma associated with caring for an autistic child has been well established in a multitude of studies with varying study designs and a range of socio-demographic and cultural contexts (e.g., Blanche et al., 2015; Broady et al., 2017; Byrne et al., 2018; Gill & Liamputtong, 2011; Gobrial, 2018; Gona et al.,

2016; Gray, 2002; Ha et al., 2014; Ijalba, 2016; Manor-Binyamini & Shoshana, 2018; Minhas et al., 2015; Neely-Barnes et al., 2011; Lowell & Wetherell, 2018; Mak & Kwok, 2010; Minhas et al., 2015). Despite the variation in the rigor of these studies, it is still clearly evident that an association between affiliate stigma and poor parental mental health among parents of autistic children exists.

Another factor frequently mentioned in previous studies which tends to be associated with high levels of stress, anxiety and depression reported by parents of autistic children is ASC severity (Osborne & Reed, 2009; Rivard et al., 2014; Duarte et al., 2005; Hastings & Johnson 2001). Although there are a number of existing studies within the literature on parental stress, anxiety and depression associated with caring for a child diagnosed with ASC which have found a positive correlation between ASC symptom severity and parental mental health issues (e.g., (Liwag, 1989; Foronda, 2000; Nikmat et al., 2008; Charnsil & Bathia, 2010; Yeo & Lu, 2012; Athari et al., 2013; Wisessathorn et al., 2013; Lai et al., 2015; Ilias et al., 2016), there is still a lack of consensus within the literature as to which factor or combination of factors is the most significant contributor to parental stress, anxiety and depression. Interestingly, a relatively significant number of studies have noted that the majority of parents reported concerns that the challenging behaviour of their autistic child were socially embarrassing. They also expressed that it was these ASC-specific behaviours that contributed the most to their experience of stigma (e.g., Blanche et al., 2015; Byrne et al., 2018; Gill & Liamputtong, 2011; Gobrial, 2018; Gona et al., 2016; Gray, 2002; Ha et al., 2014). Consequently, these parents also claimed that they tended to prevent their children from socializing with others as they feared their child would act inappropriately in a social setting. Although autism stigma has been well established as a significant factor pertaining to parental stress, anxiety and depression (Cantwell, Muldoon, & Gallagher, 2015; Chan & Chan & Lam, 2018; Green, 2003; Mak & Kwok, 2010), when it comes to children with higher ASC severity, reports of parental stress,

anxiety and depression tends to be higher as the inappropriate behaviour of the child (i.e., restricted and repetitive movements such as spinning, hand flapping, twirling, throwing tantrums, and engaging in self-destructive acts) becomes more frequent and intense (Estes et al., 2013; Herring et al., 2006; Illias, Cornish, Kummar, Park, & Golden, 2018; Lecavalier, Leone, & Wiltz, 2006; Osborne & Reed, 2009; Tomanik, Harris, & Hawkins, 2004). As such, it can be suggested that parents of children with higher ASC symptom severity tend to experience stigma more frequently (Farrugia 2009), which in turn becomes internalized and develops into affiliate stigma as a result of the repeated exposure to stigma (Mak & Cheung, 2008).

It is also important to note that knowledge on and the understanding of autism varies across cultures (Obeid et al., 2015). Considering that different cultural groups may have different perceptions about autism, it is critical to research the effect of affiliate stigma on parents of autistic children from different cultural backgrounds in order to gain a more comprehensive understanding on the experience of raising a child with autism in different parts of the world. According to Papadopoulos (2016), there is a significant difference in how stigma manifests itself in collectivist group-based cultures as opposed to individualist cultures. For instance, studies conducted by Ting et al. (2018) and Chiu et al. (2013) on the experience of affiliate stigma in parents of autistic children from China (collectivist culture) found that parents were particularly vulnerable to affiliate stigma, social rejection and isolation due to the sense of shame they felt as a result of having an autistic child. Similarly, a study by Dababnah and Parish (2013) exploring the stigma associated with parents of autistic children in Palestine (collectivist culture) also found that these parents tended to avoid socialization due to the stigma they faced from the community as well as extended family members which led to parental experiences of shame and subsequently social withdrawal. On the other hand, studies conducted in Western countries (individualist culture) did not note this specific type of affiliate

stigma which tends to be rooted in the feeling of shame as seen in a collectivist cultural context. For example, a study by Broady et al. (2018) on parents of autistic children from Australia found that parents were more likely to report feelings of hurt as a result of experiencing stigma as opposed to feelings of shame.

Although supporting a child with ASC can have a significant impact on parents despite their cultural background (Rose 2014; Vanegas & Abdelrahim 2016), the intricacy of this impact is not yet well understood across varying cultures since the bulk of research on the mental health of parents of autistic children is typically conducted in Western countries (Elsabbagh et al., 2012, Daley, 2002). For example, there are a very limited number of studies exploring autism stigma and parental wellbeing with a sample from an Arab culture (e.g., Al-Farsi et al., 2016; Almansour et al., 2013; Dababnah & Bulson, 2015). Nonetheless, these studies have indicated that parents of autistic children from an Arabian cultural background tend to experience additional stressors when caring for their child due to cultural perceptions of ASC as well as mental health issues in general being considered a taboo topic. According to Dababnah and Parish (2013), stigma surrounding disabilities in Arab communities is particularly salient. This is partially due to the direct social consequences faced by families as a result of having a family member with a disability. As a result, families tend to remain secretive about other family members with a mental health condition or disability and avoid attending social occasions where they may be seen by the public in fear of being stigmatized (Dardas & Ahmad, 2014; Donovan, 2013). Moreover, according to Fido and Saad (2013), Arab mothers in particular tend to experience high levels of stress, internalized shame and guilt caring for an autistic child due to the emphasis and importance that the Arabian culture places on the maternal role in the family with regards to the child's outcome. As such, the stigma associated with any form of disability or developmental condition negatively impacts the entire

family and also makes the idea of seeking support from mental health professionals a last resort (Dardas & Simmons, 2015; Abu-Ras, 2016; Kuaidar, 2005).

Considering the prevalence of mental health stigma within the Arab culture, this research aims to explore the effect of affiliate stigma and ASC symptom severity on parental stress, anxiety and depression specifically in Saudi Arabia. There is hardly any existing quantitative research that has been conducted in Saudi Arabia which explores multiple factors that are associated with parental mental health and ASC, and very few qualitative studies conducted on parental experiences of ASC in general (e.g., Al-Salehi et al., 2009; Alqahtani, 2012; Al-Ayadhi et al., 2013; Hussein et al., 2013). Presently, there are no studies conducted on parents of children with ASC in Saudi Arabia which explore the effects of affiliate stigma on parental mental health. The lack of research conducted on this particular population sample hinders the ability of ASC specialists and researchers from gaining a comprehensive understanding and a true representation of the parental experiences of raising a child with ASC in Saudi Arabia. Moreover, in order for parents of children with ASC to achieve the best possible outcomes for themselves and their children, it is necessary for research to explore the unique cultural aspects and perceptions that influence parental and societal attitudes towards ASC. Also, some of the studies on parental mental health and affiliate stigma have parental stress, anxiety and depression as a single outcome variable which could limit the potential for research to clearly isolate and understand how affiliate stigma may contribute to each mental health construct independently (Falk et al., 2014). Considering that it is more likely that there are multiple contributing factors which affect parental mental health in the real world outside a research setting, a comparative analysis of the factors linked to parental mental health issues will be better able to adequately assess the experiences of parents caring for a child with ASC in Saudi Arabia.

Currently, there are no such that have been conducted exploring affiliate stigma in conjunction with ASC symptom severity and parental mental health using a participant sample from Saudi Arabia. This study aims to explore how affiliate stigma and ASC symptom severity affect parental stress, anxiety and depression in parents of autistic children from Saudi Arabia. This is important as such studies can be regarded as being potentially impactful in assessing and portraying a more realistic experience of parents of children with ASC from different cultural contexts where an interplay of several variables is more likely to contribute to the increase in their reported mental health. Based on findings from previous literature on the factors associated with mental health issues in parents of children with ASC, it was hypothesized in this study that higher levels of affiliate stigma will be positively associated with increased stress, anxiety and depression (e.g., Chiu et al., 2013; Banga et al., 2016; Dalky et al., 2017; Kim-Wan et al., 2016; Kwok et al., 2014; Magana et al., 2007; Mikami et al., 2014). Moreover, this study hypothesized that in line with a small number of studies which have investigated the effect of affiliate stigma on parents of children with ASC, there will be an association between affiliate stigma and ASC symptom severity (Ting et al., 2018, Patra & Patro, 2019).

## **Method**

### **Participants**

The participant sample incorporated within the present study consisted of 128 parents from Saudi Arabia with at least one child diagnosed with ASC under the age of 18. Each participant from this opportunity sample was asked to complete an online survey exploring the relationship between affiliate stigma, ASC symptom severity and parental stress, anxiety and depression. Participants' details are shown in (Table.3.1).

## Measures

*Demographic Questionnaire* Information on the parent's and child's age and the parent's and child's gender as well as the parent's education level were collected to outline the sample characteristics. Information on the parent's nationality was also collected in order to ensure that the participant met the inclusion criteria for this study.

*The Depression Anxiety Stress Scale* (DASS-21; Lovibond & Lovibond, 1995) is a 21 item self-report scale that measures stress, anxiety and depression and was developed for use in non-psychiatric populations (Lovibond & Lovibond, 1995). This scale is not intended for the clinical diagnosis of any participant, but only used in this study to detect symptoms of stress, anxiety and depression. The DASS-21 was selected in this study as it is relatively short and consists of questions that are direct and easily understood. Importantly, the DASS-21 is able to effectively discriminate between the three constructs of stress, anxiety and depression. The DASS-21 consist of three 7-item subscales, each measuring one of the constructs of stress, anxiety and depression on a 4-point Likert scale ranging from (0 = never, 1 = sometimes, 2 = often, 3 = always). To score the DASS-21, each score must be multiplied by 2 to enable interpretation across all measures (Lovibond & Lovibond, 1995). The subscale for stress includes questions 1,6,8,11,12,14,18 which assess feelings of agitation, irritability, difficulty relaxing, impatience, nervous arousal and over-reactivity. The subscale for anxiety includes questions 2,4,7,9,15,19,20 which assess subjective and situational anxiety, physical effects of a panic attack and autonomic arousal. The subscale for depression includes questions 3,5,10,13,16,17,21 which assess dysphoria, hopelessness, self-deprecation, anhedonia, lack of interest, devaluation and inertia. The cut-off points for the stress subscale on the DASS-21 are 0-14 (normal), 15-18 (mild), 19-25 (moderate), 26-33 (severe), and > 34 (severe). As for the anxiety subscales the cut-off points are as 0-7 (normal), 8-9 (mild), 10-14 (moderate), 15-19 (severe) and >20 (extremely severe). For the depression subscale, the cut-off points are 0-9



(normal), 10-13 (mild), 14-20 (moderate), 21-27 (severe) and >28 (extremely severe) (Lovibond & Lovibond, 1995). The DASS-21 has been shown to be internally consistent and stable  $\alpha = .85$ . (Henry & Crawford, 2005; Osman et al., 2012) and has been widely used in a relatively large number of studies measuring stress, anxiety and depression. The DASS-21 has also been shown to have reasonable levels of validity compared to other similar self-report measures with a correlation of above .70 to the Beck Depression Inventory (Lovibond & Lovibond, 1995; Sahebi, Asghari, & Salari, 2004) and 0.49 for the Hospital Anxiety and Depression Scale (Musa, Ramli, Abdullah, & Sarkarsi, 2011). This study employed the existing Arabic translated version of the DASS-21 (Moussa, Lovibond & Laube, 2001). Reliability testing for this version reported a Cronbach's Alpha of =0.84. Moreover, the Cronbach's Alpha was calculated for the internal consistency of each subscale: Depression =.76, Anxiety =.80 and Stress =.79 in order to statistically analyze each mental health outcome of the DASS-21 as individual variables. In this study, reliability testing indicated high internal consistency  $\alpha = .84$ .

*The Affiliate Stigma Scale* (ASS; Mak & Cheung, 2008) is a 22-item scale developed to measure the cognitive, behavioural and affective components of affiliate stigma in parents and caregivers of people with mental illness or an intellectual disability (Mak & Cheung, 2008). This scale is often used in studies assessing the mental health of caregivers of children with ASC (Lowell & Wetherell, 2018). Parents are instructed to rate each statement (Cognitive = 7 items, Affect = 7 items, and Behaviour = 8 items) using a four-point Likert rating scale (1 = strongly agree, 2 = agree, 3 = disagree, 4 = strongly disagree). The score ranges between 22 and 88, with higher scores indicating higher levels of affiliate stigma. The score ranges between 22 and 88, with higher scores indicating higher levels of affiliate stigma. The higher the mean score on the Affiliate Stigma Scale, the higher the internalized stigma as there is no cut-off score (Mak & Cheung, 2008). Since there was no existing Arabic version of the Affiliate Stigma Scale, the original scale (Mak & Cheung, 2008) was translated into Arabic using a

forward-backward translation process. The psychometric evaluation of the scale in the original study indicated a high internal consistency  $\alpha = .94$  (Mak & Cheung, 2008) as well as in this current study  $\alpha = .86$ .

*The Gilliam's Autism Rating Scale* (GARS-3; Gilliam, 2014) is a 58-item scale developed to identify individuals with ASC and assess the severity of their symptoms. In 2014, the GARS-3 was redeveloped in order to reflect the most current perspectives on ASC in the (DSM-5). The scale is comprised of items describing the characteristic behaviors of individuals with ASC. These items are separated into 6 subscales: Restrictive and Repetitive Behaviors, Social Interaction, Social Communication, Emotional Responses, Cognitive Style, and Maladaptive Speech. The subscales have been empirically determined to be valid for identifying and assessing the symptom severity of Autistic children. Items on the scale are scored on a 4-point Likert scale. Responses include (1 = not at all like the individual, 2 = not much like the individual, 3 = somewhat like the individual, 4 = very much like the individual). The scores of each subscale are subsequently combined in order to provide a total score known as the Autism Index. Following the Autism Index score calculation, a corresponding severity level can then be identified. The GARS-3 provides 4 levels of probability of having ASD: level 0 with an Autism Index  $\leq 54$ , "unlikely;" level 1 with an Autism Index between 55 and 70, requiring "minimal support;" level 2 with an Autism Index between 71 and 100, "very likely" and requiring substantial support; level 3 with an Autism Index  $\geq 101$ , "very likely," and requiring very substantial support (Gilliam, 2014). The internal consistency reliability coefficients for GARS-3 exceed .85 and the Autism Indexes exceed .93. The GARS-3 test-retest reliability coefficients exceed 0.80 for subscales and .90 for the Autism Indexes and the interrater reliability intraclass coefficients exceed .80 and .84 for the Autism Indexes. Moreover, correlations of the GARS-3 scores with other widely used diagnostic tests for ASC are large or very large in magnitude (Gilliam, 2014). The GARS-3 measure was developed and normed on

over 1,800 individuals diagnosed with ASC between the ages 3 to 22 in the United States and has been regularly used in research concerned with Autism symptom severity levels. Since there was no existing Arabic version of the GARS-3, the original scale (Gilliam, 2014) was translated into Arabic using a forward-backward translation process. In this current study, reliability testing of the GARS-3 indicated a high internal consistency  $\alpha = .91$ .

## **Procedure**

Ethical approval to conduct this research project was obtained from the University of Lincoln Committee, U.K. The survey was developed online using the Qualtrics software. A survey distribution link was sent out to two ASC specific support groups for mothers in Saudi Arabia, two ASC learning centers and one ASC charity organization. All participants were directed to an information page which provided an overview of the study and emphasized that participation in this study is voluntary, and the process of data withdrawal was made clear. Participants were subsequently directed to a tick-box consent form prior to the survey and no personal information was collected in order to guarantee data protection and anonymity. Upon completion of the survey, participants were then taken to a debrief page which contained useful links on how to access local support in Saudi Arabia should they need it as well as the researcher's, supervisors' and university's contact details should they require more information about the study or wish to have their data withdrawn.

## **Data Analysis**

Data for each participant was scored for all measures in this study, giving a total DASS-21 (Lovibond & Lovibond, 1995) score as well as a score for each subscale measuring stress, anxiety and depression separately. A total ASS (Mak & Cheung, 2008) score for affiliate stigma was also calculated as well as a total score for GARS-3 (Gilliam, 2014) in order to determine the ASC symptom severity level. The examination of the raw dataset prior to

analyzing the data showed 5.2% of responses containing missing item values. Multiple imputation was used to estimate the average missing values to ensure that all responses would be included in the current study. The process of analyzing the data combined standard statistical methods as well as correlational analyses and regression analyses using IBM SPSS 25 for Windows (IBM Corporation, Armonk, NY, USA).

## Results

This study consisted of a total sample number of (N=128). All participants in the study identified as female. Results indicate that 76% of the children were male and 24% were female. As for the education level of the participants, 4% reported no educational qualification, 24% reported having a high-school degree, 23% reported some university but no degree, 41% reported having a bachelor's degree, 6% reported having a postgraduate degree and 2% reported having a vocational diploma. Standard descriptive statistical calculations were conducted for the demographics of the study and are displayed in (Table.3.1). Descriptive statistics for the variables explored in this study were also calculated and are displayed in (Table.3.2).

**Table 3.1**

*Descriptive statistics for demographic questions*

	N	MEAN	SD	MIN	MAX
Age of Child	128	8.15	3.00	4.00	17.00
Age of Mother	128	35.80	6.50	24.00	55.00

The results for the outcome variables of stress, anxiety and depression were normally distributed. The results for stress indicated a mean of 24.63 (SD=9.19) with a minimum score

of 4 and a maximum score of 40. The values of the stress scores show that 59.0% of participants experienced severe/extremely severe levels of stress associated with caring for a child with ASC. The anxiety scores show a mean of 21.43 (SD=10.05) with a minimum score of 2 and a maximum score of 43. The results of the anxiety scores indicate that 76.1% of participants experienced severe/extremely severe levels of anxiety associated with caring for a child with ASC. The results for the variable of depression showed a mean of 19.34 (SD=8.90) with a minimum score of 4 and a maximum score of 38. The depression scores indicate that 52.1% of participants experienced severe/extremely severe levels of depression associated with caring for a child with ASC.

The autism symptom severity scores show a mean of 2.23 (SD=.42) with a minimum score of 2 and a maximum score of 3. The results of the autism symptom severity scores indicate that 77.3% of participants have a child with Level 2 Autism (requiring substantial support) and 22.7% of parents reported that their child would be considered as having Level 3 Autism (requiring very substantial support). There were no reports of Level 1 Autism (requiring minimal support) in this present study. The results for the variable of affiliate stigma showed a mean of 58.09 (SD=17.63) with a minimum score of 32 and a maximum score of 84. The results for affiliate stigma showed a mean of 58.09 (SD=17.63) with a minimum score of 32 and a maximum score of 84. The results for ASC symptom severity showed a mean of 2.17 (SD=.38) with a minimum score of 2 and a maximum score of 3. The affiliate stigma scores indicate that 54.7% of participants experienced high levels of affiliate stigma.

**Table 3. 2***Descriptive statistics for stress, anxiety, depression, affiliate stigma and autism symptom severity*

	N	MEAN	SD	MIN	MAX
Stress	128	24.63	9.19	4.00	40.00
Anxiety	128	21.43	10.04	2.00	43.00
Depression	128	19.34	8.90	4.00	38.00
Affiliate Stigma	128	58.09	17.63	32.00	84.00
ASC Symptom Severity	128	2.23	.42	2.00	3.00

Stress, Anxiety and Depression, *Depression, Anxiety and Stress Scale: (DASS- 21)*; Affiliate Stigma, *the Affiliate Stigma Scale (ASS)*;  
Autism Symptom Severity, *Gilliam Autism Rating Scale- Third Edition (GARS-3)*

Bivariate correlational analyses were conducted to examine the relationship between all the study variables (Table.3.3). Correlation results showed a strong positive significant correlation between the outcome variable of stress and affiliate stigma ( $r = .64$ ,  $N = 128$ ,  $p < .001$ ) indicating that an increase in affiliate stigma is associated with an increase in stress. Moreover, results indicated a moderate positive significant correlation between the outcome variable of anxiety and affiliate stigma ( $r = .60$ ,  $N = 128$ ,  $p < .001$ ) suggesting that increased levels of affiliate stigma are associated with increased levels of parental anxiety. Furthermore, correlation results also indicated a moderate positive significant correlation between depression and affiliate stigma ( $r = .54$ ,  $N = 128$ ,  $p < .001$ ) indicating that higher levels of affiliate stigma are linked to higher levels of reported parental depression.

Results also indicated a weak positive correlation between stress and ASC symptom severity ( $r = .34$ ,  $N = 128$ ,  $p < .001$ ). Similarly, there was a weak positive correlation between depression and ASC symptom severity ( $r = .30$ ,  $N = 128$ ,  $p < .001$ ). Moreover, there was a moderate positive significant correlation between anxiety and of ASC symptom severity ( $r = .50$ ,  $N = 128$ ,  $p < .001$ ) which shows that an increase in the severity of ASC symptoms may

potentially increase the level of reported parental anxiety. Moreover, results indicated a moderate positive significant correlation between the ASC symptom severity and affiliate stigma ( $r = .51$ ,  $N = 128$ ,  $p < .001$ ) suggesting that the more severe the child's ASC symptoms are, the more affiliate stigma the parent experiences.

Additionally, as expected, correlational results indicated strong positive significant correlations between the variables of stress and anxiety ( $r = .63$ ,  $N = 128$ ,  $p < .001$ ), depression and stress ( $r = .60$ ,  $N = 128$ ,  $p < .001$ ) and anxiety and depression ( $r = .62$ ,  $N = 128$ ,  $p < .001$ ) supporting previous research indicating an interrelationship between these mental health issues (Bromley et al., 2004; Maxted et al., 2005; Davis & Carter, 2008).

**Table 3.3**

*Correlations between stress, anxiety, depression, affiliate stigma and autism symptom severity*

	Stress	Anxiety	Depression	Affiliate Stigma	ASC Symptom Severity
Stress	1.00				
Anxiety	.63**	1.00			
Depression	.60**	.62**	1.00		
Affiliate Stigma	.64**	.60**	.54**	1.00	
ASC Symptom Severity	.34**	.50**	.30**	.51**	1.00

Stress, Anxiety and Depression, *Depression, Anxiety and Stress Scale: (DASS- 21)*; Affiliate Stigma, *the Affiliate Stigma Scale (ASS)*; Autism Symptom Severity, *Gilliam Autism Rating Scale- Third Edition (GARS-3)*

Significance - \*\* $p < 0.01$ , \* $p < 0.05$

Considering that all mental health outcomes (stress, anxiety and depression) were associated with both ASC symptom severity and affiliate stigma, a series of linear regressions was conducted in order to explore which factor contributed the most to parental mental health issues. The first linear regression was conducted with the variable of stress as the dependent variable. The model explained 41.7% of the variance and was significant ( $F(2,125) = 44.62$ ,

$p < .001$ ). Regression results indicated that affiliate stigma was the only significant predictor of stress in parents of children with ASC ( $\beta = .60, p < .001$ ) and that ASC symptom severity did not predict parental stress. The second linear regression was conducted with the variable of anxiety as the dependent variable. The model explained 39.8% of the variance and was significant ( $F(2,125) = 41.40, p < .001$ ). Regression results indicated that affiliate stigma was the only significant predictor of anxiety in parents of children with ASC ( $\beta = .48, p < .001$ ) and that ASC symptom severity did not predict parental anxiety. The final linear regression was conducted with the variable of depression as the dependent variable. The model explained 35.8% of the variance and was significant ( $F(2,125) = 34.80, p < .001$ ). Regression results indicated that affiliate stigma was the only significant predictor of depression in parents of children with ASC ( $\beta = .60, p < .001$ ) and that ASC symptom severity did not predict parental depression.

### **Discussion**

The principle aim of this study was to explore how affiliate stigma and ASC symptom severity are associated with parental mental health issues, specifically: stress, anxiety and depression in parents of autistic children from Saudi Arabia. Five key findings emerged from this study. Firstly, consistent with previous findings, the majority of participants in this study reported high levels of stress, anxiety and depression, which was well above the population mean. Secondly, the majority of participants in this study also reported experiencing high levels of affiliate stigma. Thirdly, as predicted, a significant association between affiliate stigma and ASC symptom severity was found. Fourthly, as hypothesized, affiliate stigma was strongly associated with parental stress, anxiety and depression. Finally, although ASC symptom severity was shown to be associated with reports of parental stress, anxiety and depression, further statistical analyses had indicated that affiliate stigma was the only significant factor predicting parental mental health issues.



The results support findings from a relatively significant number of previous studies indicating that parents of children with ASC often report high levels of stress, anxiety and depression (e.g., Dabrowska & Pisula, 2010; Estes et al., 2013; Hayes & Watson, 2013; Wang et al., 2011; Dykens & Lambert, 2013; Weiss, 2002; Stein et al., 2011; Kuusikko-Gauffin et al., 2013; Falk et al., 2014). There are a number of previous studies on parental mental health issues associated with caring for an autistic child diagnosed which have found a positive correlation between ASC symptom severity and parental stress, anxiety and depression (Nikmat et al., 2008; Charnsil and Bathia, 2010). In this study, although ASC symptom severity correlated with parental mental health issues, ASC did not predict any of them. The combination of findings in this study with regards to the absence of a link between ASC symptom severity and parental stress, anxiety and depression may allude to other potential unexplored factors, such as challenging child behaviour or lack of social support, which may have an impact on the parental mental health outcomes (see chapter 3).

The results also give credence to previous studies which suggest that affiliate stigma acts as a significant contributor to stress, anxiety and depression in parents of children with developmental conditions (Mak & Cheung, 2008; Corrigan & Watson, 2002; Crabtree 2007; Green 2007; Gray 2002; Falk et al., 2014; Papadopoulos et al. 2018). Throughout the literature, autism stigma has been well established as a significant predictor of parental stress, anxiety and depression (Cantwell, Muldoon, & Gallagher, 2015; Chan & Chan & Lam, 2018; Green, 2003; Mak & Kwok, 2010). Previous studies have also shown that parents of children with higher ASC severity who exhibit more challenging behaviours, tend to report higher levels stress, anxiety and depression as opposed to parents of autistic children with less severe ASC symptoms (Estes et al., 2013; Herring et al., 2006; Illias, Cornish, Kummar, Park, & Golden, 2018; Lecavalier, Leone, & Wiltz, 2006; Osborne & Reed, 2009; Tomanik, Harris, & Hawkins, 2004). Although the majority of parents in this study reported experiencing high levels of

affiliate stigma, in accordance with the literature, this study found that parents of children with Level 3 Autism tended to report higher levels of affiliate stigma in comparison to parents of children diagnosed with Level 2 Autism. Thus, it can be suggested that parents of children with higher ASC symptom severity tend to experience more affiliate stigma (Farrugia 2009).

Since it has been well documented in the literature that parents of autistic children are at a higher risk of developing mental health issues in comparison to the general population (Da Pasz & Wallander, 2017; Zablotsky et al., 2013; Sander & Morgan, 1997), it is important to note that when parents experience poor mental health, the children they are caring for are also at a higher risk of experiencing a delay in their development (Osbourne et al., 2008; Dykens et al., 2014). Moreover, given that cultures around the world have varied perceptions towards mental health, including developmental disabilities such as ASC, it is particularly important to explore how autism is understood and managed by parents in population samples from cultures that are somewhat understudied. Parents' perception regarding their child's developmental condition among different cultural groups has been a focal point in recent literature (Daudji et al., 2011; Diken, 2006; García, Pérez, & Ortiz, 2000; Kermanshahi et al., 2008; Masasa, Irwin-Carruthers, & Faure, 2005). Such studies have highlighted the idea that developmental disabilities are perceived differently in every culture. Furthermore, these varying perceptions shaped parental perceptions towards their children as well as the time and resources these parents were willing to invest in terms of their child's treatment, education and social inclusion. As such, a cultural understating of autism is essential. According to Groce (1999), individuals with disabilities are not usually limited by their impairments but more so by the cultural interpretation of their condition. As such, it is important to understand what is normative within a particular culture with regards to developmental conditions such as ASC as parents from different cultural contexts may be impacted differently by their child's condition (Santos & Mccollum, 2007).

One of the main contributory factors for mental health issues among parents of autistic children is stigma. According to a study conducted by Kinnear et al. (2015) on 502 families of children with ASC, stigma associated with autism played a key role in the deterioration of parental mental health. Since parents of autistic children are particularly vulnerable to experiencing affiliate stigma (Mak and Cheung, 2008), whereby the public's negative attitudes towards the autistic child and parent becomes internalized by the parent, it is important to explore how affiliate stigma affects parents of autistic children from different cultural backgrounds, especially in parts of the world where parental mental health problems such as anxiety and depression also remain highly stigmatized (Papadopoulos 2016). According to Samadi and McConkey (2011), further research about the stigma faced by parents of children with ASC in developing countries is needed as the bulk of research on stigma is mostly limited to parents of children with ASC from Western countries. As such, there is a gap in the literature with regards to experiences of affiliate stigma amongst parents of autistic children from Arab countries including Saudi Arabia. Therefore, the aim of this study was to explore the relationship between parental mental health and affiliate stigma among parents of autistic children in Saudi Arabia. Research by Papadopoulos, Foster and Caldwell (2013) found that collectivist cultures were more likely to stigmatize individuals who deviate from the social norms compared to individualistic cultures. Seeing as Saudi Arabia is considered to be a collectivist culture, the impact of affiliate stigma on parents of children with ASC could therefore be particularly relevant in understanding their overall experiences of caring for an autistic child. Although some development has been made in Saudi Arabia in terms of mental health public awareness, the Saudi Arabian society still tends to marginalize individuals with disabilities and developmental conditions for several reasons such as the lack of awareness and knowledge regarding mental health conditions and the idea of shame associated with having a disability (Al-Jadid, 2014). Although there are currently no existing studies on affiliate stigma

experienced by parents of autistic children in Saudi Arabia, results from this study indicate that the majority of parents reported having experienced high levels of affiliate stigma which predicted their high levels of stress, anxiety and depression. Despite there being a relatively significant number of studies conducted on anxiety and depression in families with autistic children, studies on parental experiences of affiliate stigma are relatively few (Oz et al., 2020). For this reason, this study was conducted in order to explore how autism affiliate stigma affects parental mental health in the Saudi Arabian context. The results from this study could potentially provide professionals and future researchers with a better understanding of the stress, anxiety and depression that Saudi Arabian parents experience caring for their autistic child. This study could also help in informing care providers of the potential effects that affiliate stigma has on parental mental health which could improve the quality of care they deliver. Considering the importance of parental mental health in terms of supporting a child with ASC, culturally informed interventions targeting affiliate stigma, parental stress, anxiety and depression is somewhat necessary in order to ensure the overall wellbeing of both child and parent.

There are several limitations to note in this study. First, the measures employed in this study are self-report measures which can be subject to social desirability biases and participants who are experiencing mental health issues could perceive their child's ASC symptom severity or the affiliate stigma they experience as more severe (Bennett et al., 2012; Beurkens et al., 2013). Moreover, quantitative data using a 5-likert-scale can only provide close-ended information and does not explain why participants chose their responses (Creswell & Clark, 2007). Secondly, the size of the sample, the geographical specificity and the overrepresentation of gender in the participant sample could render the results as limited in their generalizability. In order to address some of the cultural concerns regarding the discussion of mental health, this study utilized the anonymized survey method, whereby parents of children with ASC will be

more likely to take part in the study with less hesitation. Although the online survey method is convenient and can be easily accessed, it is possible that participants were limited to those with access to the internet. Finally, factors including Saudi Arabia's cultural attitudes towards mental health in general and ASC specifically should be considered. Nevertheless, results from this current study could contribute to the limited existing research on parental mental health and affiliate stigma in Saudi Arabia and also contribute to the development of effective intervention methods and coping mechanisms that are culturally relevant for parents of children with ASC. Moreover, despite developmental conditions such as ASC becoming a more familiar phenomenon across different cultures and socio-economic backgrounds due to the increase in research on this specific topic (Avoke 2002; Botts & Owusu, 2013; Yekple, 2014), there is still more room for improvement in terms of research exploring how different factors related to caring for a child with ASC affect parents from different cultural contexts so as future interventions can be able to produce sustainable solutions and support structures that can support the mental health of parents of autistic children and provide them with the practical skills and coping mechanisms such as self-compassion, resilience, and mindfulness which can protect them against the experiences of affiliate stigma.

### **Conclusion**

This study aimed to address the following issue. Parents of autistic children experience an array of unique challenges and experience higher levels of mental health problems in comparison to parents of typically developing children and parents of children with different developmental conditions. An attempt was made in this study to understand the underlying factors that could influence the high prevalence of stress, anxiety and depression in this parental group and to explore whether stress, anxiety and depression can be predicted by similar factors commonly suggested by previous studies in parents from Saudi Arabia. This study revealed that although ASC symptom severity is associated with parental stress, anxiety and depression,

the factor of affiliate stigma was in fact the only significant predictor of parental stress, anxiety and depression. It is important for future research to explore how affiliate stigma and ASC symptom severity influence parental mental health in various geographical contexts as a lack of a clear understanding of these factors could mean that the support given to these parents may potentially be ineffective. Future research should also explore this relationship using longitudinal research methods as well as a larger sample size and use more sophisticated modelling procedures to investigate potential moderating and mediating variables that influence the high rates of reported parental mental health issues.

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## **Chapter 4: The Buffering Effect of Resilience and Religious Belief on Stress, Anxiety and Depression in Parents of Children with Autism**

### **Abstract**

**Objective:** Research suggests that parents of autistic children are more likely to report high levels of stress, anxiety and depression which subsequently has a negative effect on the overall wellbeing of the parent and child and may compromise parenting skills and intervention seeking methods. Some studies have suggested certain factors such as resilience and religious coping can potentially act as a buffer against stress, anxiety and depression in parents of autistic children. The aim of this study is to explore the relationship between parental stress, anxiety, depression, religious coping and resilience.

**Method:** 128 participants from Saudi Arabia were recruited via opportunity sampling to complete an online survey. The survey consisted of demographic questions, The Depression, Anxiety and Stress Scale (DASS- 21), The Brief Resilience Scale (BRS) and The Brief Arab Religious Coping Scale (BARCS).

**Results:** Correlational analyses indicated a significant negative association between religious coping and stress, anxiety and depression. Results also showed a significant negative correlation between resilience, stress, anxiety and depression. Regression analyses indicated that the only significant predictor of lower levels of parental stress, anxiety and depression was higher resilience.

**Conclusion:** Resilience is a key protective factor against high levels of stress, anxiety and depression in parents of autistic children in Saudi Arabia. Results imply that there is a need for family intervention providers to help parents develop their individual resilience skills to alleviate mental health issues.

*Key Words:* Autism, Stress, Anxiety, Depression, Resilience, Religious Coping

### **Introduction**

Autism is defined as a complex multifactorial neurodevelopmental disorder that is characterized by impairments in social communication and the presence of restrictive and repetitive behavioural patterns (APA, 2013). Children diagnosed with ASC typically experience a range of distinctively complex behavioural, emotional and social issues which usually pose a concern for parents and primary caregivers. As such, parents of children with ASC are reported to experience higher levels of stress, anxiety, depression and other mental health issues as a result of the intense level of support they are required to provide for their child (Hastings, 2003; Tomanik et al., 2004; Lecavalier et al., 2006). Oftentimes, children diagnosed with ASC are also diagnosed with other comorbid disorders such as Attention

Deficit Hyperactive Disorder (ADHD), seizure disorders, metabolic disorders, gastrointestinal disorders and sleep disorders (Bauman, 2010). The combination of such comorbid disorders along with the chronic nature and pervasiveness of ASC and its impairments can sometimes negatively impact a parent's mental health and increase their levels of stress, anxiety and depression. Consequently, the mental health issues faced by parents can sometimes result in further challenges associated with providing care and support for their child.

As a parent of primary caregiver, providing care and support to an autistic child can usually be more challenging than caring for a typically developing child considering that children with ASC tend to require a more intensive level of parenting (Blacher & McIntyre, 2006), more behaviour management strategies as well as more financial resources (Beighton & Wills, 2017). Research suggests that parents of autistic children tend to consistently report higher levels of depression, anxiety and stress in comparison to parents of neurotypical children and children with other developmental conditions (Hayes & Watson, 2013; Estes et al., 2013; Dabrowska & Pisula, 2010). Various studies have suggested a number of possible factors which may account for the high levels of reported parental stress, anxiety and depression associated with caring for an autistic child. These include the severity of ASC symptoms (Osborne & Reed, 2009; Rivard et al., 2014; Duarte et al., 2005, Hastings & Johnson, 2001), the child's inappropriate social behaviour (Tomanik et al., 2004; Lecavalier et al., 2006; Fiske, 2009; Gray, 2003), financial concerns in terms of intervention and education cost (Sharpe & Baker, 2011; Thomas et al., 2016) and being subjected to social stigma (DePape & Lindsay 2014; Weiss et al. 2014; Farrugia, 2009). (See chapter 2 & 3). However, there is little consensus within the literature focusing on parental mental health associated with caring for an autistic child as to which specific contributes the most to these high levels stress, anxiety and depression. Despite this lack of agreement, it has however been well documented that increased levels of parental mental health issues have a negative influence on parenting skills and

caregiving quality which can consequently negatively affect the child's mental health and overall development (Anthony et al., 2005; Hastings & Beck, 2004).

While a large bulk of research on parental mental health related to caring for a child with autism indicates that parents consistently report high levels of stress, anxiety and depression (Gray, 1994, 2002; Koegel et al., 1992; Montes & Halterman, 2008; Schieve, Blumberg, Rice, Visser, & Boyle, 2008; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2013), not all parents of autistic children report such high levels (Abidin, 1992; Ekas, Lickenbrock, & Whitman, 2010; Pozo & Sarriá, 2014). Some studies have suggested that although a child's characteristics do contribute to reported parental stress, anxiety and depression, these variables are also influenced by the parents' psychological characteristics. Although there has been comparatively little investigation into the variables specifically associated with parental characteristics and their impact on mental health outcomes, such research highlights the importance of unearthing and understanding these factors as they may be protective factors against stress, anxiety and depression.

For example, research has found that parents of children diagnosed with ASC who score highly on resilience scales tend to report lower levels of parenting stress, anxiety and depression and are more adept at managing the challenges of caring for their (Hayes & Watson, 2013; Bekhet, Johnson, & Zauszniewski, 2012). Since resilience has recently emerged as a growing field of interest, particularly in research revolving around parents of children with ASC, it is important to explore this parent-specific variable and its impact on stress, anxiety and depression. Within the literature, there are various definitions for the term resilience which differ slightly, however the general definition for resilience is the individuals' ability to maintain a more successful life than expected despite the presence of adversity (Brooks, 1994). For example, according to Alvord and Gardos (2005), resilience is an individual's capacity to navigate through life regardless of adverse conditions and misfortune. According to Ungar

(2004), resilience can be explained as a sense of competence when facing significant challenges against adaptation and development. As another example, Luthar (2000) defines resilience as a process which is dynamic and is characterized by the ability to positively adapt in an adverse context and Matsen (2004) defines resilience as a “class of phenomena characterized by good outcomes in spite of serious threats to adaptation or development” (p. 228). For the purpose of this study, the use of the term resilience can be described as the process of health adaptation despite significant sources of stress (Matsen, 2001) as well as the aptitude to withstand and bounce back from adverse situations (Heiman, 2002).

In terms of caring for an autistic child, Harris and Glasberg (2003) suggest that there are some parents of autistic children who display an extraordinary sense of strength and resilience in their experience of raising their child. They go on to explain that when a parent of an autistic child rises above the expected challenges of providing support in their daily lives while continuing to engage in healthy adaptation processes, they can be considered as resilient. In order to overcome and recover from an adverse situation, a resilient individual tends to draw upon all of their biological, psychological and environmental resources (Gordon-Rouse, Longo & Trickett, 2006). As such, parents of autistic children who are resilient invariably seek to develop the needed strategies and skills to manage their child’s atypical behaviour. It is also important to note that resilience can be achieved through proper targeted intervention (Sivberg, 2002) as it can aid in mitigating negative feelings such as guilt, shame and vulnerability associated with having a child with a developmental condition (Stern & Bruschweiler-Stern, 1998). Seeing as resilience is generally defined as a process of successful adaptation to and recovery from a significant life challenge (Whitehead, et al., 2015), the link between psychological wellbeing and resilience has been described as “compelling” (Gill & Harris, 1991, p. 131) as it has been found to have a buffering effect on mental health issues such as anxiety and depression. (Fredrickson & Joiner, 2002).

Recently, research focused on parental mental health associated with caring for a child with ASC has been striving to identify the personal characteristics of these parents who specifically have a positive perception in terms of their caregiving experiences considering the constant stressors and challenges they tend to face. As such, the variable of individual and family resilience has recently generated much interest within the relevant literature. According to Heiman (2002), the list of psychological characteristics of parents that contribute to high levels of resilience include successful adjustment regarding social support, problem-solving, self-esteem, interdependence, faith, adaptive coping skills and the ability to reframe obstacles and barriers. Such skills and characteristics allow parents to maintain their optimism, appropriately function and productively cope during times of difficulty (Heiman, 2002). For example, a study conducted by Bitsika et al (2013) looking at factors consisting of internal personal characteristic of parents of children with ASC as opposed to external support factors (N=108) has found resilience to be a protective factor by shielding against parental mental health issues. This study suggested that despite the challenges associated with parenting an autistic child being associated with severe levels of anxiety and depression, parental reports of even relatively low to moderate levels of resilience buffered against stress, anxiety and depression. Another more recent example is a study conducted by Whitehead et al. (2015) which also confirmed the link between resilience and psychological wellbeing of mothers of children diagnosed with ASC (N=438). According to the study, resilience was characterized by acceptance, positive reframing and action-oriented strategies which contributed the most to lower levels of psychological distress. Mothers who had a relatively higher score on the resilience scale also scored highly on the wellness scale in comparison to mothers who engaged in avoidant strategies such as self-blame and disengagement which subsequently contributed to their increased levels of anxiety, stress symptoms and depressed mood.



Seeing as parents of children with ASC tend to face a higher risk of mental health issues, according to Fergus and Zimmerman (2005), the absence of symptomology associated with distress can be characterized as resilience. Thus, parents of autistic children who are classified as resilient are better able to cope with the stressful demands of caregiving while maintaining their wellbeing as well as their child's. Despite the recent traction within the relevant literature towards studies focusing on family resilience in families of children with developmental conditions, individual resilience especially in parents of autistic children is not yet a well-researched area, however, it is apparent that this phenomena does indeed exist (Carter et al., 2009; Ekas et al., 2010; Siman-Tov & Kaniel, 2011; Tobing & Glenwick, 2006; Siman-Tov & Kaniel, 2011; Kuhn & Carter, 2006; Ekas & Whitman, 2010). It is also important to note that identifying factors such as resilience in parents of autistic is essential as it could potentially be regarded as an element that enables these parents to effectively cope when faced with the various challenges of providing care for their autistic child (See chapter 2 and 3). Such research could also assist other parents with autistic children as well as interventionists with finding more effective strategies that will enable these parents to adaptively cope with adversity while positively reframing daily challenging situations.

Despite the emerging body of literature on parental mental health and resilience as a protective factor in parents of children diagnosed with ASC (Bekhet et al., 2012; McConnell et al., 2014; Leone et al., 2016), the majority of these studies are conducted using a sample from Western countries. The efficacy of resilience as a protective factor has yet to be extensively explored in a country such as Saudi Arabia. Seeing as cultural aspects such as traditions, beliefs and values do tend to shape how parents of autistic children perceive their child's condition as well as the challenges they experience caring for their child, there is also a possibility that these cultural factors play a role in how these parents cope and how it affects their level of resilience (Ghosh and Magana, 2009; Cridland et al., 2014; Xue et al., 2014).

Therefore, one aspect of this study aims to explore how individual resilience in parents of autistic children in Saudi Arabia impacts their levels of stress, anxiety and depression. In the Saudi Arabian society, stigma associated with ASC is extremely prevalent (Alenazi et al., 2020) (See chapter 3). Consequently, parents of autistic children tend to socially isolate both themselves and their children as a result of the negative experiences they face. However, not all parents share such similar negative experiences, and it is therefore imperative to explore how protective factors such as resilience impact parental experiences of caring for a child with autism in Saudi Arabia in order to help mental health care providers, pediatricians and autism specialists intervene with parents in order to support their child's development and also reinforce their resilience and overall wellbeing (Bravo-Benítez et al., 2019).

According to some studies, another potentially salient factor which could act as a protective element against parental stress, anxiety and depression is religious coping. A growing number of studies have shown that religious coping is a form of adaptive coping that alleviates parental stress, anxiety and depression (Kim & Esquivel, 2011; Pargament, Tarakeshwar, Ellison, & Wulff, 2001) and acts as a buffer against stressors such as difficult child behaviour and stigma (Friedrich et al., 1988). Although some research suggests that higher levels of religious coping lower the rates of reported stress, anxiety and depression in parents of children with ASC, this field of research remains largely understudied despite it being an integral part of daily life in many cultures.

The meaning of religion can vary greatly from one person to the next. According to Koenig (2009), religion is defined as “beliefs, practices, and rituals related to the sacred, rooted in an established tradition” (p. 284). According to Hood et al. (2009), “Religion may encompass the supernatural, the non-natural, theism, deism, atheism, monotheism, polytheism, and both finite and infinite deities; it may also include practices, beliefs, and rituals that almost totally defy circumscription and definition” (p. 7). According to Pargament (1997), religion is

a search for significance in ways related to the sacred which involves different pathways which lead to different religious destinations. While some individuals look to religion for comfort and meaning, others look to religion for physical, psychological and emotional wellbeing. Although religion tends to get overlooked in mental health research, it does however play a significant role in the lives of many people as a coping tool (Loewenthal, 2000; Moreira-Almeida, Lotufo Neto, & Koenig, 2006). According to Spilka, Hood and Gorsuch (1985), religious coping can be explained as a multidimensional process which consists of ideological, ritualistic, experiential, intellectual and consequential dimensions. Moreover, religious coping can also be described as a process of using tools that are associated with religion in order to adjust to challenging situations (Avent Harris et al., 2019; Pargament et al., 1998). Studies on religious coping have highlighted a variety of religious coping mechanisms. For example, Pargament et al. (1988) has categorized three varying approaches to coping in a stressful situation. The first is the self-directing approach whereby the person relies on themselves as opposed to God. The second is the deferring approach whereby the person places the responsibility for coping on God. Finally, the third is the collaborative approach whereby the person and God are both active partners in the coping process. Furthermore, other religious coping methods identified by Pargament (1997) include seeking support from the religious community, religious appraisals and seeking spiritual support. Other methods of religious coping such as reframing illness as the will of God, the use of collaborative religious coping and a religious fatalistic approach to life have been found to be linked to better adjusted psychological status (Jenkins & Pargament, 1988; Pargament et al, 1990; Wright, Pratt, & Schmall, 1985).

Recently studies have indicated that religious coping is correlated with lower psychopathology (Abdel-Khalek, 2009; Abdel-Khalek & Lester, 2007; Bullock, Nadeau, & Renaud, 2012; Meltzer, Dogra, Vostanis, & Ford, 2011; Pearce, Little, & Perez, 2003; Robbins & Francis, 2009; Scales Rostosky, Danner, & Riggle, 2008; Schludermann, Schludermann, &

Huynh, 2003). This correlation can be explained by the possibility of individuals using religion as an adaptive coping mechanism when faced with a difficult challenge (Pargament, 1997). Thus, individuals facing difficulty may potentially use religion as a framework from which they can derive a deeper meaning for their situation which could help them in understanding and interpreting any future negative situation where that individual may need to adapt and adjust to a certain stressor. In some cases, although an individual may comprehend the stressor they are facing, they may feel that they have no control over situation at hand. Therefore, various religious coping features such as prayer and other similar rituals may aid the individual in achieving a sense of control during challenging situations (Pargament et al., 2000). For example, a study conducted by Ai, Peterson and Huang (2003) exploring how religious coping can predict positive mental health outcomes in Kosovan and Bosnian refugees (N=149) have indicated that religious coping significantly predicted optimism using structural equation modeling. Although studies such as the above mentioned demonstrate the ability of religious coping to alleviate stress during difficult situations, a more comprehensive understanding on how individuals engage in religious coping to deal with stressors across varying cultures is needed.

A growing number of studies have shown that religious coping is greatly beneficial for individuals facing challenging circumstances (Pargament, 1997). However, research focused on parents of children with developmental disabilities, including parents of autistic children, have tended to neglect the role of religious coping. Some studies have suggested that parents of children with autism commonly use religious coping in their everyday life (Ault et al., 2013, Ekas et al., 2009; Gallagher et al., 2015). For example, a number of parents of children diagnosed with autism reported using religious coping to overcome experiences of stigma and other stressors associated with providing care and support for their child (Ault et al., 2013a; Ekas et al., 2009; Richardson & Stoneman, 2015; White, 2009). A number of studies have also

found that parents of autistic children described religious coping as a method in which they can accept and derive meaning of their child's diagnosis, as a way of providing support for their own mental health, as way to improve their overall quality of family life and as a mechanism to mitigate stress (Ault et al., 2013; Carter & Boehm, 2019; Ekas et al., 2009; White, 2009; Resurreccion, 2013; Wahyuni, 2013; Santoso et al., 2015; Chong & Kua, 2016; Ilias et al., 2016). Similarly, other studies have indicated that parents of autistic children accepted their child as a gift from God despite their diagnosis (Ting & Chuah, 2010; Tait & Mundia, 2012), found comfort in prayer and reading holy books after a stressful situation with their child (Wahyuni, 2013; Santoso et al., 2015; Ilias et al., 2016; Ilias et al., 2016) and felt better through church involvement (Ilias et al., 2016). Moreover, a study by Ekas, Whitman, and Shivers (2009) exploring levels of religious coping in mothers of children with ASC found that religious coping had had a considerably positive effect on the mother's wellbeing, specifically in terms of the mothers' levels of confidence, contentment and hope. Furthermore, a study by Tarakeshwar & Pargament (2001) examining the impact of religious coping on the wellbeing of families of children with ASC indicated that positive religious coping was associated with better outcomes. As such, religious coping appeared to act as a factor that helped families constructively manage a crisis (Spilka, Hood, & Gorsuch, 1985). Similarly, Haworth, Hill, & Glidden (1996), looked into religious coping in parents of children with developmental disabilities and indicated that some mothers do gain strength and support from using religion as an adaptive coping mechanism. In summary, according to such studies, religious coping may potentially act as a protective factor against daily stressors for parents of autistic children (Koenig, McCullough, & Larson, 2001) and also provide parents with a positive framework by which they can interpret their child's developmental condition (Jegatheesan, Miller & Fowler, 2010). Therefore, the buffering effect of religious coping against stress, anxiety and depression across varying cultural groups is an important topic to explore in order to better understand the

way in which different groups of parents perceive their child's developmental condition and how they personally manage the difficulties associated with caring for their child (Dyches, Wilder, Sudweeks, Obiakor & Algozzine, 2004; Skinner, Correa, Skinner & Bailey, 2001).

Across a wide range of cultures, religious coping has been found to have a positive influence on an individual's mental health (Abu-Rayya & Abu-Rayya, 2009; Cochrane & Bal, 1990; Cohen & Hall, 2009; Fisher, Newbold, Eyles, & Elliot, 2013; Flannelly & Inouye, 2001; Frazier, Mintz, & Mobley, 2005; Jang et al., 2013; Morris & McAdie, 2009; Pargament et al., 2001; Proffitt, Cann, Calhoun, & Tedeschi, 2007; Suhail & Chaudhry, 2004; Tarakeshwar, Pargament, & Mahoney, 2003; Tiliouine, Cummins, & Davern, 2009). The majority of, but not all, of this research has been conducted on a Christian population sample on Western countries. As such, the second aim of the current study is to better understand the impact that religious coping has on the levels of stress, anxiety and depression in parents of autistic children from Saudi Arabia.

Within the Saudi Arabian cultural context where the participant sample explored in this research is from, religion is the foundation and the fabric of life in general. It can be essentially regarded as the way of life. While religion can be regarded as one of the various cultural values in different societies, in Saudi Arabia, religion is considered as the most dominant influential factor in all life matters by most of the members of society. Therefore, the significance of religion can be seen in the diagnosis, treatment, and wellbeing of parents with autistic children (Alqunaibet, 2019). An awareness of the culturally specific mechanisms to coping with the experience of caring for a child with ASC in Saudi Arabia is therefore necessary when it comes to an attempt to explore the various ways in which parents perceive and cope with the ASC. Although coping is a multifaceted concept, considering the cultural context of this study, religious coping was selected as a variable in this study as opposed to other forms of coping. There have been on a handful of studies exploring the perception of parents of children with a

developmental disorder in Saudi Arabia. For example, according to a study by Almosa (1999), the Saudi Arabian society tends to perceive disability as a punishment from God as a result of one of the parents being disrespectful towards another family with a child with a disability. Almosa (1999) also states that some individuals in the Saudi Arabian society perceive their child having a disability as a test from God and that the patience of those who are tested will not go unrewarded. These perceptions are based on the Islamic faith and the Quran and Hadith which is what the majority of Saudi Arabian Muslims strictly adhere to following (Alqunaibet, 2019; Al-Mosa, 1999; Al-Aoufi, Al-Zyoud & Shahminan, 2012). To date, there are only two studies that have been found which primarily focus on the role of religious coping in parents of children with ASC specifically (Tarakeshwar & Pargament, 2001; Ekas, Whitman, & Shivers, 2009). Moreover, there has only been one further study which has investigated how parents of children with autism in Saudi Arabia use religion as a coping mechanism (Alqunaibet, 2019).

Considering the lack of research on factors that alleviate stress, anxiety and depression in parents of children with ASC in the Arab region, this research aims to explore the effect of resilience and religious coping on parental stress, anxiety and depression specifically in Saudi Arabia. There is hardly any existing quantitative research that has been conducted in Saudi Arabia which explores multiple factors that are associated with parental mental health and ASC, and very few qualitative studies conducted on parental experiences of ASC in general (e.g., Al-Salehi et al., 2009; Alqahtani, 2012; Al-Ayadhi et al., 2013; Hussein et al., 2013). Presently, there are no studies conducted on parents of children with ASC in Saudi Arabia which explore the effects of both resilience and religious coping on parental mental health. The lack of research conducted on this particular participant sample hinders the ability of specialists and researchers in gaining a thorough understanding and a true representation of the parental experiences of caring for a child with ASC in the Arab region. Moreover, in order for parents

of children with ASC to achieve the best possible outcomes for themselves and their children through suitable intervention methods, it is necessary for research to acknowledge both the universal aspects of ASC as well as the idiosyncratic cultural aspects and perceptions that influence parental and societal attitudes towards ASC.

Seeing as this study is the first of its kind to be conducted with a participant sample from Saudi Arabia, this study aims to explore how resilience and religious coping affects parental stress, anxiety and depression in parents of autistic children from Saudi Arabia. This is important as such studies can be regarded as being potentially impactful in assessing and portraying a more realistic experience of parents of children with ASC from different cultural contexts where an interplay of several variables and culturally relevant variables are more likely to contribute their mental health issues. Based on findings from previous literature on the factors associated with mental health issues in parents of children with ASC, it was hypothesized in this study that higher levels of resilience will be associated with decreased stress, anxiety and depression (Hayes & Watson, 2013; Bekhet, Johnson, & Zauszniewski, 201). Moreover, this study hypothesized that higher levels of religious coping will be associated with decreased stress, anxiety and depression (Salgado, 2014; Kulis, Hodge, Ayers, Brown, & Marsiglia, 2012).

## **Method**

### **Participants**

An opportunity sample consisting of 128 parents from Saudi Arabia completed an online survey for this study. The inclusion criteria were restricted to parents with at least one child diagnosed with autism under the age of 18, specifically from Saudi Arabia. Each parent was asked to complete a survey exploring the relationship between individual resilience, religious coping, stress, anxiety and depression.



## Measures

The online survey included in this study consisted of a short demographic questionnaire as well as an Arabic translated version of three psychometric scales which explore the relationship between resilience, religious coping and parental stress, anxiety and depression. At the time of this study being conducted, an evaluated Arabic version of the (BRS and BARCS) were not available and therefore the English version of the scales (Smith, Wiggings, Tooley, Christopher & Bernard, 2008; Amer, Hovey, Fox & Rezcallah, 2008) were translated and subsequently validated. The translation of the two scales involved a forward-backward translation process between English and Arabic by two other independent native Arabic speakers and the translated versions of the scales were evaluated in terms of validity and reliability. A validated Arabic translation of Depression, Anxiety and Stress Scale (DASS-21; Lovibond & Lovibond, 1995; Moussa, Lovibond & Laube, 2001) was already available and indicated adequate validity and consistency (Ali et al., 2017).

*Demographic Questionnaire* Information in terms of the parent's and child's age, the parent's and child's gender as well as the parent's educational level were collected to outline the sample characteristics. Information on the parent's nationality was also collected in order to ensure that the participant fitted into the inclusion criteria for this study.

*The Depression Anxiety Stress Scale (DASS-21; Lovibond & Lovibond, 1995)* is a 21 item self-report scale that measures stress, anxiety and depression and was developed for use in non-psychiatric populations (Lovibond & Lovibond, 1995). This scale is not intended for the clinical diagnosis of any participant, but only used in this study to detect symptoms of stress, anxiety and depression. The DASS-21 was selected in this study as it is relatively short and consists of questions that are direct and easily understood. Importantly, the DASS-21 is able to effectively discriminate between the three constructs of stress, anxiety and depression. The

DASS-21 consist of three 7-item subscales, each measuring one of the constructs of stress, anxiety and depression on a 4-point Likert scale ranging from (0 = never, 1 = sometimes, 2 = often, 3 = always). To score the DASS-21, each score must be multiplied by 2 to enable interpretation across all measures (Lovibond & Lovibond, 1995). The subscale for stress includes questions 1,6,8,11,12,14,18 which assess feelings of agitation, irritability, difficulty relaxing, impatience, nervous arousal and over-reactivity. The subscale for anxiety includes questions 2,4,7,9,15,19,20 which assess subjective and situational anxiety, physical effects of a panic attack and autonomic arousal. The subscale for depression includes questions 3,5,10,13,16,17,21 which assess dysphoria, hopelessness, self-deprecation, anhedonia, lack of interest, devaluation and inertia. The cut-off points for the stress subscale on the DASS-21 are 0-14 (normal), 15-18 (mild), 19-25 (moderate), 26-33 (severe), and > 34 (severe). As for the anxiety subscales the cut-off points are as 0-7 (normal), 8-9 (mild), 10-14 (moderate), 15-19 (severe) and >20 (extremely severe). For the depression subscale, the cut-off points are 0-9 (normal), 10-13 (mild), 14-20 (moderate), 21-27 (severe) and >28 (extremely severe) (Lovibond & Lovibond, 1995). The DASS-21 has been shown to be internally consistent and stable  $\alpha = .85$ . (Henry & Crawford, 2005; Osman et al., 2012) and has been widely used in a relatively large number of studies measuring stress, anxiety and depression. The DASS-21 has also been shown to have reasonable levels of validity compared to other similar self-report measures with a correlation of above .70 to the Beck Depression Inventory (Lovibond & Lovibond, 1995; Sahebi, Asghari, & Salari, 2004) and .49 for the Hospital Anxiety and Depression Scale (Musa, Ramli, Abdullah, & Sarkarsi, 2011). This study employed the existing Arabic translated version of the DASS-21 (Moussa, Lovibond & Laube, 2001). Reliability testing for this version reported a Cronbach's Alpha of  $=.84$ . Moreover, the Cronbach's Alpha was calculated for the internal consistency of each subscale: Depression  $=.76$ , Anxiety  $=.80$

and Stress = .79 in order to statistically analyze each mental health outcome of the DASS-21 as individual variables. In this study, reliability testing indicated high internal consistency  $\alpha = .84$ .

*The Brief Arab Religious Coping Scale* (BARCS; Amer et al., 2008) is a 15-item scale developed to assess religious coping methods specifically for Arab individuals. Items on the BARCS are answered on a 4-point Likert scale ranging from '0 = not used at all/does not apply' to '3 = used always'. The total score of the BARCS is calculated by adding the total responses of all of the items. The total possible score ranges from 0 to 75, with higher scores indicating greater levels of religious coping (Amer et al., 2008). Example items include, "I prayed for strength," and "I put my problem in God's hands." The BARCS has demonstrated a strong internal reliability  $\alpha = .95$ , a strong face validity and satisfactory construct validity (Amer et al. 2008) as well as in this current study  $\alpha = .86$ .

*The Brief Resilience Scale* (BRS; Smith et al., 2008) is a 6-item scale developed to measure a persons' ability to recover from stress (Smith et al., 2010) and is regarded as a measure that relates closely to the original meaning of resilience. According to Smith et al. (2010), "resilience" or the ability to bounce back from stress is a different concept compared to "resilience resources" considering that resilience resources are related to constructs such as optimism and self-esteem which are not restricted to the domain of stress and negative events, whereas resilience itself is directly oriented towards stress. The BRS consists of 6 items which are answered using a 5-point Likert scale with responses such as: strongly disagree, disagree, neutral, agree and strongly agree. Three of the items on the BRS are positively worded while the other three are negatively worded to reduce the likelihood of social desirability bias and positive response bias. The total BRS score is calculated by adding all the responses and subsequently dividing the sum by the number of items answered. The scores on the BRS range between 3-60, with higher scores indicating higher individual resilience (Smith et al., 2008). The BRS was reported to be positively correlated with aspects associated with resilience such

as social support and purpose in life and negatively correlated with variables such as self-blame, anxiety and depression (Smith et al., 2008). The BRS was originally validated with two samples of university students (N=192) and was reported to have adequate results for factorial structure, convergent and discriminant validity as well as reliability (Smith et al., 2008). The BRS also demonstrated good internal consistency  $\alpha = .91-.98$  as well as test-retest reliability. In this study, reliability testing indicated high internal consistency  $\alpha = .85$ .

## **Procedure**

Ethical approval to conduct this research project was obtained from the University of Lincoln Committee, U.K. The survey was developed online using the Qualtrics software. A survey distribution link was sent out to two ASC specific support groups for mothers in Saudi Arabia, two ASC learning centers and one ASC charity organization. All participants were directed to an information page which provided an overview of the study and emphasized that participation in this study is voluntary, and the process of data withdrawal was made clear. Participants were subsequently directed to a tick-box consent form prior to the survey and no personal information was collected in order to guarantee data protection and anonymity. Upon completion of the survey, participants were then taken to a debrief page which contained useful links on how to access local support in Saudi Arabia should they need it as well as the researcher's, supervisors' and university's contact details should they require more information about the study or wish to have their data withdrawn.

## **Data Analysis**

Data for each participant was scored for all measures in this study, giving a total DASS-21 (Lovibond & Lovibond, 1995) score as well as a score for each subscale measuring stress, anxiety and depression separately. A total BARCS (Amer et al., 2008) score for religious coping was also calculated as well as a total score for the BRS (Smith, 2008) in order to

determine the level of resilience. The examination of the raw dataset prior to analyzing the data showed 5.8% of responses containing missing item values. Multiple imputation was used to estimate the average missing values to ensure that all responses would be included in the current study. The process of analyzing the data combined standard statistical methods as well as correlational analyses and regression analyses using IBM SPSS 25 for Windows (IBM Corporation, Armonk, NY, USA).

## Results

This study consisted of a total sample number of (N=128) participants. All participants were female. Results indicate that 76% of the children were male and 24% were female. As for the education level of the participants, 4% reported no educational qualification, 24% reported having a high-school degree, 23% reported some university but no degree, 41% reported having a bachelor's degree, 6% reported having a postgraduate degree and 2% reported having a vocational diploma. Standard descriptive statistical calculations were conducted for the demographics of the study and are displayed in (Table.4.1). Descriptive statistics for the variables explored in this study were also calculated and are displayed in (Table.4.2).

**Table 4.1**

*Descriptive statistics for demographic questions*

	N	MEAN	SD	MIN	MAX
Age of Child	128	8.15	3.00	4.00	17.00
Age of Mother	128	35.80	6.50	24.00	55.00

The results for the variables of stress, anxiety and depression were normally distributed. The results for stress indicated a mean of 24.63 (SD=9.19) with a minimum score of 4 and a

maximum score of 40. The values of the stress scores show that 59.0% of participants experienced severe/extremely severe levels of stress associated with caring for a child with ASC. The anxiety scores show a mean of 21.43 (SD=10.05) with a minimum score of 2 and a maximum score of 43. The results of the anxiety scores indicate that 76.1% of participants experienced severe/extremely severe levels of anxiety associated with caring for a child with ASC. The results for the variable of depression showed a mean of 19.34 (SD=8.90) with a minimum score of 4 and a maximum score of 38. The depression scores indicate that 52.1% of participants experienced severe/extremely severe levels of depression associated with caring for a child with ASC.

The results for individual resilience indicated a mean of 19.16 (SD=5.76) with a minimum score of 13 and a maximum score of 29. The values of the resilience scores show that 71.1% of participants reported high levels of individual resilience. The results for the variable of religious coping showed a mean of 21.84 (SD=13.81) with a minimum score of 6 and a maximum score of 45. The religious coping scores indicate that 52.3% of participants reported high levels of religious coping.

**Table 4. 2**

*Descriptive statistics for stress, anxiety, depression, religious coping and resilience*

	N	MEAN	SD	MIN	MAX
Stress	128	24.63	9.19	4.00	40.00
Anxiety	128	21.43	10.04	2.00	43.00
Depression	128	19.34	8.90	4.00	38.00
Religious Coping	128	21.84	13.81	6.00	45.00
Resilience	128	19.16	5.80	13.00	29.00

Stress, Anxiety and Depression, *Depression, Anxiety and Stress Scale: (DASS- 21)*; Religious Coping, *the Brief Arab Religious Coping Scale (BARCS)*; Resilience, *Brief Resilience Scale (BRS)*

Correlational analyses were conducted to examine the relationship between all the study variables (Table.4.3). Correlation results indicated a moderate negative significant correlation between the outcome variable of stress and the variable of religious coping ( $r = -.63$ ,  $N = 128$ ,  $p < .001$ ) indicating that an increase in religious coping is associated with a decrease in stress. Moreover, results showed a strong negative significant correlation between the outcome variable of anxiety and religious coping ( $r = -.70$ ,  $N = 128$ ,  $p < .001$ ) suggesting that increased levels of religious coping are associated with decreased levels of parental anxiety. Furthermore, correlation results also indicated a moderate negative significant correlation between depression and religious coping ( $r = -.64$ ,  $N = 128$ ,  $p < .001$ ) indicating that higher levels of religious coping are linked to lower levels of reported parental depression.

Results also indicated a significant strong negative correlation between the outcome variable of stress the variable of resilience ( $r = -.70$ ,  $N = 128$ ,  $p < .001$ ) suggesting that higher levels of resilience are associated with lower levels of reported parental stress. Moreover, there was a significant strong negative correlation between the outcome variable of anxiety and resilience coping ( $r = -.74$ ,  $N = 128$ ,  $p < .001$ ) suggesting that higher levels of resilience are linked to lower levels of reported anxiety. Furthermore, there was a strong negative significant correlation between depression and resilience ( $r = -.70$ ,  $N = 128$ ,  $p < .001$ ) which shows that an increase in resilience may potentially decrease the level of reported depression. Additionally, results indicated a very strong positive significant correlation between religious coping and resilience ( $r = .90$ ,  $N = 128$ ,  $p < .001$ ) suggesting that high levels of resilience are associated with high levels of religious coping.

**Table 4.3***Correlations between stress, anxiety, depression, religious coping and resilience*

	Stress	Anxiety	Depression	Religious Coping	Resilience
Stress	1.00				
Anxiety	.63**	1.00			
Depression	.60**	.62**	1.00		
Religious Coping	-.63**	-.70**	-.64**	1.00	
Resilience	-.70**	-.74**	-.70**	.90**	1.00

Stress, Anxiety and Depression, *Depression, Anxiety and Stress Scale: (DASS- 21)*; Religious Coping, *the Brief Arab Religious Coping Scale (BARCS)*; Resilience, *Brief Resilience Scale (BRS)*

Significance - \*\* $p < 0.01$ , \* $p < 0.05$

Considering that both resilience and religious belief were negatively associated with stress, anxiety and depression a linear regression analysis was conducted to explore which factor contributed the most to lower parental mental health issues. First, a regression analysis was conducted to determine whether religious coping or resilience predicted lower levels of parental stress. The model explained 43.2% of the variance and was significant ( $F(2,125) = 49.30, p < .001$ ). Regression results indicated that resilience was the only significant predictor of lower levels of stress in parents of children with ASC ( $\beta = -.40, p < .001$ ) and that religious coping did not predict lower levels of stress. Secondly, another regression analysis was conducted to determine whether lower levels of parental anxiety were predicted by higher levels of religious coping or resilience. The model explained 54.1% of the variance and was significant ( $F(2,125) = 67.00, p < .001$ ). Regression results indicated that resilience was the only significant predictor of lower levels of anxiety in parents of children with ASC ( $\beta = -.74, p < .001$ ) and that religious coping did not predict a decrease in parental anxiety. Finally, a regression analysis was conducted in order to determine whether resilience or religious coping was the main predictor of lower levels of depression. The model explained 48.0% of the



variance and was significant ( $F(2,125) = 70.00, p < .001$ ). Regression results indicated that resilience was the only significant predictor of lower levels of reported depression in parents of children with ASC ( $\beta = -.60, p < .001$ ) and that religious coping did not predict lower levels of depression.

### **Discussion**

The principle aim of this study was to explore how resilience and religious coping are associated with parental mental health issues, specifically: stress, anxiety and depression in parents of children with ASC from Saudi Arabia. Five key findings emerged from this study. Firstly, in line with previous research, the majority of participants in the present study reported high levels of stress, anxiety and depression, which were relatively above the population mean. Secondly, as predicted, a significant association between high levels of resilience and low levels stress, anxiety and depression were found. Thirdly, as hypothesized, high levels of religious coping were also strongly associated with decreased levels of parental stress, anxiety and depression. Fourthly, there was an association and an overlap between resilience and religious coping. Finally, although high levels of resilience and religious coping were shown to be associated with reports of lower parental stress, anxiety and depression, further statistical analyses had indicated that resilience was the only significant factor predicting a decrease in parental stress, anxiety and depression.

The results support the findings from a relatively significant number of previous studies indicating that parents of children with ASC often report higher levels of stress, anxiety and depression in comparison to typically developing children and children with other disorders (e.g., Dabrowska & Pisula, 2010; Estes et al., 2013; Hayes & Watson, 2013). Moreover, the results from this study also support findings from various studies which suggest that religious coping can be considered as a buffer against stress, anxiety and depression (Haworth et al., 1996; McIntosh et al., 1993; Tarakeshwar & Pargament, 2001). Seeing as the participant

sample is constricted to individuals from Saudi Arabia, it was predicted that most if not all participants would score highly on the religious coping scale.

Although the majority of participants did report high levels of religious coping, it was the parents who reported above average scores which also reported the lowest scores for stress, anxiety and depression. These findings support research suggests that religious coping helps parents of children with ASC alter their perception of challenging situations while also helping them find meaning in it. As such, once a parent finds significance in their child's condition, they may potentially view their situation more positively which in turn increases the quality of care they provide. Since religious coping has been found to act as a buffer against stressors challenging child behaviour (Friedrich et al., 1988; Hill & Glidden, 1996), which has been cited by literature as the main predictor for parental stress, anxiety and depression (see chapter 2), an exploration of how different cultures use religious coping to overcome such stressors may help in our understanding of the mechanisms that effect parental acceptance of their child's condition in general. During stressful circumstances, an individual's religious beliefs tend to be transformed into certain coping mechanisms (Pargament, 1997). This concept and its subsequent coping behaviours are usually shaped by the individual's experiences and culture, as individuals will usually employ the coping tools that are most available to them (Klinger, 1977; Pargament, 1997). Thus, religious coping becomes a more accessible tool to people in a society where religion is deeply embedded in the framework for living. Results from this study suggest that religious coping plays a positive role in the lives of parents of children with ASC (Al-Kandari et al., 2017; Beighton & Wills, 2017; Ekas et al., 2009). This can be expected given the cultural context of the participant sample in the present study.

Moreover, the results in this study also give credence to previous studies which suggest that resilience acts as a buffer against high levels of stress, anxiety and depression in parents of children with ASC (Hayes & Watson, 2013; Bekhet, Johnson, & Zauszniewski, 2012;

Bitsika, 2013). Interestingly, although results from this study had shown an association between higher levels of resilience and religious coping with lower levels of parental stress, anxiety and depression, further statistical analyses indicated that resilience was the main predictor of decreased stress, anxiety and depression in parents of autistic children in Saudi Arabia. Throughout the literature, resilience has been well established as a significant buffering factor against stress, anxiety and depression (Bonanno et al., 2015; Garmezy, 1987; Luthar et al., 2000; Masten, 2011; Masten, 2014; Masten & Obradovic, 2006; Rutter, 1987; Rutter, 2013; Werner, 2005; Ungar et al, 2013). However, it remains significantly understudied in terms of parents of children with ASC outside Western countries. Since it is well established that parents of autistic children across different cultures face a variety of challenges when caring for their autistic child, exploring how resilience influences their mental health is important as it could inform the way they appraise their situation. It is suggested that resilience can positively contribute to a parent's problem-solving skills as well as aid them in effectively coping with stress (Berliner & Benard, 1995). According to Pastor-Cerezuela et al. (2016), parents who score high on the resilience scale tend to have lower levels of depression and a higher sense of self-efficacy which also decreases their levels of anxiety. This notion can be seen clearly in the results of the present study whereby parents who reported high levels of resilience also reported lower levels of stress, anxiety and depression. Since there is a dearth in empirical studies on the resilience of parents of children with ASC in Saudi Arabia as well as the majority of studies on this specific population sample focusing on the negative aspects of caring for a child with ASC (see chapter 2 and 3), this study aimed to address these gaps by exploring how a protective factor such as resilience can potentially reframe a parent's perception positively and mitigate parental stress, anxiety and depression.

Although some development has been made in Saudi Arabia in terms of mental health public awareness and access to mental health resources, the Saudi Arabian society still tends

to marginalize individuals with developmental conditions for several reasons including the lack of awareness and knowledge about the condition itself and the idea of shame associated with having a disability (Al-Jadid, 2014). Although there are currently no existing studies on the effect of religious coping and resilience on parents of autistic children in Saudi Arabia, results from this study indicate that of parents who are resilient reported having experienced lower levels of stress, anxiety and depression. The results from this study could potentially provide professionals and future researchers with a clearer understanding of the experiences that Saudi Arabian parents have when caring for their child with ASC. This study could also help in informing care providers of the beneficial effects that resilience has on parental mental health which could improve the quality of care they deliver.

There are several limitations to note in this study. First, the measures employed in this study are self-report measures which can be subject to social desirability biases. Moreover, quantitative data using a 5-likert-scale can only provide close-ended information and does not explain why participants chose their responses (Creswell & Clark, 2007). Secondly, the size of the sample, the geographical specificity and the overrepresentation of gender in the participant sample could limit the generalizability of the results. In order to address some of the cultural concerns regarding the discussion of mental health, this study utilized the anonymized survey method, whereby parents of children with ASC would be less hesitant to take part in the study. Although the online survey method is convenient and can be easily accessed, it is possible that participants were limited to those with access to the internet.

Despite literature indicating that parents of children with ASC resort to varying coping mechanisms and internal resources that could protect their mental health, parents from different cultural backgrounds oftentimes differ in their perception and responses to the challenges associated with caring for their autistic child and the type of resources they employ in order to cope. Therefore, it is important for future research to explore how different protective factors

and coping mechanisms influence parental mental health as a lack of a clear understanding of these factors could mean that the support given to these parents may potentially be ineffective. Future research should also explore this relationship with a larger sample size and use more sophisticated modelling procedures to investigate to gain a more comprehensive understanding of the factors that contribute to parental stress, anxiety and depression and the factors that protect against them.

### **Conclusion**

This study aimed to address the following issue. Although parents of autistic children often experience higher levels of mental health problems in comparison to parents of typically developing children and parents of children with different disorders, not all parents suffer from mental health issues associated with caring for their autistic child. An attempt was made in this study to understand the underlying factors that could alleviate the high prevalence of stress, anxiety and depression in this parental group and to explore whether stress, anxiety and depression can be buffered by similar factors commonly suggested by previous studies conducted in Western countries in parents from Saudi Arabia. This study revealed that although religious coping is associated with lower levels of parental stress, anxiety and depression, the parent's resilience level was in fact the only significant predictor of decreased stress, anxiety and depression.

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## **Chapter 5: The Impact of Social Support on Stress, Anxiety and Depression in Parents of Children with Autism in Saudi Arabia**

### **Abstract**

**Objective:** Previous studies suggest that parents of autistic children tend to report high levels of stress, anxiety and depression which in turn can negatively affect both the wellbeing of the parent and child and may compromise the quality of care provided by the parent. Some studies have suggested that social support is an essential factor that helps alleviate the experiences of parental stress, anxiety and depression in parents of autistic children. The aim of this study is to explore the relationship between parental stress, anxiety, depression, and social support as well as to explore which source of informal social support was more effective in buffering experiences of parental stress, anxiety and depression.

**Method:** 128 participants from Saudi Arabia were recruited via opportunity sampling to complete an online survey. The survey consisted of demographic questions, The Depression, Anxiety and Stress Scale (DASS- 21), and The Multidimensional Scale for Perceived Social Support (MSPSS).

**Results:** Correlational analyses indicated a significant negative association between perceived social support and stress, anxiety and depression. Regression analyses indicated that social support from a spouse was the only predictor of lower levels of stress and anxiety, but not depression.

**Conclusion:** Social support is a key protective factor against high mental health issues in parents of autistic children in Saudi Arabia, particularly perceived social support from a spouse. Results imply that there is a need for more societal awareness on autism in Saudi Arabia in order for parents to have more access to various types of social support when needed.

### **Introduction**

Autism is commonly defined as a complex multidimensional neurodevelopmental disorder that is characterized by impairments in social communication as well as the presence of restrictive and repetitive behavioural patterns (APA, 2013). Children who are diagnosed with ASC tend to experience a range of distinctively complex behavioural, emotional and social challenges which usually cause a concern for their parents or primary caregivers. As such, parents of children with ASC are reported to experience higher levels of stress, anxiety, depression and other mental health disorders as a result of the intense level of support they are required to provide for their child (Hastings, 2003; Tomanik et al., 2004; Lecavalier et al., 2006). Commonly, children diagnosed with ASC are also diagnosed with other comorbid disorders such as Attention Deficit Hyperactive Disorder (ADHD), seizure disorders, metabolic disorders, gastrointestinal disorders and sleep disorders (Bauman, 2010). The

combination of such disorders along with the chronic nature and pervasiveness of ASC can sometimes impact a parent's mental health negatively and increase their risk of developing high levels of stress, anxiety and depression. Consequently, the mental health issues faced by parents can sometimes result in further challenges associated with providing care for their child as a greater need for a more intricate wellbeing and support system for that child is typically required.

Providing care and support for an autistic child can sometimes be more challenging than caring for a typically developing child seeing as children with ASC tend to require a variety of parenting resources and an overall more rigorous level of parenting (Blacher & McIntyre, 2006). Research suggests that parents of autistic children tend to consistently report higher levels of depression, anxiety and stress in comparison to parents of neurotypical children and children with other developmental disorders (Hayes & Watson, 2013). Previous studies have suggested a number of possible factors which could account for the high levels of reported parental stress, anxiety and depression associated with caring for a child diagnosed with ASC including the severity of ASC symptoms (Osborne & Reed, 2009; Rivard et al., 2014; Duarte et al., 2005, Hastings & Johnson 2001), challenging child behaviour (Tomanik et al., 2004; Lecavalier et al., 2006; Fiske 2009; Gray 2003), and being subjected to stigma (DePape & Lindsay 2014; Weiss et al. 2014; Farrugia, 2009). (See chapter 2 & 3). However, there is little consensus within the literature focusing on parental mental health associated with caring for an autistic child as to which specific factor, or group of factors, act as a significant contributor to these elevated levels stress, anxiety and depression or which factors are effective at alleviating them. Despite this lack of agreement, it has however been well documented that parental mental health issues have a significantly negative influence on parenting skills and caregiving quality which can also negatively affect the child (Anthony et al., 2005; Hastings & Beck, 2004).

While a large number of studies on parental mental health related to caring for a child with autism indicate that parents consistently report high levels of stress, anxiety and depression (Gray, 1994, 2002; Koegel et al., 1992; Montes & Halterman, 2008; Schieve, Blumberg, Rice, Visser, & Boyle, 2008; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2013), not all parents caring for a child with ASD report such high levels (Abidin, 1992; Ekas, Lickenbrock, & Whitman, 2010; Pozo & Sarriá, 2014). Some studies have suggested that although a child's characteristics (ASC symptom severity, challenging child behaviour) do contribute to the elevated levels of reported parental stress, anxiety and depression, these variables are also influenced by the parents' psychological characteristics (e.g., individual resilience, social support) (Boyce, Behl, Mortensen, & Akers, 1991; Bristol, 1984; Hastings & Johnson, 2001). Although there has been comparatively little investigation into the variables specifically associated with parental characteristics and their impact on mental health issues, such research highlights the importance of exploring these variables as they may potentially act as protective factors against stress, anxiety and depression. For example, research has found that parents of children diagnosed with ASC who perceive to have higher levels of social support tend to report lower levels of stress, anxiety and depression (Dunn et al., 2001; Ramisch, 2010; Sanders & Morgan, 1997; SimanTov & Kaniel, 2011; Stuart & McGrew, 2009).

Social support is commonly defined as a multidimensional construct that is comprised of the psychological, instrumental, emotional and physical support that an individual receives from another person or persons whereby the receiver feels cared for, love (Cobb, 1976; Boyd, 2002; Dunst, Trivette, & Cross, 1986). Throughout the literature, social support is generally broken down into two categories: Formal and informal support. Formal support is defined as the support an individual receives from professional organizations, community resources or governmental agencies. For example, parents of autistic children tend to receive formal support



from social service support, therapy sessions, or a relevant organization that is directly involved in the intervention provided for the child. However, informal support is generally defined as the support an individual receives from family, friends, partners and other informal groups. This type of support tends to be influenced by the number of persons available in the individual's network as well as their perceived satisfaction regarding the quality of support they receive (Sarason et al., 1983). Although it has been well established in previous studies that both forms of social support have been found to increase the overall wellbeing of parents of autistic children to some extent (Pottie et al., 2009), the majority of studies have indicated that parents who are more likely to report lower levels of stress, anxiety and depression are they parents who also report high levels of informal social support as opposed to formal social support (Hastings & Johnson, 2001; Boyd, 2002; Bishop et al., 2007; Ekas, et al., 2010).

A great deal of literature on social support postulates that perceived social support is the key interpersonal resource that alleviates stress and mediates the link between a significant life-stressor and negative psychological outcomes such as anxiety and depression (Haber, Cohen, Lucas, & Baltes, 2007; Lin & Margolin, 2014; Norris & Kaniasty, 1996; Wesley, Zelikovsky, & Schwartz; 2013; Russell & Cutrona, 1991; Dour et al., 2014). Previous studies on social support have also suggested that an individual's perception of the availability of others in times of need, as opposed to the actual level of support received plays a critical role in the effectiveness of coping as well as the state of physical and psychological health (Dolbier & Steinhardt, 2000). Studies on the effect of perceived social support have also been extended to include a variety of populations including parents of autistic children (Chiang & Wineman, 2014; Dardas & Ahmad, 2014). According to Pottie et al. (2009), perceived social support in parents of children with ASC is more important for their mental health than the actual degree of the social support they receive. For example, a study conducted by Gray and Holden (1992) found that mothers of children with ASC who reported higher levels of perceived social support

tended to report lower levels of anger, anxiety and depression. Parents of autistic children often report relying on social support as a way to ameliorate their experiences of stress and a means to cope with depression and anxiety (Tunali & Power, 2002; Weiss, 2002; Benson, 2006; Luther, Canham, & Cureton, 2005; Siklos & Kerns, 2006). Moreover, social support is the most frequently reported factor reported by parents of children with ASC that helps them cope with daily stressors associated with caring for their child (Meadan, Halle, & Ebata, 2010; Luther, Canham, & Cureton, 2005).

Although perceived social support has been frequently reported as a significant protective factor against poor parental mental health associated with caring for a child diagnosed with ASC (Halstead et al., 2018; Handley & Chassin, 2008; Onyedibe et al., 2018; Sharpley et al., 1997; Ullrich et al., 2015), a relatively large number of studies have found that informal social support tends to be more effective than formal support in buffering the effects of stress, anxiety and depression in parents of autistic children. For example, a study by Sipal and Sayin (2012) found that greater perceived social support from friends and family was a predictor of lower levels of depression. Similarly, a study by Bonds, Gondoli, Sturge-Apple and Salem (2002) found that social support from family members and friends is linked to lower levels of stress and increased parenting skills. In support of this study, a recurrent theme in studies on the mechanisms of social support is that perceived social support significantly enhances positive parenting behaviours which in turn enhances the quality of life for both parent and child (Hassall et al., 2005; Lederberg & Golbach, 2002; Russo & Fallon, 2001). Another example of the importance of social support for parents of children with ASC is a study by Luther, Canham, and Cureton (2005) who found that parents of autistic children are more likely to be in need for social support as opposed to parents of non-autistic children as these parents report that they consistently rely on friends and family as opposed to neighbors. In addition, Ekas, Lickenbrock, and Whitman's (2010) study indicated that mothers of autistic

children who reported higher levels of informal support also reported lower levels of distress as the variable of stress in the study was mediated by informal social support. Furthermore, a study by Burrell, Ives and Unwin (2017) found that the most effective source of informal support for parents of autistic children was their spouse or partner. According to the participant sample in their study, parents reported that relying on their spouse for social support was most effective as they could easily share their concerns and experiences with someone who could understand what they go through on a daily basis.

Indeed, it has been well established in the literature that different sources of perceived social support are linked to an increase in the psychological wellbeing of parents of children with ASC, however, there is little research on the systematic examination of whether one source of informal support is more effective than another in terms of alleviating stress, anxiety and depression in parents of autistic children. Although a study by Coyne, Ellard and Smith (1990) suggested that informal social support from a spouse may not be effective as the spouse could also potentially be equally distressed and that family members and friends may be more helpful in terms of promoting a parent's psychological wellbeing, a study by Dunn et al. (2001) and a study by Boyd (2002) have found that mothers of children with developmental conditions first turn to their partner or spouse for social support, then to members of their family as a secondary source of support and finally to other parents with children that have similar conditions. Similarly, a study by Hassall et al. (2005) indicated that parents receiving support from their spouse tended to report happier marriages and lower levels of parental depression associated with caring for their child. Additionally, Macfie et al. (2005) found that mothers of autistic children cited their spouse as the main source of social support. A recent study on social support and parents of autistic children by Dey and Amponsah (2020) reported that the factor of perceived support from a significant other acted as a buffer against psychological distress. These findings suggest that a partner tends to play a significant role in the other partner's life

by providing guaranteed emotional, instrumental and informational support as well as being non-judgmental and empathetic (Thoits, 2020), thus rendering spousal support a central source of social support. In support of these findings, a meta-synthesis on parenting a child with autism by Ooi, Jacob and Khan (2016) found that parents of children with ASC tended to perceive lack of support from friends and family as opposed to their partner. Their findings are consistent with previous studies in the field which had found that parents of autistic children reported that family members did not accept the autism diagnosis, nor did they even understand the condition and therefore were not an adequate source of support (Picardi et al., 2018; Safe et al., 2012). Furthermore, Kuhaneck et al. (2010) found that parents of autistic children indicated that they relied on their spouse the most for support as they could easily split the required responsibilities since their spouse understood the home routines and was more likely to be physically available at home as opposed to family members and friends. As such, it is important to explore which source of informal social support deems to be more effective for parents of autistic children considering that several studies suggest that one source could potentially be more effective than another. It is important to note that the majority of studies on social support and parents of autistic children have been conducted in Western countries. Therefore, this study aimed to explore the nature of informal social support and the effectiveness of its different sources in an understudied population sample, namely Saudi Arabia in order to enrich the existing multicultural understanding of social support according to parents of autistic children from other cultural backgrounds.

Previous research has demonstrated that different cultural factors can potentially affect how parents of children with ASC cope with caring for their child as well as the type of assistance they seek. For example, a large number of parents of children with developmental conditions from the Middle East refuse to seek formal social support as they generally regard it as a sign of weakness (Zhang & Bennett, 2003). Additionally, seeing as a child's

developmental condition not only affects the child itself but also extends to their family (Goforth, 2011), parents of autistic children from an Arabian cultural background are more likely to keep their child hidden from society for fear of the stigma they might face (Al-Kandari & Al-Qashan, 2010; Al Thani, 2007; Crabtree, 2007). These negative social implications can be linked to the reluctance of parents of autistic children from the Middle East to seek formal means of support as well as informal means due to their fear of other individuals not accepting their child's condition or the idea of shame attached to having a child with a developmental condition. (Donovan, 2013; Goforth, 2011; Haboush, 2007; Reilly, 2011). Literature on parents of autistic children from the Middle East indicates that the Arabian society in general holds negative perceptions towards individuals with disabilities as opposed to individuals from Western societies, thus Arab parents are less likely to accept their child's diagnosis which consequently affects their likelihood to seek out any form of social support (Al Khateeb et al., 2014; Al Thani, 2006; Gharaibeh, 2009; Haboush, 2007; Sharifzadeh, 2011; Turmusani, 2003).

In the case of Saudi Arabia, cultural dimensions of autism are generally unexplored and there is a gap in evidence-based literature on this topic (Alallawi, Hastings & Gray, 2020). Only a handful of studies have been conducted on social support in Saudi Arabia. For example, a study conducted by Ebrahim and Alothman (2021) found that informal social support predicted post-traumatic growth in parents of autistic children, however they also found that social support from friends was the least favored form of support according to their participant sample. Another similar study conducted by Hassanein, Adawi, and Johnson (2021), found that increased levels of social support perceived by parents of autistic children were linked to significant elevation in quality of life. Similarly, a recent study by Khusaifan and El-Keshky (2020) found that social support acted as a protective factor against stress in parents of children with ASC. Additionally, a study by Gehan and Moawad (2012) found that informal social support was the most utilized factor as a means for coping with daily stressors for parents of

autistic children in Saudi Arabia. According to Alenazi et al. (2020), due the social stigma associated with ASC within the Saudi Arabian society, parents tend to dismiss the ASC diagnosis and keep their child away from others due to the lack of social support they receive as they tend to feel isolated and are not fully accepted by the community, friends or family. This in turn leads to increased stress, anxiety and depression in parents of autistic children as the acceptance for autistic behaviours in society is low (Chime et al., 2008) which in turn leads to a decrease in perceived social support (Obeid & Daou, 2015) and higher incidences of experienced stigma (Čolić & Milačić-Vidojević, 2020).

Seeing as previous studies have suggested that parent's perception of autism and how they provide support for their child are significantly influenced by their cultural background background (Gona, Newton, Rimba, Mapenzi, Kihara, Van de Vijver, et al., 2015; Mandell & Novak, 2005; Mire, Gealy, Kubiszyn, Burrige, & Goin-Kochel, 2015; Ponde & Rousseau, 2013), it is important to explore the dynamics of perceived social support amongst an understudied population sample such as Saudi Arabia in order to gain a better understand on how caring for an autistic child in other parts of the world can have an influence on family functioning and parental psychological wellbeing (Bayat, 2007). Such studies can also inform professionals in the field on the cultural variations in terms of social support as well provide them with the basis to further develop culturally appropriate interventions for parents of autistic children in Saudi Arabia. Based on findings from previous literature on the factors associated with mental health issues in parents of children with ASC, it was hypothesized in this study that higher levels of social support will be associated with decreased stress, anxiety and depression (Benson, 2012; Iacob et al., 2020; Meadan et al., 2010; Shepherd et al., 2020). Moreover, this study hypothesized that, in line with previous studies exploring the efficacy of sources of informal support for parents of children with ASC (e.g., Bristol, 1984; Hall & Graff,

2011; Herman & Thompson, 1995), perceived social support from a spouse will be more effective for the participants as opposed to perceived social support from family or friends.

## **Method**

### **Participants**

This study consisted of an opportunity sample of 128 parents from Saudi Arabia. Participants were asked completed an online survey for this study. The survey explored the relationship between social support, stress, anxiety and depression. The inclusion criteria were restricted to parents with at least one child diagnosed with Autism under the age of 18, specifically from Saudi Arabia.

### **Measures**

The online survey included in this study consisted of a demographic questionnaire as well as Arabic translated versions of two psychometric scales which explore the relationship between social support and parental stress, anxiety and depression. A validated Arabic translation of the Depression, Anxiety and Stress Scale (DASS-21; Lovibond & Lovibond, 1995; Moussa, Lovibond & Laube, 2001) was already available and indicated adequate validity and consistency (Ali et al., 2017). Additionally, a validated Arabic translation of the Multidimensional Scale of Perceived Social Support (Arabic-MSPSS; Merhi & Kazarian, 2012) was already available and indicated adequate validity and reliability as well.

*Demographic Questionnaire* Information on the parent's and child's age gender were collected to outline the participant sample characteristics. Data on the parent's nationality was also collected to ensure that the participant met the inclusion criteria for this study.

*The Depression Anxiety Stress Scale* (DASS-21; Lovibond & Lovibond, 1995) is a 21 item self-report scale that measures stress, anxiety and depression and was developed for use in non-psychiatric populations (Lovibond & Lovibond, 1995). This scale is not intended for the

clinical diagnosis of any participant but is only employed in this study to detect symptoms of stress, anxiety and depression. The DASS-21 was selected in this study as it is conveniently short and consists of questions that are direct and easily comprehensible. Essentially, the DASS-21 is able to effectively discriminate between the three constructs of stress, anxiety and depression. The DASS-21 consist of three 7-item subscales, each measuring one of the constructs of stress, anxiety and depression on a 4-point Likert scale ranging from (0 = never, 1 = sometimes, 2 = often, 3 = always). To score the DASS-21, each score must be multiplied by 2 to enable interpretation across all measures (Lovibond & Lovibond, 1995). The subscale for stress includes questions 1,6,8,11,12,14,18 which assess feelings of agitation, irritability, difficulty relaxing, impatience, nervous arousal and over-reactivity. The subscale for anxiety includes questions 2,4,7,9,15,19,20 which assess subjective and situational anxiety, physical effects of a panic attack and autonomic arousal. The subscale for depression includes questions 3,5,10,13,16,17,21 which assess dysphoria, hopelessness, self-deprecation, anhedonia, lack of interest, devaluation and inertia. The cut-off points for the stress subscale on the DASS-21 are 0-14 (normal), 15-18 (mild), 19-25 (moderate), 26-33 (severe), and > 34 (severe). As for the anxiety subscales the cut-off points are as 0-7 (normal), 8-9 (mild), 10-14 (moderate), 15-19 (severe) and >20 (extremely severe). For the depression subscale, the cut-off points are 0-9 (normal), 10-13 (mild), 14-20 (moderate), 21-27 (severe) and >28 (extremely severe) (Lovibond & Lovibond, 1995). The DASS-21 has been shown to be internally consistent and stable  $\alpha = .85$ . (Henry & Crawford, 2005; Osman et al., 2012) and has been widely used in a relatively large number of studies measuring stress, anxiety and depression. The DASS-21 has also been shown to have reasonable levels of validity compared to other similar self-report measures with a correlation of above .70 to the Beck Depression Inventory (Lovibond & Lovibond, 1995; Sahebi, Asghari, & Salari, 2004) and .49 for the Hospital Anxiety and Depression Scale (Musa, Ramli, Abdullah, & Sarkarsi, 2011). This study employed the existing



Arabic translated version of the DASS-21 (Moussa, Lovibond & Laube, 2001). Reliability testing for this version reported a Cronbach's Alpha of  $\alpha = .84$ . Moreover, the Cronbach's Alpha was calculated for the internal consistency of each subscale: Depression  $\alpha = .76$ , Anxiety  $\alpha = .80$  and Stress  $\alpha = .79$  in order to statistically analyze each mental health outcome of the DASS-21 as individual variables. In this study, reliability testing indicated high internal consistency  $\alpha = .84$ .

*The Multidimensional Scale for Perceived Social Support* (MSPSS; Zimet, Dahlem, Zimet & Farley, 1988) is a 12 item self-report scale that measures an individual's perceived level of support from three sources: friends, family and significant other. Each subscale consists of four items and scores can be obtained for each subscale separately. Items on the MSPSS are answered on a 7-point Likert scale ranging from '1 = very strongly disagree' to '7 = very strongly agree'. The total score of the MSPSS is calculated by adding the total responses of all of the items. The total possible score ranges from 12 to 84, with higher scores indicating greater levels perceived social support and lower scores indicating less perceived social support (Zimet, Dahlem, Zimet & Farley, 1988). The MSPSS is considered conveniently short and consists of clear and straightforward questions. Strong psychometric properties have been reported for the MSPSS with a strong internal consistency being reported for the family subscale  $\alpha = .90$ , the friends subscale  $\alpha = .94$ , the significant other subscale  $\alpha = .95$  as well as the total score  $\alpha = .91$  (Doku et al., 2015). This present study reported a  $\alpha = .90$  for the total score. The MSPSS is the most commonly used measure for perceived social support and has been widely used in research on parental mental health associated with caring for a child with a disability (Osman et al., 2014).

## **Procedure**

Ethical approval to conduct this research project was obtained from the University of Lincoln Committee, U.K. The survey was developed online using the Qualtrics software. A

survey distribution link was sent out to two ASC specific support groups for mothers in Saudi Arabia, two ASC learning centers and one ASC charity organization. All participants were directed to an information page which provided an overview of the study and emphasized that participation in this study is voluntary, and the process of data withdrawal was made clear. Participants were subsequently directed to a tick-box consent form prior to the survey and no personal information was collected in order to guarantee data protection and anonymity. Upon completion of the survey, participants were then taken to a debrief page which contained useful links on how to access local support in Saudi Arabia should they need it as well as the researcher's, supervisors' and university's contact details should they require more information about the study or wish to have their data withdrawn.

### **Data Analysis**

Data for each participant was scored for all measures in this study, giving a total DASS-21 (Lovibond & Lovibond, 1995) score as well as a score for each subscale measuring stress, anxiety and depression separately. A total MSPSS (Zimet et al., 1988) score for social support was also calculated as well as a score for each of the MSPSS's (Zimet et al., 1988) subscales (friends, family, significant other) in order to determine the level of perceived social support in each separate domain. The examination of the raw dataset prior to analyzing the data showed 5.1% of responses containing missing item values. Multiple imputation was used to estimate the average missing values to ensure that all responses would be included in the current study. The process of analyzing the data combined standard statistical methods as well as correlational analyses and regression analyses using IBM SPSS 25 for Windows (IBM Corporation, Armonk, NY, USA).

### **Results**

This study consisted of a total sample number of (N=128) participants. All participants reported as female. Results indicate that 76% of the children were male and 24% were female.

As for the education level of the participants, 4% reported no educational qualification, 24% reported having a high-school degree, 23% reported some university but no degree, 41% reported having a bachelor's degree, 6% reported having a postgraduate degree and 2% reported having a vocational diploma. Standard descriptive statistical calculations were conducted for the demographic data of the study and are shown in (Table.5.1). Descriptive statistics for the variables investigated in this study were also calculated and are displayed in (Table.5.2).

**Table 5.1**

*Descriptive statistics for demographic questions*

	N	MEAN	SD	MIN	MAX
Age of Child	128	8.15	3.00	4.00	17.00
Age of Mother	128	35.80	6.50	24.00	55.00

The results for the variables of stress, anxiety and depression were normally distributed. The results for stress indicated a mean of 24.63 (SD=8.92) with a minimum score of 4 and a maximum score of 40. The values of the stress scores show that 58.0% of participants experienced severe/extremely severe levels of stress associated with caring for a child with ASC. The anxiety scores show a mean of 21.43 (SD=10.04) with a minimum score of 2 and a maximum score of 43. The results of the anxiety scores indicate that 77.1% of participants experienced severe/extremely severe levels of anxiety associated with caring for a child with ASC. The results for the variable of depression showed a mean of 19.34 (SD=8.90) with a minimum score of 4 and a maximum score of 38. The depression scores indicate that 52.1% of participants experienced severe/extremely severe levels of depression associated with caring for a child with ASC. The results for the independent variable of perceived social support

showed a mean of 52.72 (SD=15.07) with a minimum score of 32 and a maximum score of 75. The results of the perceived social support scores indicate that 32.8% of participants reported low levels of social support while 67.2% of the participants reported high levels of social support.

**Table 5.2**

*Descriptive statistics for stress, anxiety, depression and perceived social support*

	N	MEAN	SD	MIN	MAX
Stress	128	24.63	9.19	4.00	40.00
Anxiety	128	21.43	10.04	2.00	43.00
Depression	128	19.34	8.90	4.00	38.00
Social Support	128	52.72	15.07	32.00	75.00

Stress, Anxiety and Depression, *Depression, Anxiety and Stress Scale: (DASS- 21)*; Social Support, *The Multidimensional Scale for Perceived Social Support (MSPSS)*

Correlational analyses were conducted to examine the relationship between the study variables of stress, anxiety, depression and social support (Table.5.3). Correlation results indicated a moderate negative significant correlation between the outcome variable of stress and the variable of perceived social support ( $r = -.54$ ,  $N = 128$ ,  $p < .001$ ) indicating that an increase in social support is associated with a decrease in stress. Moreover, results showed a moderate negative significant correlation between the outcome variable of anxiety and perceived social support ( $r = -.50$ ,  $N = 128$ ,  $p < .001$ ) suggesting that increased levels of social support are associated with decreased levels of parental anxiety. Furthermore, correlation results also indicated a strong negative significant correlation between the outcome variable of depression and the variable of perceived social support ( $r = -.64$ ,  $N = 128$ ,  $p < .001$ ) indicating that higher levels of social support are also linked to lower levels of reported parental depression.

Additionally, as expected, correlational results indicated strong positive significant correlations between the variables of stress and anxiety ( $r = .63$ ,  $N = 128$ ,  $p < .001$ ), depression and stress ( $r = .60$ ,  $N = 128$ ,  $p < .001$ ) and anxiety and depression ( $r = .62$ ,  $N = 128$ ,  $p < .001$ ) supporting previous research indicating an interrelationship between these mental health issues (Bromley et al., 2004; Maxted et al., 2005; Davis & Carter, 2008).

**Table 5.3**

*Correlations between stress, anxiety, depression and social support*

	Stress	Anxiety	Depression	Social Support
Stress	1.00			
Anxiety	.63**	1.00		
Depression	.60**	.62**	1.00	
Social Support	-.54**	-.50**	-.64**	1.00

Stress, Anxiety and Depression, *Depression, Anxiety and Stress Scale: (DASS- 21)*; Social Support, The Multidimensional Scale for Perceived Social Support (MSPSS)

Significance - \*\* $p < 0.01$ , \* $p < 0.05$

In order to further investigate the relationship between parental mental health and social support, another correlational analysis was conducted for the three subsets (family, friends, significant other) of the Multidimensional Scale for Perceived Social Support (MSPSS) and the variables of stress, anxiety and depression.

**Table 5.4**

*Correlations between stress, anxiety, depression and sources of social support*

	Stress	Anxiety	Depression	Family	Friends	Spouse
Stress	1.00					

Anxiety	.63**	1.00				
Depression	.60**	.62**	1.00			
Family	-.33**	-.30**	-.29**	1.00		
Friends	-.36**	-.28**	-.26**	.80**	1.00	
Spouse	-.41**	-.33**	-.30**	.62**	.72**	1.00

Stress, Anxiety and Depression, *Depression, Anxiety and Stress Scale: (DASS- 21)*; Social Support, The Multidimensional Scale for Perceived Social Support (MSPSS)

Significance - \*\* $p < 0.01$ , \* $p < 0.05$

Correlation results (Table.5.4) revealed a negative significant correlation between the variable of stress and the family subscale on the Multidimensional Scale for Perceived Social Support (MSPSS) ( $r = -.33$ ,  $N = 128$ ,  $p < .001$ ) indicating that an increase in perceived social support from family members is associated with a decrease in stress. Moreover, results also showed a negative significant correlation between the variable of anxiety and the family subscale ( $r = -.30$ ,  $N = 128$ ,  $p < .001$ ) suggesting that increased levels of social support from family are associated with decreased levels of parental anxiety. Furthermore, correlation results also indicated a negative significant correlation between the outcome variable of depression and the subscale perceived social support from family members ( $r = -.29$ ,  $N = 128$ ,  $p < .001$ ) indicating that higher levels of perceived familial social support are also linked to lower levels of reported parental depression. Additionally, results also revealed a negative significant correlation between the variable of stress and the friends subscale on the Multidimensional Scale for Perceived Social Support (MSPSS) ( $r = -.36$ ,  $N = 128$ ,  $p < .001$ ) indicating that an increase in perceived social support from friends is associated with a decrease in stress. Moreover, results also showed a negative significant correlation between the variable of anxiety and the friends subscale ( $r = -.28$ ,  $N = 128$ ,  $p < .001$ ) suggesting that increased levels of social support from friends are associated with decreased levels of parental anxiety. Furthermore, correlation results also indicated a negative significant correlation between the

outcome variable of depression and the subscale perceived social support from friends ( $r = -.26$ ,  $N = 128$ ,  $p < .001$ ) indicating that higher levels of perceived social support specifically from friends are also linked to lower levels of reported parental depression. The results from the correlational analysis also showed a negative significant relationship between the variable of stress and the significant other subscale on the Multidimensional Scale for Perceived Social Support (MSPSS) ( $r = -.41$ ,  $N = 128$ ,  $p < .001$ ) indicating that an increase in perceived social support from a significant other is associated with a decrease in stress. Moreover, results also showed a negative significant correlation between the variable of anxiety and the significant other subscale ( $r = -.33$ ,  $N = 128$ ,  $p < .001$ ) suggesting that increased levels of social support from a significant other are associated with decreased levels of parental anxiety. Furthermore, correlation results also indicated a negative significant correlation between the outcome variable of depression and the subscale perceived social support from a significant other ( $r = -.30$ ,  $N = 128$ ,  $p < .001$ ) indicating that higher levels of perceived spousal social support are also linked to lower levels of reported parental depression.

Considering that social support was significantly associated with all of the three outcome variables (stress, anxiety, depression) and that the three subscales of the perceived social support scale (friends, family, significant other) were also significantly linked to parental stress, anxiety and depression, linear regression analyses were conducted to explore which subscale contributed the most to alleviating parental mental health issues.

First, a regression analysis was conducted to determine whether perceived social support from friends, family or significant other predicted lower levels of parental stress. The model explained 16.2% of the variance and was significant ( $F(3,124) = 9.20$ ,  $p < .001$ ). Regression results indicated that perceived social support from a significant other was the only significant predictor of lower levels of stress in parents of children with ASC ( $\beta = -.32$ ,  $p < .008$ ) and that perceived social support from family and friends did not predict lower levels of stress.

Secondly, another regression analysis was conducted to determine whether lower levels of parental anxiety were predicted by higher levels of social support from family, friends or significant other. The model explained 10.3% of the variance and was significant ( $F(3,124) = 5.90, p < .001$ ). Regression results indicated that social support from a significant other was the only significant predictor of lower levels of anxiety in parents of children with ASC ( $\beta = -.24, p < .042$ ) and that social support from friends and family did not predict a decrease in parental anxiety. Finally, a regression analysis was conducted in order to determine which of social support domains (friends, family or significant other) was the main predictor of lower levels of depression. The model explained 11% of the variance and was significant ( $F(3,124) = 5.130, p < .002$ ). Regression results indicated that neither support from friends, family nor significant other acted as a significant predictor of lower levels of reported depression in parents of children with ASC despite the variable of support from a significant other approaching near significance ( $\beta = -.21, p < .076$ ).

### **Discussion**

The main aim of this study was to explore how perceived social support is associated with parental mental health issues, specifically: stress, anxiety and depression in parents of autistic from Saudi Arabia. Moreover, this study aimed to investigate which source of informal social support, specifically: friends, family, spouse, was most effective in protecting against experiences of parental stress, anxiety and depression. Three key findings emerged from this study. Firstly, in line with previous studies, the most participants in the study reported high levels of stress, anxiety and depression, which were relatively above the population mean. Secondly, as predicted, a significant association between high levels of perceived social support and low levels stress, anxiety and depression were found. Thirdly, as hypothesized, social support from a spouse was the only predictor of lower levels of both stress and anxiety.



However, contrary to the hypothesis, this study found that perceived social support from neither friends, family nor spouse predicted the level of reported parental depression.

The results in this study support the findings from a large number of previous studies indicating that parents of autistic children often report higher levels of stress, anxiety and depression in comparison to non-autistic children and children with other disorders (e.g., Dabrowska & Pisula, 2010; Estes et al., 2013; Hayes & Watson, 2013; Wang et al., 2011; Dykens & Lambert, 2013; Weiss, 2002; Stein et al., 2011; Kuusikko-Gauffin et al., 2013; Falk et al., 2014). Moreover, the results from this study also support findings from studies which suggest that perceived social support tends to act as a buffer or a protective factor against stress, anxiety and depression (Dunn et al., 2001; Ramisch, 2010; Sanders & Morgan, 1997; SimanTov & Kaniel, 2011; Stuart & McGrew, 2009). These findings give credence to the notion that mothers who perceive higher levels of social support also experience less stress, anxiety, depression as well as physical issues in comparison to mothers who perceive lower levels of social support (Konstantareas & Homatidis, 1989). According to SimanTov and Kaniel (2011), the decrease in levels of parental distress when higher levels of perceived social support are reported can be explained by the idea that the sense of feeling supported by others increases an individual's feeling of control and therefore contribute to the decrease in levels of mental health issues. Thus, it can be suggested that although the majority of studies on social support for parents of autistic children have been conducted in Western countries (Button, Pianta, & Marvin, 2001; Figueiredo & Costa, 2009; Singer et al., 2007), this study found similar results whereby perceived social support is significantly associated with lower levels of mental health issues in parents of autistic children from Saudi Arabia.

Moreover, the results from the study also support findings from several previous studies regarding the type of informal social support perceived as most effective. This study found that although high levels of perceived social support from either friends, family and spouse were

significantly associated with lower levels of stress, anxiety and depression, further statistical analyses revealed that high levels of perceived social support from a spouse was the only significant predictor of lower levels of stress and anxiety. Similar results can be seen in previous research identifying spousal support as the most important source of informal social support for parents of children with ASC (Bristol, 1984; Hall & Graff, 2011; Herman & Thompson, 1995). Results from the studies conducted by Bristol (1984) and Hall and Gaff (2011) both point towards a hierarchy of support effectiveness where spousal support was ranked the highest in comparison to support by friends and family. Interestingly, both studies found that support from parental groups, social clubs and schools were the least helpful. Similarly, a study by Johnson and Simpson (2013) showed that the participants tended to report their family members being unhelpful and showing no support, often even hesitating to interact with their autistic child. Such findings highlight the lack of understanding of the condition amongst some family members which consequently leaves parents feeling isolated or generally unsupported. The idea that parents of autistic children place an importance on spousal support can be explained by the idea that when it comes to parenting a child with autism, spousal support can be regarded as a quick relay response as well as an immediate form of response which is not usually available when it comes to support from family and friends (Burrell, Ives & Unwin, 2017). Although high levels of perceived spousal support were found to be the only predictor of lower levels of stress and anxiety among parents of autistic children in this study, spousal support did not predict lower levels of parental depression despite being significantly associated with it. There are a significantly relevant number of studies which suggest that perceived social support from a spouse is a critical factor that protects against parental depression (Bishop, Richler, Cain, & Lord, 2007; Bromley et al., 2004; Hassall, Rose, & McDonald, 2005; Dunn et al., 2001), similar findings were not found in this study. This

could potentially be due to other protective factors at play such as individual resilience or religious coping predicting lower levels of parental depression (See chapter 4).

Although recent developments have been made in Saudi Arabia with regards to public mental health awareness and access to professional services, the Saudi Arabian society still tends to marginalize individuals with developmental conditions for several reasons including the lack of awareness and knowledge about the condition itself and the idea of shame associated with having a disability (Al-Jadid, 2014). There are currently a very limited number of studies on the effect of perceived social support on parents of autistic children in Saudi Arabia. Despite this, Saudi Arabia, similar to other countries around the world has been seeing an increase in the prevalence of ASC cases (Al-Gadani, El-Ansary, Attas, & Al-Ayadhi, 2009; Alqahtani, 2012; Al-Salehi, Al-Hifthy, & Ghaziuddin, 2009). It is important to note that although the data on the prevalence of ASC and any factors associated with it including parental experiences caring for a child with ASC in Saudi Arabia are very limited, the increase in the number of diagnosed ASC cases also means that more parents of autistic children will potentially require more formal and informal support. The outcomes of this study can be considered as a response to the call to increase the quantity and quality of scientific studies focused on parents of autistic children within the cultural context of Saudi area (Sulaimani & Gut, 2019). The results from this study could potentially provide professionals and future researchers with a clearer understanding of the experiences that Saudi Arabian parents have when caring for their child with ASC. This study could also help in informing care providers of the beneficial effects that social support has on parental mental health which could improve the quality of care they deliver. Results from this study have a significant practical relevance since enhancing social support for parents of autistic children in Saudi Arabia can greatly improve their overall mental health and reduce experiences of stress, anxiety and depression. Firstly, although somewhat culturally challenging, public awareness campaigns to reduce autism stigma is an important

factor to consider in order for parents of autistic children to feel more socially supported (Sulaimani & Gut, 2019). Secondly, results from this study could help health workers and autism specialists increase their understanding of the significance of highlighting the role of social support for parents of autistic children (Alzuyaydi, Aldukhayel, & Alsweed, 2020). Thirdly, findings from this study could help clinicians providing support for parents of autistic children in Saudi Arabia encourage families to find support from other family members, friends and local communities in order to reduce their levels of stress, anxiety and depression. Finally, seeing as social media platforms have become increasingly accessible to everyone including parents of autistic children in Saudi Arabia (Saha & Agarwal, 2016), healthcare professionals could potentially advise these parents to connect with specifically relevant online groups as a means of accessible social support which can aid in improving their overall mental health (Zhao, Zhang, & Wu, 2019).

There are several limitations to note in this study. Firstly, the scales used in this study are self-report measures which can be subject to social desirability biases. Secondly, quantitative data using a Likert-scales are only able provide close-ended information and does not explain why a participant chose those specific responses (Creswell & Clark, 2007). Thirdly, the size of the sample, the geographical specificity and the overrepresentation of gender in the participant sample may limit the generalizability of the results. In order to address some of the cultural concerns regarding the discussion of mental health, this study utilized the anonymized survey method, whereby parents of children with ASC would be less hesitant to take part in the study. Despite the online survey method being convenient and easily accessible, it is possible that participants were limited to those with access to the internet. Even so, results from this study could help enrich what little quantitative data that exists on parental mental health and the protective factors associated with it in Saudi Arabia and also contribute to the

development of effective intervention methods and coping mechanisms that are culturally relevant for parents of autistic children.

### **Conclusion**

It is well established that parents of autistic children experience a variety of unique challenges caring for their child which can sometimes have a negative impact on their mental health. It is also important to note that not all parents suffer from mental health issues associated with caring for an autistic child. This study was conducted in order to understand how a protective factor such as perceived social support can alleviate the high prevalence of stress, anxiety and depression in parents of autistic children from Saudi Arabia and to explore whether stress, anxiety and depression can be ameliorated by similar factors commonly suggested by previous research conducted with a parents of children with ASC from Western cultural backgrounds. This study revealed that although perceived social support is strongly associated with lower levels of parental stress, anxiety and depression, it was the social support from their spouses that contributed the most in protecting them against the experiences of high levels of stress and anxiety. Finally, in this study, spousal support did not predict lower levels of depression. Therefore, future research should explore other protective factors which may protect parents of autistic children in Saudi Arabia from experiencing depressive symptoms.

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## Chapter 6: Factors Affecting Stress, Anxiety and Depression in Parents of Autistic Children in Saudi Arabia

### Abstract

**Objective:** Research suggests that parents of children with autism tend to experience high levels of stress, anxiety and depression which can negatively affect both the wellbeing of the parent and child and may even compromise the level of support the child receives. Previous studies have suggested that factors such as challenging child behaviour, autism symptom severity and affiliate stigma can lead to parental stress, anxiety depression. Studies also suggest that factors such as resilience, religious coping and social support can sometimes act as a protective factor against stress, anxiety and depression. The aim of this study is to explore the relationship between the aforementioned variables and their effect on the mental health of parents of autistic children from Saudi Arabia.

**Method:** 128 parents from Saudi Arabia were recruited via opportunity sampling to complete an online survey. The survey consisted of demographic questions, The Depression, Anxiety and Stress Scale (DASS- 21), The Affiliate Stigma Scale (ASS), The Child's Challenging Behavior Scale (CCBS), The Gilliam Autism Rating Scale (GARS-3), The Brief Resilience Scale (BRS), The Brief Arab Religious Coping Scale (BARCS) and The Multidimensional Scale for Perceived Social Support (MSPSS).

**Results:** Correlational analyses indicated a significant positive association between challenging child behaviour, autism symptom severity, affiliate stigma and parental mental health issues. Results also indicated a significant negative association between parental mental health, resilience, social support and religious coping. Regression analyses indicated that the only significant predictor of higher levels of parental stress, anxiety and depression was affiliate stigma. Mediation analyses indicated that resilience and social support mediated the relationship between affiliate stigma and depression but only resilience was a significant mediator in the relationship between stigma and anxiety.

**Conclusion:** Although there are various factors which may be associated with reported parental mental health issues, affiliate stigma seems to be a significant contributor to the high levels of stress, anxiety and depression in parents of autistic children from Saudi Arabia. As such, there is an urgent need for the Saudi Arabian society to tackle the issue of stigma effectively. Resilience has shown to be a key protective factor against mental health issues; therefore, intervention providers are encouraged to help parents develop their individual resilience skills to improve their mental health.

### Introduction

Autism is a term that is used to refer to a group of neurodevelopmental conditions characterized by atypical development in the areas of social communication along with the presence of restricted and repetitive behaviour patterns. The term spectrum denotes to a wide range of symptoms, impairments, skills and levels that individuals with an ASC diagnosis may experience (DSM-5; APA, 2013). According to the DSM-5, a diagnosis of ASC consists of

three levels used to determine severity. Level 1 implies that the individual requires support, Level 2 indicates that the individual requires substantial support and Level 3 implies that the individual requires very substantial support. A large number of previous studies have indicated that caring for an autistic child presents a unique set of challenges that can sometimes have a long-term negative impact on a parent's mental health and wellbeing (Patterson, 2005; Turnbull, Turnbull, Erwin, & Soodak, 2006). It is well established throughout the literature on parental experiences caring for an autistic child, that these parents frequently report higher levels of stress (e.g., Blacher & McIntyre, 2006; Hastings & Johnson, 2001; Sanders & Morgan, 1997), anxiety (e.g., Stein et al., 2011; Kuusikko-Gauffin et al., 2013; Falk et al., 2014), depression (e.g., Stein et al., 2011; Hayes & Watson, 2013; Zablotsky et al., 2013; Falk et al., 2014; Weitlauf et al., 2014; Greenberg, Seltzer, Krauss, Chou & Hong, 2004), as well as physical health issues (e.g., Stein et al., 2011; Dykens & Lambert, 2013; Giallo et al., 2013; Fairthorne et al., 2015). Moreover, studies comparing parents of autistic children, non-autistic children and children with other developmental disorders have found that parents of children with ASC are more likely to report higher stress, anxiety and depression levels in comparison to the other groups (Hayes & Watson, 2013). Some studies have suggested that this trend is due the nature of support required for a child with autism which tends to encompass a more intensive level of parenting (Blacher & McIntyre, 2006; DePape & Lindsay, 2014), seeing as children with ASC require more time, resources and behavioural management (Beighton & Wills, 2017).

Various studies have suggested several possible factors which may contribute to the high levels of reported mental health issues associated with parenting an autistic child. According to the literature, the sources of stress, anxiety and depression in parents of children with ASC include the challenging behaviour (e.g., Tomanik et al., 2004; Herring et al., 2006; Lecavalier et al., 2006; Osborne and Reed, 2009; Estes et al., 2013; Woodgate, Ateah, & Secco,

2008), autism symptom severity (e.g., Osborne & Reed, 2009; Ingersoll & Hambrick, 2011; Rivard et al., 2014), the cost of treatment, intervention and education (e.g., Sharpe & Baker, 2011; Vohra et al., 2014; Zablotsky et al., 2014; Thomas et al., 2016) and the experience of stigma (e.g., DePape & Lindsay 2014; Weiss et al., 2014; Farrugia, 2009). However, there is little consensus within the literature as to which specific factor, or group of factors, significantly impacts these elevated levels of reported parental stress, anxiety and depression. Despite this lack of agreement, it has however been well documented that the reported parental mental health issues have a significantly negative influence on parenting skills which can consequently have a negative effect on the child's mental health and overall wellbeing as well as the quality of support provided for the child (Anthony et al., 2005; Hastings & Beck, 2004). The lack of congruence within the literature highlights the importance of exploring the underlying factors which could potentially predict the increase in parental mental health issues associated with caring for a child with ASC and warn us against assuming that the sheer diagnosis of autism in a child is an adequate factor that increases parental stress, anxiety and depression (Herring et al., 2006).

Across the existing research in this field, it has been commonly suggested that the main factor leading to the development of stress, anxiety and depression in parents of children with ASC is the child's challenging behaviour which has been commonly described as unpredictable and disruptive (e.g., Donenberg & Baker, 1993; Seltzer et al., 2001; Tomanik et al., 2004; Herring et al., 2006; Lecavalier et al., 2006; Osborne and Reed, 2009; Estes et al., 2013). These studies have emphasized that the high levels of reported parental mental health issues are mostly linked to child related factors that are not ASC-symptom specific, specifically, the presence of difficult child behaviours in general, such as irritability, aggression and noncompliance, which could potentially be attributed to a variety of sources including the



child's age, gender, emotional development, temperament, rearing practices and existing comorbidities (Davis & Carter, 2008; Estes et al., 2009; Hastings et al., 2005).

Children diagnosed with developmental conditions usually exhibit more challenging behaviours in comparison to typically developing children. According to a relatively significant number of studies, children diagnosed with ASC specifically, usually display even higher levels of challenging behaviours compared to children with other developmental disorders (Eisenhower et al., 2005; Estes et al., 2009; Kozlowski & Matson, 2012; Jang et al., 2011). Moreover, autistic children who are also diagnosed with comorbidities, such as ADHD and anxiety disorders, are more likely to display even higher levels of challenging behaviours (Simnoff et al., 2008). These studies suggest that a child's challenging behaviour not only increases parental stress but can also contribute to creating an environment that is more conducive to parental anxiety and depression.

A meta-analysis study conducted by Hayes and Watson (2013) on parental stress associated with caring for an autistic child and children diagnosed with other developmental conditions indicated that parents of children diagnosed with ASC tend to report higher levels of stress compared to the other groups of parents. In support of these findings, a study conducted by Lecavelier, Leone and Wiltz (2006) exploring stress in parents of autistic children, found that child behaviour problems were strongly associated with stress and that the results were considerably stable over the one-year interval in which parents were being rated. Similarly, Griffith, Hastings, Nash and Hill (2010) conducted a study on adaptive and difficult behaviour in children diagnosed with ASC, Down syndrome and intellectual disabilities. The participants were grouped according to their age, gender and communication skills. Results from this study indicated that the parents of autistic children reported the highest levels of stress as a result of their child's self-injurious behaviour and lower social competency in comparison to the other groups of children. Seeing as research has revealed a strong correlation between a

child's challenging behaviour and parental stress, anxiety and depression (Beck et al., 2004; Hassall, Rose, & McDonald, 2005; Hastings, 2003), it is important to note that the relationship between parental mental health issues and challenging child behaviour is reciprocal and bidirectional. Such that an increase in challenging child behaviours leads to an increase in parental distress which further exacerbates the child's maladaptive behaviour (Baker et al., 2003; Pesonen et al., 2008; Neece et al., 2012) and that parents who experience mental health issues are more likely to rate their child's behaviour as difficult. (See chapter 1).

Despite a large number of studies highlighting the link between high levels of parental stress, anxiety and depression being associated with challenging child behaviour, there are a number of studies have posited that the most significant factors associated with parental mental health issues are ASC symptom severity and ASC-specific behaviours (e.g., Liwag, 1989; Foronda, 2000; Nikmat et al., 2008; Charnsil & Bathia, 2010; Yeo & Lu, 2012; Athari et al., 2013; Wisessathorn et al., 2013; Ilias et al., 2016; Gabriels et al., 2005; Davis & Carter, 2008; Kasari & Sigman, 1997; Bebko, Konstantareas & Springer, 1987; Tomanik et al., 2004; Estes et al., 2013; Hastings & Johnson, 2001; Ingersoll & Hambrick, 2010). For example, a study by Lecavalier et al. (2006) showed that behaviours linked to ASC, specifically - self-isolation and ritualistic behaviors- were associated with parental mental health issues when controlling for externalizing challenging behaviors. Similarly, in a study by Konstantareas and Papageorgiou (2006), high levels of autism severity predicted stress as opposed to general challenging child behavior. In support of these findings, by Kissel and Nelson (2016) examining the link between parental stress and ASC symptom severity found that parents of children who presented with more severe autistic behaviours were more likely to report higher levels of stress, including in the clinically significant range, as opposed to parents of children who displayed less severe autistic behaviours. On the other hand, other studies have found no significant link between parental mental health issues and ASC symptom severity (Estes et al., 2009; Ben-Sasson et al.,

2013; Giovagnoli et al., 2015). For example, a study on the predictive factors determining parental stress in parents of children diagnosed with ASC which consists of participants recruited directly from the community as opposed to participants recruited from a clinical sample found that ASC symptom severity was not associated with parental stress (Hastings et al., 2006). Similarly, a study by Davis and Carter (2008) indicated that the core symptoms of autism such as deficits in social communication and repetitive and restricted behaviours were not predictive of parental stress either. In spite of the debate within the literature regarding whether it is the challenging child behaviours or ASC symptom severity that is a more prominent predictor of parental stress, anxiety and depression, it is important to explore the impact ASC symptom severity has on parents as higher levels of symptom severity can pertain to a greater dependency on parents which may consequently increase levels of parental distress due to the great caring demands placed on parents by children who are in need for a more support (Blacher & McIntyre, 2006; DePape & Lindsay, 2015; Beighton & Wills, 2017). (See chapter 2).

Recently, the impact of stigma upon the mental health of parents of children with ASC has been receiving increased recognition. Stigma has been commonly defined as a mark of social disgrace whereby an individual is discredited as a result of certain characteristics such as ethnicity, mental health issues, disability, drug-use or religion (Goffman, 1963). The construct of stigma refers to the discrimination, attitudes and stereotypes that stem from misconceptions about a person's characteristics by a more dominant cultural group (Corrigan, Roe & Tsang, 2011; Corrigan, 2000). According to Goffman (1963), stigma does not solely affect the person with the stigmatizing characteristic or attribute, but it also extends to other individuals affiliated with them to some extent. Affiliate stigma is typically explained as the process by which the individual affiliated with a stigmatized person, such as a parent or caregiver, is also subjected to stigma. Subsequently, the affiliated person may begin to

internalize certain negative beliefs derived from the stigmatizing experience and consequently incorporate those negative beliefs into their own core beliefs (Mak & Kwok, 2012). It has been well established in previous literature that consistent exposure to any form of stigma is linked to higher levels of stress, anxiety, depression, lower life satisfaction and overall mental health problems (Clark et al., 1999; Paradies, 2006; Pascoe & Sutin, 2015; Williams et al., 2003). A number of studies have found affiliate stigma to be a significant predictor of poor mental health among parents of children with developmental conditions (e.g., Chiu et al., 2013; Banga et al., 2016; Dalky et al., 2017; Kim-Wan et al., 2016; Kwok et al., 2014; Magana et al., 2007; Mikami et al., 2014), however, according to Werner and Schulman (2013), parents of children with ASC were found to be the most negatively impacted by affiliate stigma compared to parents of children with other developmental disorders.

Parents of autistic children tend to experience stigma more frequently due to societal views that hold these parents responsible for their child's condition, particularly the child's challenging behaviour (Blum, 2015; Davis & Manago, 2016; Gray, 2003; Green, 2003; Manago et al., 2017; Ryan, 2010). Moreover, it is important to highlight the importance of the cultural context in terms of exploring affiliate stigma experienced by parents of autistic children. Previous research has indicated parents of children with ASC from collectivist cultures are more likely to experience stigma as collectivist societies are more likely to stigmatize individuals who deviate from social norms in comparison to individualist societies (Papadopoulos, Foster & Caldwell, 2013). The influence of culture in terms of affiliate stigma is therefore especially relevant in collectivist cultures where having a child with a developmental condition is in itself stigmatizing (Chiu et al., 2013). Recent research has begun to explore the effect that affiliate stigma may have on parents of autistic children (Mak & Kwok, 2010; Papadopoulos et al., 2019; Saini et al., 2015; Werner & Shulman, 2015). The most recent systematic review conducted by Mitter et al. (2019) aimed at exploring stigma

experienced by the families of individuals with ASC. The study concluded that the majority of parents reported experiencing affiliate stigma, however, the extent of their experiences varied across cultures. Interestingly, the review indicated that some parents of autistic children reported being marginalized by their own family members, communities as well as professionals. According to Mitter et al. (2019), there are three facets that are conducive to affiliate stigma in parents of children with ASC. First, parents may experience negative emotions related to experiences of stigma. Second, parents may experience cognitive aspects of stigma such as internalizing negative beliefs. Finally, as a result of the first two facets, parents may engage in the behavioural dimension of affiliate stigma whereby they actively avoid social situations which could lead to an increase in mental health issues. Moreover, the review conducted by Mitter et al. (2019) indicates that there are also other several psychological factors associated with affiliate stigma such as lower self-esteem, increased stress, caregiver burden and depressive symptomology. Considering that previous research with varying study designs and a range of socio-demographic and cultural contexts have found a significant link between parental stress, anxiety, depression and affiliate stigma associated with caring for an autistic child (e.g., Blanche et al., 2015; Broady et al., 2017; Byrne et al., 2018; Gill & Liamputtong, 2011; Gobrial, 2018; Gona et al., 2016; Gray, 2003; Ha et al., 2014) it is clearly evident that an association between affiliate stigma and poor parental mental health among parents of autistic children exists. As such, it is important to explore the extent of this issue across different cultures (Daley, 2002) in order gain a better understanding of how autism is perceived in different places and to inform future researchers and specialists on the culturally significant factors that may influence mental health outcomes in parents of autistic children. (See chapter 3).

Although a large amount of research on parental mental health related to caring for an autistic child indicates that parents consistently report high levels of stress, anxiety and

depression (Gray, 1994; Koegel et al., 1992; Montes & Halterman, 2008; Schieve, Blumberg, Rice, Visser, & Boyle, 2008; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2013), it is important to emphasize that not all parents of autistic children report such high levels of mental health issues (Abidin, 1992; Ekas, Lickenbrock, & Whitman, 2010; Pozo & Sarriá, 2014). There are a number of studies that have suggested that a child's challenges alone do not solely contribute to the elevated levels of reported parental stress, anxiety and depression. This is because parental mental health is also influenced by the parents' own internal resources such as coping strategies, resilience and locus of control (Boyce, Behl, Mortensen, & Akers, 1991; Bristol, 1984; Hastings & Johnson, 2001). There has been comparatively little investigation into the variables associated with parental internal resources and their effect on mental health outcomes, however, the aforementioned studies highlight the importance of unearthing and understanding these parent-centered variables as they may potentially act as protective factors against stress, anxiety and depression commonly reported by parents of autistic children. For example, research has indicated that parents of autistic children who score highly on resilience scales are less likely to report high levels of mental health issues and are more adept at managing the challenges of caring for their child (Hayes & Watson, 2013; Bekhet, Johnson, & Zauszniewski, 2012). (See chapter 4).

Resilience is often defined as a multidimensional construct that depicts a person's ability to positively adapt after experiencing high degrees of adversity and successfully overcome psychological vulnerabilities associated with the adverse event (Ganellen & Blaney, 1984; Kobasa, 1979). Previous research has frequently pointed to the inverse relationship between resilience and stress (Seligman, 2011), anxiety, insomnia, depression, and somatic symptoms (Hilliard et al., 2014; Nabors et al., 2013). Such researchers have also highlighted the potential of resilience-based interventions to act as a pivotal factor that can target mental health issues (Agaibi & Wilson, 2005; Kent et al., 2011; Seligman, 2011). Despite it being well

established that parents of autistic children often experience high levels of stress, anxiety and depression, only a few studies have been conducted on resilience levels among parents of autistic children (Ruiz-Robledillo et al., 2014). For example, a study conducted by Bitsika et al. (2013) which explored parental internal resources and the personal attributes of parents of autistic children found that the factor of resilience acted as protective factor that lowered levels of stress, anxiety and depression. This study suggested that despite the challenges associated with parenting an autistic child, even parental reports of relatively low to moderate levels of resilience buffered against stress, anxiety and depression. In support of these findings, a study conducted by Whitehead et al. (2015) also confirmed the association between resilience and psychological wellbeing in mothers of children with ASC. According to this study, mothers who had a relatively higher score on the resilience scale also scored highly on the wellness scale compared to mothers who engaged in avoidant strategies and self-blame which contributed to their high levels of anxiety, stress symptoms and depressed mood. It is important to note that identifying factors such as resilience in parents of autistic children is essential as it could potentially be regarded as an element that enables these parents to effectively cope when faced with the various challenges of providing care for their child. This is because resilience has the ability to improve a parent's problem-solving skills as well as help them develop the ability to actively and positively cope with stressors associated with their autistic child (Berliner & Benard 1995; Pastor-Cerezuela et al., 2016; Bitsika et al. 2013). (See study 3)

According to some studies, another factor which could potentially circumvent experiences of high parental stress, anxiety and depression in parents of autistic children is religious coping. A growing number of studies have shown that religious coping is a form of adaptive coping that alleviates the experiences of stress, anxiety and depression (Kim & Esquivel, 2011; Pargament, Tarakeshwar, Ellison, & Wulff, 2001) since it acts as a buffer against stressors such as challenging child behaviour and stigma (Friedrich et al., 1988).

Although a few previous studies have suggested that religious coping lowers the levels of reported mental health issues in parents of autistic children, this field of research remains largely understudied despite it being an integral part of daily life in many cultures (Loewenthal, 2000; Moreira-Almeida, Lotufo Neto & Koenig, 2006). According to Spilka, Hood and Gorsuch (1985), religious coping can be defined as a multidimensional process that consists of ideological, ritualistic, experiential, intellectual and consequential dimensions. Moreover, religious coping can also be explained as a process whereby an individual uses tools that are associated with religion in order to adjust to adverse or challenging situations (Avent Harris et al., 2019; Pargament et al., 1998). There are a number of qualitative studies which have indicated that parents of autistic children use religious coping as a means by which they can accept and derive meaning for their child's condition as well as a means of providing support for their own mental health, and improve the quality of their and their family's lives (Ault et al., 2013; Carter & Boehm, 2019; Ekas et al., 2009; White, 2009; Ting & Chuah, 2010; Tait & Mundia, 2012; Resurreccion, 2013; Wahyuni, 2013; Santoso et al., 2015; Chong and Kua, 2016; Ilias et al., 2016). Additionally, other studies have found that parents of autistic children accepted their child as a gift from God despite their condition (Ting & Chuah, 2010; Tait & Mundia, 2012) and found comfort in prayer and reading holy books after a challenging situation with their child (Wahyuni, 2013; Santoso et al., 2015; Ilias et al., 2016; Resurreccion, 2013; Ilias et al., 2016). Moreover, a study by Tarakeshwar & Pargament (2001) looking at the impact of religious coping on the wellbeing of families of children with ASC indicated that religious coping was associated with better mental health outcomes. As such, religious coping appeared to act as a factor that helped families constructively manage a stressful event (Spilka, Hood, & Gorsuch, 1985). In summary, although significantly unexplored across the existing literature, studies similar to the aforementioned ones highlight that religious coping may potentially act as a protective factor against daily stressors for parents of autistic children (Koenig,



McCullough, & Larson, 2001) and also provide parents with a positive framework by which they can interpret their child's condition (Jegatheesan, Miller & Fowler, 2010), especially parents of autistic children from a religious background. Therefore, the buffering effect of religious coping against stress, anxiety and depression across varying cultural groups is an important topic to explore in order to better understand the way in which different groups of parents perceive their child's developmental condition and how they personally manage the difficulties associated with caring for their child (Dyches, Wilder, Sudweeks, Obiakor & Algozzine, 2004; Skinner, Correa, Skinner & Bailey, 2001). (See chapter 4). Another commonly cited significant factor across the relevant literature is social support. Social support is defined as a multidimensional construct that is characterized by the psychological, instrumental, emotional and physical support that an individual receives from others resulting in the receiver feeling cared for and loved (Cobb, 1976; Boyd, 2002; Dunst, Trivette, & Cross, 1986). Throughout the literature, social support is generally broken down into two categories: Formal and informal support. Formal support is defined as the support an individual receives from professional organizations, community resources or governmental agencies. For example, parents of autistic children tend to receive formal support from social service support, therapy sessions, or a relevant organization that is directly involved in the intervention provided for the child. However, informal support is generally defined as the support an individual receives from family, friends, partners and other informal groups. Although it has been well established in previous studies that both forms of social support have been found to increase the overall wellbeing of parents of autistic children to some extent (Pottie et al., 2009), the majority of studies have indicated that parents who are more likely to report lower levels of stress, anxiety and depression are the parents who also report high levels of informal social support as opposed to formal social support (Hastings & Johnson, 2001; Boyd, 2002; Bishop et al., 2007; Ekas, et al., 2010).

Studies on the effect of perceived social support have also been extended to include parents of autistic children (Chiang & Wineman, 2014; Dardas & Ahmad, 2014). For example, a study conducted by Gray and Holden (1992) found that mothers of children with ASC who reported higher levels of perceived social support tended to report lower levels of anger, anxiety and depression. Other examples include studies conducted by Bristol (1984) and Hall and Gaff (2011) which both point towards a hierarchy of support effectiveness where spousal support was ranked the highest in comparison to support from friends and family. Interestingly, both studies found that support from parental groups, social clubs and schools were the least helpful. Similarly, a study by Johnson and Simpson (2013) showed that the participants tended to report their family members being unhelpful and showing no support, often even hesitating to interact with their child. Such findings highlight the lack of understanding of the condition amongst some family members and friends which consequently leaves parents feeling isolated or generally unsupported. Parents of autistic children often report relying on social support as a way to alleviate their experiences of stress and as a means to cope with depression and anxiety (Tunali & Power, 2002; Weiss, 2002; Benson, 2006; Luther, Canham, & Cureton, 2005; Siklos & Kerns, 2006). In summary, informal social support is the most frequently reported factor by parents of children with ASC that helps them cope with daily stressors associated with caring for their child (e.g., Meadan, Halle, & Ebata, 2010; Luther, Canham, & Cureton, 2005; Barker et al., 2011; Boyd, 2002; Bromley, Hare, Davison, & Emerson, 2004; Ekas, Lickenbrock, & Whitman, 2010; Lu et al., 2018; Pepperell, Paynter, & Gilmore, 2018; Zaidman et al., 2017). As such, it is an important factor to incorporate when exploring the factors that are associated with mental health in parents of autistic children. (See chapter 5).

When conducting research on the mental health of parents who have an autistic child, cultural factors are also very important to consider (e.g., Daley et al., 2013; Freeth et al., 2014, Mandell & Novak, 2005; Bernier et al., 2010). In some cases, there is a lack of information and

acceptance of autism in certain societies, which may lead to parents of autistic children to face stigmas or even themselves be negatively influenced by cultural beliefs about their child's condition which in turn may affect their parenting skills (e.g., Gray, 2002; Mak & Kwok, 2010; Neely-Barnes et al., 2011; Ravindran & Myers, 2012; Sarrett, 2015; Riany et al., 2016). Due to the lack of support and awareness available at the societal level, such parents may also potentially struggle to make sense of their child's challenging behaviors which may consequently increase their level of mental health issues and affect their intervention seeking behaviour (Karst & Van Hecke, 2012). The majority of studies that have explored mental health in parents of autistic children are conducted in Western contexts. The large number of studies conducted in the Western context signifies a greater awareness and societal support for the autistic community. On the other hand, mental health awareness which also encompasses developmental conditions such as autism is still growing in the Middle East region. (See chapter 1). Hence, this study sought out to explore how factors commonly mentioned in previous studies (challenging child behaviour, autism symptom severity, affiliate stigma, resilience, religious coping and social support) affect the mental health of parents of autistic children from Saudi Arabia. Findings from such a study can be impactful as they highlight the idea that parents of autistic children in different parts of the world can have different experiences and perceptions about autism. This study can also play a major role in contributing to what little research exists on autism in Saudi Arabia as well as help future researchers and specialists in the field take into account the different meanings parents from different cultural backgrounds attach to autism and how having an autistic child affects their mental health.

Moreover, numerous studies on parental experiences caring for an autistic focuses predominantly on parental stress. Currently, there is a scarcity in both qualitative and quantitative data exploring parental anxiety and depression as well as the potential predictive variables associated with them and the factors that might ameliorate them. Moreover, some of

the studies on parental mental health related to caring for a child with ASC have combined and investigated parental stress, anxiety and depression as a single outcome variable which could compromise the potential for research to clearly isolate and understand the specific variables that may contribute to each mental health construct independently (Falk et al., 2014). Considering that it is more likely that there are multiple contributing factors which affect parental mental health in the real world outside a research setting, an analysis incorporating a variety of factors linked to parental mental health issues will be better able to adequately assess the experiences of parents caring for an autistic child in any part of the world.

Studies on parental mental health associated with caring for an autistic child has consistently demonstrated that these parents are the most likely to report high levels of stress, anxiety and depression in comparison to parents of children with other disabilities and parents of typically developing children (Dabrowska & Pisula, 2010; Estes et al., 2013; Hayes and Watson, 2013). However, previous studies which have investigated the ability for multiple variables to simultaneously predict, mediate or moderate stress, anxiety and depression in parents of children with ASC is extremely limited (Falk et al., 2014). Moreover, there are currently no such studies that have been conducted using a participant sample from Saudi Arabia. The majority of studies on parental mental health and caring for a child with autism are conducted using partial analysis of the variables investigated (Pozzo, Sarriá & Brioso, 2014). This highlights the need for research to incorporate a multi-dimensional and holistic approach in order to simultaneously explore the influence of a variety of relevant factors on parental mental health. The growing number of studies that have begun to adopt the multi-dimensional approach have employed the double ABC-X model (McCubbin & Patterson, 1983) in their study in order to gain a more integrated and comprehensive understanding of the factors influencing parental mental health associated with caring for an autistic child. The current study is framed within the double ABC-X model (Fig.6.1) in order to explore the factors

that influence parenting stress, anxiety and depression in a sample of parents of autistic children from Saudi Arabia. The double ABC-X model of family stress and adaptation (McCubbin & Patterson, 1983) is regarded as flexible as it allows the choice of which variables to include. The primary strength of the model is that instead of solely exploring child characteristics, parent characteristics and parental mental health in an isolated manner, it instead provides an overarching framework which incorporates each of the mentioned fundamental attributes. In summary, the double ABC-X model enables the analysis of the relationships between several variables simultaneously using multiple indicators which provides a clearer and more realistic picture of the experiences of parents of autistic children.

The double ABC-X model had been widely used in studies looking at parental experiences caring for a child with autism (Manning et al., 2011). The model begins with the stressor variables (aA) which denote the severity of a stressors and the pile-up of stressors. They are typically defined as a life event or transition which impacts a family or individual in a way that causes a change in the typical system (McCubbin & Patterson, 1983). Several studies have used autism symptom severity (e.g., Konstantareas & Homatidis 1998; Hastings & Johnson 2001; Hastings & Brown 2002; Davis & Carter 2008) as a variable in the (aA) domain of stressors as autism symptom severity is commonly reported as a predictive variable of parental mental health issues. Other studies have suggested behaviour problems as a predictor of parental mental health issues (e.g., Lecavalier et al. 2006) and depressive symptoms in (Abbeduto et al., 2004; Seltzer et al. 1995; Dumas et al. 1991) and is therefore also frequently inserted into the (aA) domain. It is important to note that parents of autistic children also face other life stressors that are not strictly related to ASC such as divorce, financial concern and social stigma.

Following the severity of stress and pile-up of stress domain (aA), the double ABC-X model consists of two other domains. The (bB) domain of internal and external resources is

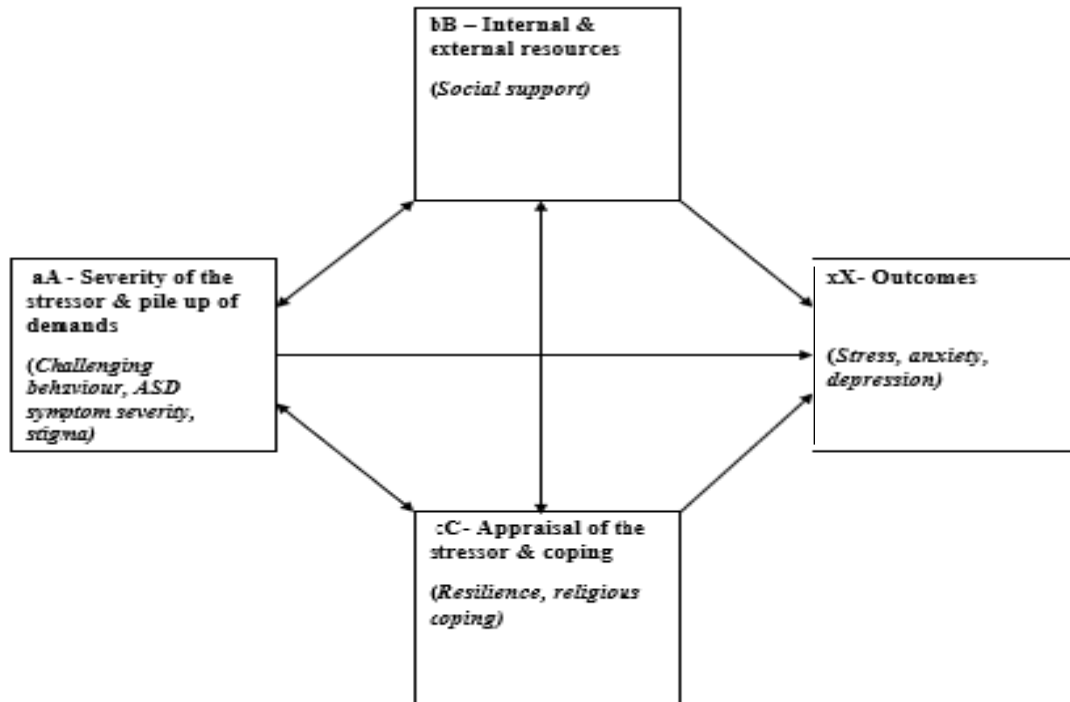
defined as the resources a family or parent has access to, which allows the parent to adaptively meet the demands of stressor (aA). Social support has been widely used in the (bB) domain as it is a factor that has been found to be associated with alleviating the effects of mental health problems in parents of children with developmental conditions. The second domain following with severity of stress and pile-up of stress domain is the meaning the family or parent assigns to their situation domain as well as the type of coping they engage in (cC). This domain refers to the way a family or parent appraises the stressors and the means of coping they typically employ in order to adapt to the stressor they are faced with. Resilience has often been used in the (cC) domain as studies have shown it to be a variable that also protects against high levels of stress, anxiety and depression (Hayes & Watson, 2013; Bekhet, Johnson, & Zauszniewski, 2012). Although religious coping often serves parents of children with developmental conditions by providing them with meaning in terms of their child's condition (Turnbull et al., 2010), only a handful of studies which have explored the role of religious coping within the double ABC-X model (Kamei, 2014; Amfani-Joe, 2012; Toliver, 2015). Nonetheless, it is an important variable to explore within the double ABC-X model especially when taking the cultural context of the participants into consideration. The final domain known as the outcome domain (xX) can either consist positive adaptation outcomes or maladaptation (McCubbin & Patterson, 1983).

Previous studies have used variety of variables in the (xX) outcome domain such as marital adjustment (Bristol, 1987), general health status (Pakenham et al., 2005) and psychological distress symptoms (Pakenham et al., 2005; Carnes & Quinn, 2005; Bristol, 1987). The double ABC-X model postulates that the two domains of (bB) (cC) can sometimes play mediating roles in the relationship between the stressors (aA) and the outcome (xX). As such, this model can potentially convey the idea that a variety of factors including the child's characteristics, the parent's characteristics as well as the parent's external resources can all

influence the outcome to some extent. To date, there are no existing studies that have employed the double ABC-X model when exploring parental experiences of ASC in Saudi Arabia

**Fig 6.1.**

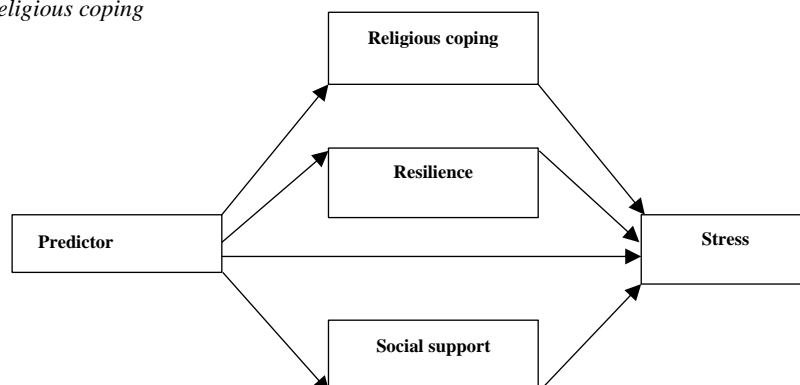
*The Double ABC-X Model Based on McCubbin & Patterson (1983)*



Based on findings from previous studies on the factors associated with mental health issues in parents of children with ASC, this study employed two exploratory hypotheses. First, this study sought to investigate which factor significantly predicts stress, anxiety and depression in parents of autistic children in Saudi Arabia. Second, this study aimed to explore whether social support, religious coping and resilience mediates the relationship between parental mental health issues and the predictor variable. (Fig. 6.2,6.3,6.4).

**Fig 6.2**

*Theoretical model showing the relationship between the predictor variable and stress mediated by social support, resilience and religious coping*

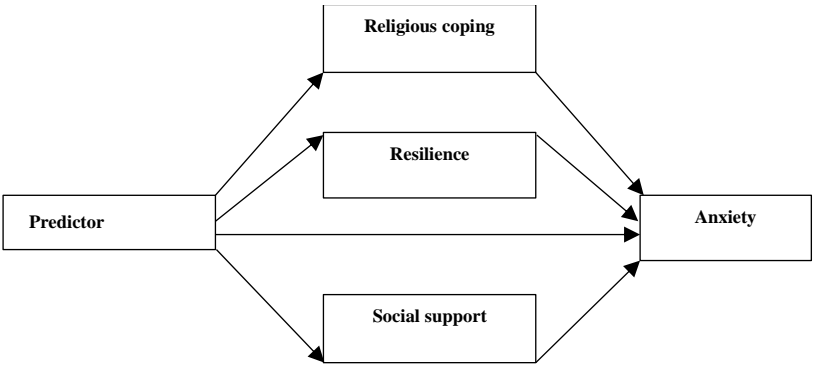






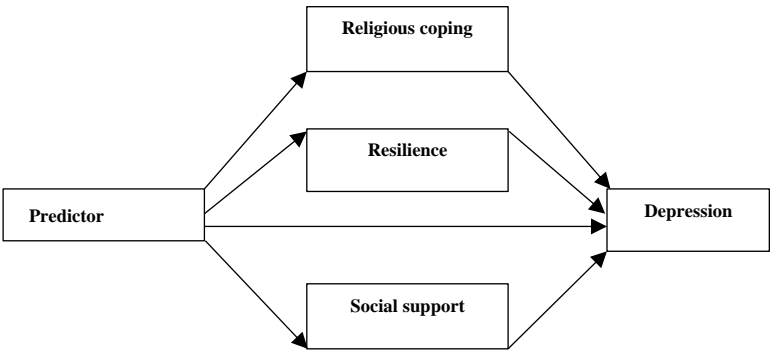
**Fig 6. 3**

*Theoretical model showing the relationship between the predictor variable and anxiety mediated by social support, resilience and religious coping*



**Fig 6.4**

*Theoretical model showing the relationship between the predictor variable and depression mediated by social support,*



**Method**

**Participants**

The present study consisted of an opportunity sample of 128 parents from Saudi Arabia. Participants were asked completed an online survey for this study. The survey explored the relationship between stress, anxiety, depression, challenging child behaviour, autism symptom severity, stigma, resilience, religious coping and social support. The inclusion criteria were restricted to parents with at least one child diagnosed with autism under the age of 18, specifically from Saudi Arabia. All participants were female aged between 24 and 55 (Mean age= 35.80; SD= 6.50). Children of the participants were between the ages of 4 and 17 (Mean age= 8.15; SD= 3.00) with 75.8% being male and 24.2% being female. Participants’ details are shown in (Table.6.1)

## Measures

The online survey included in this study consisted of a demographic questionnaire and the following psychometric scales: A validated Arabic translation of the Depression, Anxiety and Stress Scale (DASS-21; Lovibond & Lovibond, 1995; Moussa, Lovibond & Laube, 2001) which was already available and indicated adequate validity and consistency (Ali et al., 2017). A forward-backward translated version of The Child's Challenging Behaviour Scale (CCBS-Version 2; Bourke-Taylor, Law, Howie & Pallant, 2013) as well as a the The Gilliam's Autism Rating Scale (GARS-3; Gilliam, 2014) and The Affiliate Stigma Scale (ASS; Mak & Cheung, 2008). Participants were also given a validated Arabic translation of the Multidimensional Scale of Perceived Social Support (Arabic-MSPSS; Merhi & Kazarian, 2012), The Brief Resilience Scale (BRS; Smith et al., 2008) and The Brief Arab Religious Coping Scale (BARCS; Amer et al., 2008).

*Demographic Questionnaire* Information regarding the parent's and child's age, the parent's and child's gender as well as the parent's education level were collected to outline the sample characteristics. Information on the parent's nationality was also collected in order to ensure that the participant fitted into the inclusion criteria for this study.

*The Depression Anxiety Stress Scale* (DASS-21; Lovibond & Lovibond, 1995) is a 21 item self-report scale that measures stress, anxiety and depression and was developed for use in non-psychiatric populations (Lovibond & Lovibond, 1995). This scale is not intended for the clinical diagnosis of any participant, but only used in this study to detect symptoms of stress, anxiety and depression. The DASS-21 was selected in this study as it is relatively short, convenient and consists of questions that are direct and can be easily understood. Notably, the DASS-21 is able to effectively differentiate between the three constructs of stress, anxiety and depression. The DASS-21 consist of three 7-item subscales, each measuring one of the constructs of stress, anxiety and depression on a 4-point Likert scale ranging from (0 = never,

1 = sometimes, 2 = often, 3 = always). In order to score the DASS-21, each score must be multiplied by 2 to for the interpretation across all measures (Lovibond & Lovibond, 1995). The subscale for stress includes questions 1,6,8,11,12,14,18 which measures feelings of agitation, irritability, difficulty relaxing, impatience, nervous arousal and over-reactivity. The subscale for anxiety includes questions 2,4,7,9,15,19,20 which measures subjective and situational anxiety, physical effects of a panic attack and autonomic arousal. The subscale for depression includes questions 3,5,10,13,16,17,21 which measure dysphoria, hopelessness, self-deprecation, anhedonia, lack of interest, devaluation and inertia. The cut-off points for the stress subscale on the DASS-21 are 0-14 (normal), 15-18 (mild), 19-25 (moderate), 26-33 (severe), and  $> 34$  (severe). As for the anxiety subscales the cut-off points are as 0-7 (normal), 8-9 (mild), 10-14 (moderate), 15-19 (severe) and  $>20$  (extremely severe). For the depression subscale, the cut-off points are 0-9 (normal), 10-13 (mild), 14-20 (moderate), 21-27 (severe) and  $>28$  (extremely severe) (Lovibond & Lovibond, 1995). The DASS-21 has been shown to be internally consistent and stable  $\alpha = .85$ . (Henry & Crawford, 2005; Osman et al., 2012) and has been commonly used in a large number of studies measuring stress, anxiety and depression. The DASS-21 has also been shown to have reasonable levels of validity compared to other similar self-report measures with a correlation of above .70 to the Beck Depression Inventory (Lovibond & Lovibond, 1995; Sahebi, Asghari, & Salari, 2004) and .49 for the Hospital Anxiety and Depression Scale (Musa, Ramli, Abdullah, & Sarkarsi, 2011). This study employed the existing Arabic translated version of the DASS-21 (Moussa, Lovibond & Laube, 2001). Reliability testing for this version reported a Cronbach's Alpha of  $=.84$ . Moreover, the Cronbach's Alpha was calculated for the internal consistency of each subscale: Depression  $=.76$ , Anxiety  $=.80$  and Stress  $=.79$  in order to statistically analyze each mental health outcome of the DASS-21 as individual variables. In this study, reliability testing indicated high internal consistency  $\alpha = .84$ .

*The Child's Challenging Behaviour Scale* (CCBS-Version 2; Bourke-Taylor, Law, Howie & Pallant, 2013) is a 9-item scale for parents to report the difficult behaviours exhibited by their child who is diagnosed with a developmental condition or disability. This scale is frequently used in studies assessing parental mental health associated with caring for a child with a disability (Bourke-Taylor, Law, Howie & Pallant, 2013). Parents are instructed to rate each item on the scale corresponding to a specific behaviour exhibited by their child which they agree or disagree with using a four-point Likert rating scale (1 = strongly agree, 2 = agree, 3 = disagree, 4 = strongly disagree). The score ranges between 9 and 36, with higher scores representing more challenging child's behavior (Bourke-Taylor et al., 2017). The CCBS-Version 2 was initially developed by Bourke-Taylor, Howie and Law (2010) using a mixed method instrument design whereby qualitative and quantitative data was collected from (n=152) mothers of school aged children diagnosed with a disability. The psychometric evaluation of the scale indicated excellent internal consistency and produced a Cronbach's alpha value of .89. Considering that there was no existing Arabic version of the CCBS-Version 2, the original scale (Bourke-Taylor, Law, Howie & Pallant, 2013) was translated into Arabic using a forward-backward translation process. In this current study, reliability testing of the CCBS-Version 2 reported a Cronbach's Alpha of =.74.

*The Gilliam's Autism Rating Scale* (GARS-3; Gilliam, 2014) is a 58-item scale developed to identify persons with autism and assess the severity of their symptoms. In 2014, the GARS-3 was redeveloped to reflect the most current perspectives on ASC in the (DSM-5). The scale consists of items describing the characteristic behaviors of individuals with ASC. The items are separated into 6 subscales: Restrictive and Repetitive Behaviors, Social Interaction, Social Communication, Emotional Responses, Cognitive Style, and Maladaptive Speech. These subscales have been empirically determined to be valid for identifying and assessing the symptom severity of children with ASC. Items on the scale are scored on a 4-point Likert type

scale. Responses include (1 = not at all like the individual, 2 = not much like the individual, 3 = somewhat like the individual, 4 = very much like the individual). The scores of each subscale are then combined in order to provide a total score known as the Autism Index. Following the Autism Index score calculation, a corresponding severity level can then be identified. The GARS-3 provides 4 levels of probability of having ASD: level 0 with an Autism Index  $\leq 54$ , “unlikely;” level 1 with an Autism Index between 55 and 70, requiring “minimal support;” level 2 with an Autism Index between 71 and 100, “very likely” and requiring substantial support; level 3 with an Autism Index  $\geq 101$ , “very likely,” and requiring very substantial support (Gilliam, 2014). The internal consistency reliability coefficients for GARS-3 exceed .85 and the Autism Indexes exceed .93. The GARS-3 test-retest reliability coefficients exceed .80 for subscales and .90 for the Autism Indexes and the interrater reliability intraclass coefficients exceed .80 and .84 for the Autism Indexes. Moreover, correlations of the GARS-3 scores with other widely used diagnostic tests for ASC are large or very large in magnitude (Gilliam, 2014). The GARS-3 measure was developed and normed on over 1,800 individuals diagnosed with ASC between the ages 3 to 22 in the United States and has been frequently used in research concerned with Autism symptom severity levels. Since there was no existing Arabic version of the GARS-3, the original scale (Gilliam, 2014) was translated into Arabic using a forward-backward translation process. In this current study, reliability testing of the GARS-3 reported a Cronbach’s Alpha of  $\alpha = .91$ .

*The Affiliate Stigma Scale (ASS; Mak & Cheung, 2008)* is a 22-item scale which was developed in order to measure the cognitive, behavioural and affective components of affiliate stigma in parents or caregivers of people with mental illness or an intellectual condition (Mak & Cheung, 2008). This scale is usually used in studies assessing the mental health of caregivers of children with ASC (Lowell & Wetherell, 2018). Parents are instructed to rate each statement (Cognitive = 7 items, Affect = 7 items, and Behaviour = 8 items) using a 4-point Likert rating scale (1 =

strongly agree, 2 = agree, 3 = disagree, 4 = strongly disagree). The score ranges between 22 and 88, with higher scores indicating higher levels of affiliate stigma. The higher the mean score on the Affiliate Stigma Scale, the higher the internalized stigma as there is no cut-off score (Mak & Cheung, 2008). Considering that there was no existing Arabic version of the Affiliate Stigma Scale, the original scale (Mak & Cheung, 2008) was translated into Arabic using a forward-backward translation process. The psychometric evaluation of the scale in the original study indicated a high internal consistency  $\alpha = .94$  (Mak & Cheung, 2008) as well as in this current study  $\alpha = .86$ .

*The Brief Arab Religious Coping Scale* (BARCS; Amer et al., 2008) is a 15-item scale developed to assess religious coping methods specifically for Arab individuals. Items on the BARCS are answered on a 4-point Likert scale ranging from '0 = not used at all/does not apply' to '3 = used always'. The total score of the BARCS is calculated by adding the total responses of all of the items. The total possible score ranges from 0 to 75, with higher scores indicating greater levels of religious coping (Amer et al., 2008). Example items include, "I prayed for strength," and "I put my problem in God's hands." The BARCS has demonstrated a strong internal reliability  $\alpha = .95$ , a strong face validity and satisfactory construct validity (Amer et al., 2008) as well as in this current study  $\alpha = .86$ .

*The Brief Resilience Scale* (BRS; Smith et al., 2008) is a 6-item scale developed to measure a persons' ability to recover from stress (Smith et al., 2010) and is considered as a measure that relates closely to the original meaning of resilience. According to Smith et al. (2010), "resilience" or the ability to recover from stress is a different concept compared to "resilience resources" since resilience resources are related to constructs such as optimism and self-esteem which are not limited to the domain of stress and negative events, on the other hand, resilience itself is directly oriented towards stress. The BRS consists of 6 items which are answered using a 5-point Likert scale with responses such as: strongly disagree, disagree, neutral, agree and

strongly agree. Three of the items on the BRS are positively worded while the other three are negatively worded to reduce the likelihood of social desirability bias and positive response bias. The total BRS score is calculated by adding all the responses and subsequently dividing the sum by the number of items answered. The scores on the BRS range between 3-60, with higher scores indicating higher individual resilience (Smith et al., 2008). The BRS was reported to be positively correlated with aspects associated with resilience such as social support and purpose in life and negatively correlated with variables such as self-blame, anxiety and depression (Smith et al., 2008). The BRS was originally validated with two samples of university students (N=192) and was reported to have adequate results for factorial structure, convergent and discriminant validity as well as reliability (Smith et al., 2008). The BRS also demonstrated good internal consistency  $\alpha = .91-.98$  as well as test-retest reliability. In this study, reliability testing indicated high internal consistency  $\alpha = .85$ .

*The Multidimensional Scale for Perceived Social Support* (MSPSS; Zimet, Dahlem, Zimet & Farley, 1988) is a 12 item self-report scale that measures an individual's perceived level of support from three informal sources: friends, family and significant other. Each subscale consists of four items and scores can be obtained for each subscale separately. Items on the MSPSS are answered on a 7-point Likert scale ranging from '1 = very strongly disagree' to '7 = very strongly agree'. The total score of the MSPSS is calculated by adding the total responses of all of the items. The total possible score ranges from 12 to 84, with higher scores indicating greater levels perceived social support and lower scores indicating less perceived social support (Zimet, Dahlem, Zimet & Farley, 1988). The MSPSS is considered conveniently short and consists of clear and straightforward questions. Strong psychometric properties have been reported for the MSPSS with a strong internal consistency being reported for the family subscale  $\alpha = .90$ , the friends subscale  $\alpha = .94$ , the significant other subscale  $\alpha = .95$  as well as the total score  $\alpha = .91$  (Doku et al., 2015). This present study reported a  $\alpha = .90$  for the total

score. The MSPSS is the most commonly used measure for perceived social support and has been widely used in research on parental mental health associated with caring for a child with a disability (Osman et al., 2014).

## **Procedure**

Ethical approval to conduct this research project was obtained from the University of Lincoln Committee, U.K. The survey was developed online using the Qualtrics software. A survey distribution link was sent out to two ASC support groups for mothers in Saudi Arabia, two ASC learning centers and one ASC charity organization. All participants were directed to an information page which provided an overview of the study and emphasized that participation in this study is voluntary, and the process of data withdrawal was made clear. Participants were subsequently directed to a tick-box consent form prior to the survey and no personal information was collected in order to guarantee data protection and anonymity. Upon completion of the survey, participants were then taken to a debrief page which contained useful links on how to access local support in Saudi Arabia should they need it as well as the researcher's, supervisors' and university's contact details should they require more information about the study or wish to have their data withdrawn.

## **Data Analysis**

Data for each participant was scored for all measures in this study, giving a total DASS-21 (Lovibond & Lovibond, 1995) score as well as a score for each subscale measuring stress, anxiety and depression separately. A total CCBS (Bourke-Taylor, Law, Howie & Pallant, 2013) score for challenging child behaviour was also calculated as well as a total score for GARS-3 (Gilliam, 2014) in order to determine the ASC symptom severity level. Moreover, a total BARCS (Amer et al., 2008) score for religious coping was also calculated as well as a total score for the BRS (Smith, 2008) in order to determine the level of resilience. Furthermore, a total ASS (Mak & Cheung, 2008) score for affiliate stigma was also calculated as well as a



total MSPSS (Zimet et al., 1988) score for social support was also calculated as well as a score for each of the MSPSS's (Zimet et al., 1988) subscales (friends, family, significant other) in order to determine the level of perceived social support in each separate domain.

The examination of the raw dataset prior to analyzing the data showed 4.8% of responses containing missing item values. Multiple imputation was used to estimate the average missing values to ensure that all responses would be included in the current study. The process of analyzing the data combined standard statistical methods, correlational analyses, regression analyses were also conducted to assess whether specific variables statistically explain the amount of variance for the dependent variables using IBM SPSS 25 for Windows (IBM Corporation, Armonk, NY, USA). Multiple mediation modeling using PROCESS (Preacher & Hayes, 2008), an SPSS macro, was also employed to assess if any variables mediate the relationship between the dependent and independent variables or influence the conducted correlations. Model number 4 was used in the PROCESS macro to calculate three bootstrapped simple mediation models for the selected variables (Hayes, 2013). This method uses bootstrapping to estimate the parameters, which is particularly suitable for small samples. Affiliate stigma was used as the independent variable, parental stress, anxiety and depression were used as dependent variables, and resilience, religious coping and social support were used as mediator variables. The mediation analyses employed the bootstrap procedure with 1,000 repetitions in order to verify the effect of the mediator on the variables with a 95% confidence interval.

## **Results**

This study consisted of a total sample number of (N=128) participants. All participants in this study were female. Results indicate that 76% of the children were male and 24% were female. As for the education level of the participants, 4% reported no educational qualification, 24% reported having a high-school degree, 23% reported some university but no degree, 41%

reported having a bachelor's degree, 6% reported having a postgraduate degree and 2% reported having a vocational diploma. Standard descriptive statistical calculations were conducted for the demographic data of the study and are shown in (Table.6.1). Descriptive statistics for the variables investigated in this study were also calculated and are displayed in (Table.6.2).

**Table 6.1**

*Descriptive statistics for demographic questions*

	N	MEAN	SD	MIN	MAX
Age of Child	128	8.15	3.00	4.00	17.00
Age of Mother	128	35.80	6.50	24.00	55.00

The results for the outcome variables of stress, anxiety and depression were normally distributed. The results for stress indicated a mean of 24.63 (SD=9.19) with a minimum score of 4 and a maximum score of 40. The values of the stress scores show that 59.0% of participants experienced severe/extremely severe levels of stress associated with caring for a child with ASC. The anxiety scores show a mean of 21.43 (SD=10.05) with a minimum score of 2 and a maximum score of 43. The results of the anxiety scores indicate that 76.1% of participants experienced severe/extremely severe levels of anxiety associated with caring for a child with ASC. The results for the variable of depression showed a mean of 19.34 (SD=8.90) with a minimum score of 4 and a maximum score of 38. The depression scores indicate that 52.1% of participants experienced severe/extremely severe levels of depression associated with caring for a child with ASC.

The results for the potential predictor variables of challenging child behaviour, autism symptom severity and affiliate stigma were also normally distributed. The results for

challenging child behaviour indicated a mean of 25.94 ( $SD=5.09$ ) with a minimum score of 17 and a maximum score of 36. The values of the challenging behaviour scores show that 91.5% of participants rated their child's behaviour as challenging. The autism symptom severity scores show a mean of 2.23 ( $SD=.42$ ) with a minimum score of 2 and a maximum score of 3. The results of the autism symptom severity scores indicate that 77.3% of participants have a child with Level 2 Autism (requiring substantial support) and 22.7% of parents reported that their child would be considered as having Level 3 Autism (requiring very substantial support). There were no reports of Level 1 Autism (requiring minimal support) in this present study. The results for the variable of affiliate stigma showed a mean of 58.09 ( $SD=17.63$ ) with a minimum score of 32 and a maximum score of 84. The affiliate stigma scores indicate that 54.7% of participants experienced high levels of affiliate stigma.

The results for the potential mediating variables of individual resilience, religious coping and social support were also normally distributed. The results for individual resilience indicated a mean of 19.16 ( $SD=5.76$ ) with a minimum score of 13 and a maximum score of 29. The values of the resilience scores show that 71.1% of participants reported high levels of individual resilience. The results for the variable of religious coping showed a mean of 21.84 ( $SD=13.81$ ) with a minimum score of 6 and a maximum score of 45. The religious coping scores indicate that 52.3% of participants reported high levels of religious coping. The results for the variable of perceived social support showed a mean of 52.72 ( $SD=15.07$ ) with a minimum score of 32 and a maximum score of 75. The results of the perceived social support scores indicate that 32.8% of participants reported low levels of social support while 67.2% of the participants reported high levels of social support.

**Table 6.2**

*Descriptive statistics for stress, anxiety, depression, challenging behaviour, autism symptom severity, affiliate stigma, resilience, religious coping and perceived social support*

	N	MEAN	SD	MIN	MAX
Stress	128	24.63	9.19	4.00	40.00
Anxiety	128	21.43	10.04	2.00	43.00
Depression	128	19.34	8.90	4.00	38.00
Challenging Behaviour	128	25.94	5.09	17.00	36.00
ASC Symptom Severity	128	2.23	.42	2.00	3.00
Affiliate Stigma	128	58.09	17.63	32.00	84.00
Resilience	128	19.16	5.80	13.00	29.00
Religious Coping	128	21.84	13.81	6.00	45.00
Social Support	128	52.72	15.07	32.00	75.00

Stress, Anxiety and Depression, *Depression, Anxiety and Stress Scale: (DASS- 21)*; Challenging Child Behaviour, *Child's Challenging Behavior – CCBS (Version 2)*; Autism Symptom Severity, *Gilliam Autism Rating Scale- Third Edition GARS-3*; Affiliate Stigma, *the Affiliate Stigma Scale (ASS)*; Religious Coping, *the Brief Arab Religious Coping Scale (BARCS)*; Resilience, *Brief Resilience Scale (BRS)*; Social Support, *The Multidimensional Scale for Perceived Social Support (MSPSS)*

Correlational analyses were conducted to explore the relationship between all the study variables (Table.6.3). Pearson's Correlation results indicated positive significant correlations between the variable of stress and the variable of challenging behaviour ( $r = .50$ ,  $N = 128$ ,  $p < .001$ ) indicating that an increase in challenging child behaviour is associated with an increase in levels of stress. Similarly, results indicate that an increase in autism symptom severity ( $r = .34$ ,  $N = 128$ ,  $p < .001$ ) is also associated with an increase in parental stress. Moreover, results indicate a positive significant association between stress and affiliate stigma ( $r = .64$ ,  $N = 128$ ,  $p < .001$ ) indicating that an increase in affiliate stigma is linked to higher levels of parental stress. Additionally, results showed a negative significant correlation between the variable of stress and resilience ( $r = -.74$ ,  $N = 128$ ,  $p < .001$ ) suggesting that increased levels of resilience

are associated with decreased levels of parental stress. Also, results indicate that an increase in religious coping ( $r = -.63$ ,  $N = 128$ ,  $p < .001$ ) is associated with a decrease in parental stress. Furthermore, correlation results also show a negative significant correlation between the parental stress and the variable of social support ( $r = -.55$ ,  $N = 128$ ,  $p < .001$ ) indicating that higher levels of social support are linked to lower levels of reported parental stress.

In addition, correlational results indicated a positive significant correlation between the variable of anxiety and the variable of challenging behaviour ( $r = .41$ ,  $N = 128$ ,  $p < .001$ ) indicating that an increase in challenging child behaviour is associated with an increase in levels of anxiety. Similarly, results indicate that an increase in autism symptom severity ( $r = .50$ ,  $N = 128$ ,  $p < .001$ ) is also associated with an increase in parental anxiety. Moreover, results indicate a positive significant association between anxiety and affiliate stigma ( $r = .60$ ,  $N = 128$ ,  $p < .001$ ) indicating that an increase in affiliate stigma is linked to higher levels of parental anxiety. Additionally, results showed a negative significant correlation between the variable of anxiety and resilience ( $r = -.74$ ,  $N = 128$ ,  $p < .001$ ) suggesting that increased levels of resilience are associated with decreased levels of parental anxiety. Also, results indicate that an increase in religious coping ( $r = -.70$ ,  $N = 128$ ,  $p < .001$ ) is associated with a decrease in parental anxiety. Furthermore, correlation results also show a negative significant correlation between the parental anxiety and the variable of social support ( $r = -.59$ ,  $N = 128$ ,  $p < .001$ ) indicating that higher levels of social support are linked to lower levels of reported parental anxiety.

Moreover, correlational results indicated a positive significant correlation between the variable of depression and the variable of challenging behaviour ( $r = .44$ ,  $N = 128$ ,  $p < .001$ ) indicating that an increase in challenging child behaviour is associated with an increase in levels of depression. Similarly, results indicate that an increase in autism symptom severity ( $r = .30$ ,  $N = 128$ ,  $p < .001$ ) is also associated with an increase in parental depression. In addition, results indicate a positive significant association between depression and affiliate stigma ( $r =$

.54,  $N = 128$ ,  $p < .001$ ) indicating that an increase in affiliate stigma is linked to higher levels of parental depression. However, results showed a negative significant correlation between the variable of depression and resilience ( $r = -.70$ ,  $N = 128$ ,  $p < .001$ ) suggesting that increased levels of resilience are associated with decreased levels of parental depression. Also, results indicate that an increase in religious coping ( $r = -.90$ ,  $N = 128$ ,  $p < .001$ ) is associated with a decrease in parental depression. Furthermore, correlation results also show a negative significant correlation between the parental depression and the variable of social support ( $r = -.64$ ,  $N = 128$ ,  $p < .001$ ) indicating that higher levels of social support are linked to lower levels of reported parental depression.

Additionally, correlational results indicated a positive significant correlation between the variables of challenging child behaviour and autism symptom severity ( $r = .42$ ,  $N = 128$ ,  $p < .001$ ) and challenging child behaviour and affiliate stigma ( $r = .62$ ,  $N = 128$ ,  $p < .001$ ) indicating that reports of increased challenging child behaviour are associated with increased levels of affiliate stigma as well as autism symptom severity. On the other hand, increased levels of challenging child behaviour were associated with lower levels of resilience ( $r = -.41$ ,  $N = 128$ ,  $p < .001$ ), lower levels of religious coping ( $r = -.39$ ,  $N = 128$ ,  $p < .001$ ) and lower levels of social support ( $r = -.42$ ,  $N = 128$ ,  $p < .001$ ). Moreover, results show a significant positive correlation between autism symptom severity and affiliate stigma ( $r = .51$ ,  $N = 128$ ,  $p < .001$ ) but a negative significant correlation between autism symptom severity and resilience ( $r = -.23$ ,  $N = 128$ ,  $p < .001$ ), religious coping ( $r = -.30$ ,  $N = 128$ ,  $p < .001$ ) and social support ( $r = -.20$ ,  $N = 128$ ,  $p < .05$ ). Furthermore, results indicated a negative significant correlation between the variable of affiliate stigma and the variables of resilience ( $r = -.64$ ,  $N = 128$ ,  $p < .001$ ), religious coping ( $r = -.67$ ,  $N = 128$ ,  $p < .001$ ) as well as social support ( $r = -.53$ ,  $N = 128$ ,  $p < .001$ ). Finally, correlation results show a significant positive correlation between resilience and

religious coping ( $r = .90$ ,  $N = 128$ ,  $p < .001$ ), resilience and social support ( $r = .81$ ,  $N = 128$ ,  $p < .001$ ) and between religious coping and social support ( $r = .76$ ,  $N = 128$ ,  $p < .001$ ). (Table 6.3).

**Table 6.3**

*Correlations between stress, anxiety, depression, challenging child behaviour, autism symptom severity, affiliate stigma, religious coping, resilience and social support*

	Stress	Anxiety	Depression	Challenging Behaviour	ASC Symptom Severity	Affiliate Stigma	Resilience	Religious Coping	Social Support
Stress	1.00	.63**	.60**	.50**	.34**	.64**	-.74**	-.63**	-.55**
Anxiety		1.00	.62**	.41**	.50**	.60**	-.74**	-.70**	-.59**
Depression			1.00	.44**	.30**	.54**	-.70**	-.90**	-.64**
Challenging Behaviour				1.00	.42**	.62**	-.41**	-.39**	-.42**
ASC Symptom Severity					1.00	.51**	-.23**	-.30**	-.20*
Affiliate Stigma						1.00	-.64**	-.67**	-.53**
Resilience							1.00	.90**	.81**
Religious Coping								1.00	.76**
Social Support									1.00

Stress, Anxiety and Depression, *Depression, Anxiety and Stress Scale: (DASS- 21)*; Challenging Child Behaviour, *Child's Challenging Behavior – CCBS (Version 2)*; Autism Symptom Severity, *Gilliam Autism Rating Scale- Third Edition GARS-3*; Affiliate Stigma, *the Affiliate Stigma Scale (ASS)*; Religious Coping, *the Brief Arab Religious Coping Scale (BARCS)*; Resilience, *Brief Resilience Scale (BRS)*; Social Support, *The Multidimensional Scale for Perceived Social Support (MSPSS)*

Significance - \*\* $p < 0.01$ , \* $p < 0.05$

Considering that the variables of challenging child behaviour, ASC symptom severity and affiliate stigma were all significantly and negatively associated with stress, anxiety and depression, three linear regression analyses were conducted in order to explore which factor contributed the most to elevating the levels of reported parental mental health issues. First, a regression analysis was conducted to determine whether challenging child behaviour, autism symptom severity or affiliate stigma predicted lower levels of parental stress. The model explained 41.2% of the variance and was significant ( $F(3,124) = 30.72, p < .001$ ). Regression results indicated that affiliate stigma was the only significant predictor of stress in parents of children with ASC ( $\beta = .28, p < .001$ ) and that ASC symptom severity and challenging child behaviour did not predict parental stress. Secondly, another regression analysis was conducted to determine whether parental anxiety could be predicted by challenging child behaviour, autism symptom severity or affiliate stigma. The model explained 39.6% of the variance and was significant ( $F(3,124) = 28.75, p < .001$ ). Regression results indicated that affiliate stigma was also the only significant predictor of anxiety in parents of children with ASC ( $\beta = .23, p < .001$ ) and that ASC symptom severity and challenging child behaviour were not predictors of anxiety. Finally, a regression analysis was conducted in order to determine whether ASC symptom severity, challenging child behaviour or affiliate stigma could potentially predict parental depression. The model explained 36% of the variance and was significant ( $F(3,124) = 23.87, p < .001$ ). Regression results indicated that affiliate stigma was also the only significant predictor of reported levels of depression in parents of children with ASC ( $\beta = .27, p < .001$ ) and that ASC symptom severity and challenging child behaviour did not predict depression.

Three multiple mediation analyses for each outcome variable of (stress, anxiety, depression) were conducted using the SPSS macro PROCESS (Hayes, 2013) to explore whether the variables of social support, resilience and religious coping would act as mediating variables in the relationship between the dependent variables of stress, anxiety, depression and



the independent variable of affiliate stigma. For the mediation, model 4 in the SPSS macro PROCESS was used and its specifications recommend using boot=1000 which uses 1000 bootstrap samples in order to estimate the 95% confidence interval for the indirect effects of the variables. The macro PROCESS does not calculate effect size “ $\kappa^2$ ” when there is more than one mediator (Hayes, 2013, p.432). Moreover, Wen and Fan (2009) suggest avoiding the use of effect size calculations in mediation analysis due to “ $\kappa^2$ ” lacking in property of rank preservation and its tendency to produce paradoxical mediation results.

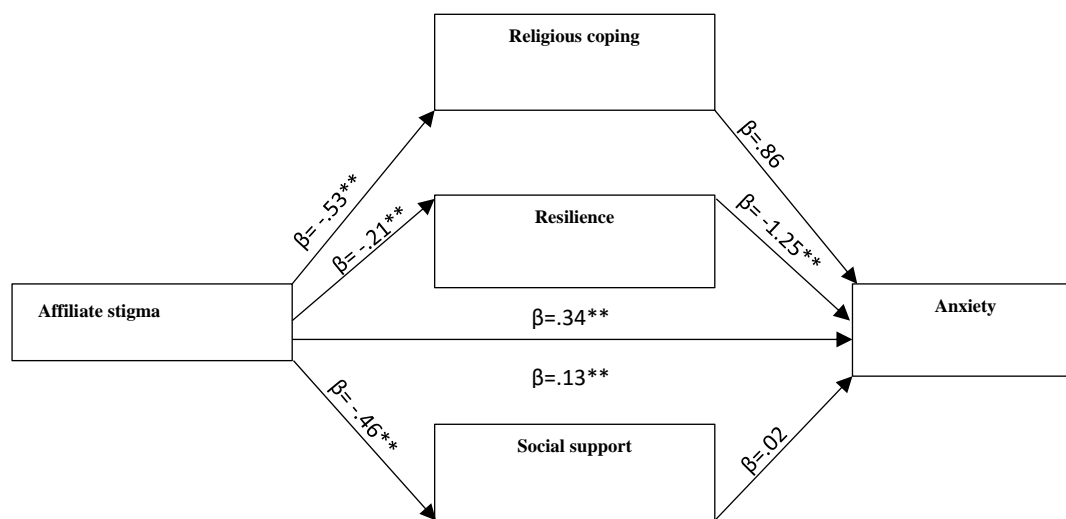
This study assessed the mediating roles of resilience, religious coping and social support on the relationship between affiliate stigma and the outcomes variables of stress, anxiety and depression using three separate multiple mediation models. Firstly, the demographic variables were entered as covariates for each mediation model. The first mediation model assessed the relationship between affiliate stigma and stress. In support of the research assumption, the direct relationship between the independent variable of affiliate stigma and the dependent variable of stress was significantly maintained ( $c'=.18, p<.001$ ) along with a significant total effect of ( $c=.03, p<.001$ ) which is in line with the regression and correlations and was not altered by entering the mediating variables. Although there was a significant relationship between all the mediating variables and the independent variable of affiliate stigma, this relationship did not extend to the dependent variable of stress, thus rendering the mediation model insignificant.

The second mediation model explored the relationship between affiliate stigma and anxiety. In support of the research assumption, the relationship between the independent variable of affiliate stigma and the dependent variable of anxiety showed a significant indirect effect ( $c'=.13, p<.001$ ) and had a significant total effect of ( $c=.34, p<.001$ ) indicating that affiliate stigma positively predicts anxiety. The variables of religious coping and social support did not significantly mediate the relationship between affiliate stigma and anxiety despite

maintaining a significant relationship to the independent variable of affiliate stigma. However, resilience was the only variable that significantly mediated the relationship between affiliate stigma and anxiety ( $b = -1.26$ , 95% BCa CI  $[-1.75, -.76]$ ). Hence, resilience partially mediated the relationship between affiliate stigma and anxiety. (Fig.6.5)

**Fig 6.5**

*Mediation model showing the relationship between affiliate stigma and anxiety mediated by resilience*



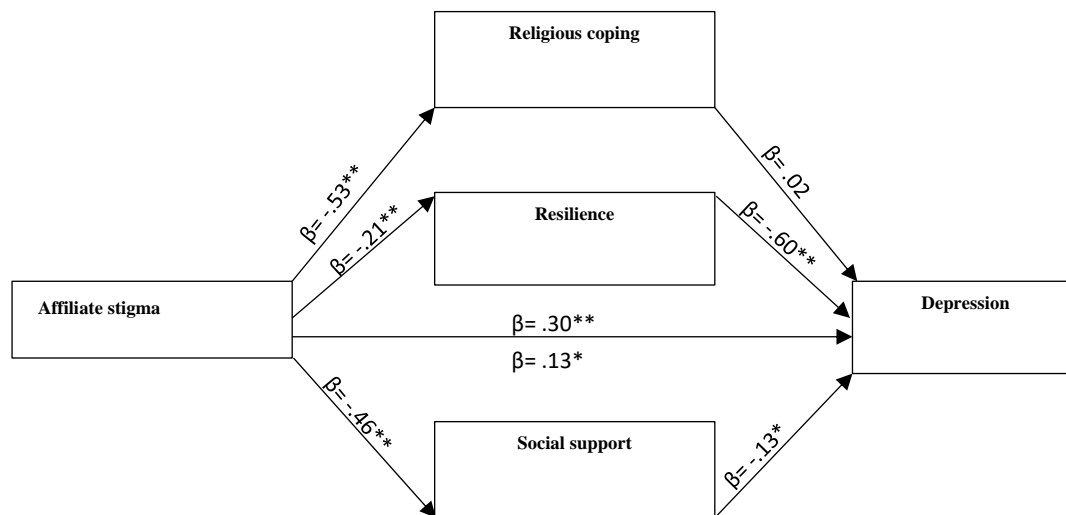
Significance -  $^{**}p < 0.01$ ,  $^{*}p < 0.05$

The third mediation model assessed the relationship between affiliate stigma and depression. In support of the research assumption, the relationship between the independent variable of affiliate stigma and the dependent variable of depression showed a significant indirect effect ( $c' = .13$ ,  $p < .05$ ) and had a significant total effect of ( $c = .30$ ,  $p < .001$ ) indicating that affiliate stigma positively predicts depression. The variable of religious coping did not significantly mediate the relationship between affiliate stigma and depression despite maintaining a significant relationship to the independent variable of affiliate stigma. On the other hand, both resilience ( $b = -.60$ , 95% BCa CI  $[-1.05, -.14]$ ) and social support ( $b = -.13$ , 95% BCa CI  $[-.25, -.03]$ ) significantly mediated the relationship between affiliate stigma and

depression ( $b = -1.26$ , 95% BCa CI  $[-1.75, -.76]$ ). Hence, both resilience and social support partially mediated the relationship between affiliate stigma and anxiety. (Fig.6.6)

**Fig 6.6**

*Mediation model showing the relationship between the affiliate stigma and depression mediated by resilience.*



Significance -  $^{**}p < 0.01$ ,  $^*p < 0.05$

## Discussion

The aim of this study was to explore the impact resilience, religious coping and social support have on the relationship between affiliate stigma, autism symptom severity and challenging child behavior and parental mental health issues, specifically: stress, anxiety and depression in parents of children with ASC from Saudi Arabia. Five key findings emerged from this study. Firstly, in line with previous research, the majority of participants in the present study reported high levels of stress, anxiety and depression, which were relatively above the population mean. Secondly, also in line with previous research, challenging child behaviour, autism symptom severity and affiliate stigma were positively and significantly associated with stress, anxiety and depression. Moreover, resilience, religious coping and social support were negatively and significantly associated with stress, anxiety and depression. Thirdly, this study

found affiliate stigma to be the only significant predictor of stress, anxiety and depression in this participant sample. Fourthly, the relationship between affiliate stigma and anxiety is partially explained by levels of resilience in parents. Finally, the relationship between affiliate stigma and depression is partially explained by resilience and perceived social support.

The results support the findings from a relatively significant number of previous studies indicating that parents of autistic children often report high levels of stress, anxiety and depression (e.g., Dabrowska & Pisula, 2010; Estes et al., 2013; Hayes & Watson, 2013; Wang et al., 2011; Dykens & Lambert, 2013; Weiss, 2002; Stein et al., 2011; Kuusikko-Gauffin et al., 2013; Falk et al., 2014). Moreover, the results from this study also support findings from studies which suggest that challenging child behaviour (e.g., Donenberg & Baker, 1993; Seltzer et al., 2001; Tomanik et al., 2004; Herring et al., 2006; Lecavalier et al., 2006; Osborne and Reed, 2009; Estes et al., 2013), autism symptom severity (e.g., Liwag, 1989; Foronda, 2000; Nikmat et al., 2008; Charmsil & Bathia, 2010; Yeo & Lu, 2012; Athari et al., 2013; Wisessathorn et al., 2013; Lai et al., 2015; Ilias et al., 2016) and affiliate stigma (e.g., Mak & Cheung, 2008; Corrigan & Watson, 2002; Crabtree 2007; Green, 2007; Gray, 2002; Falk et al., 2014; Papadopoulos et al. 2018) are associated with higher levels of parental stress, anxiety and depression (See chapter 2 & 3). Furthermore, the results from this study also support findings from previous studies which suggest that high levels of resilience (e.g., Hayes & Watson, 2013; Bekhet, Johnson, & Zauszniewski, 2012; Bitsika, 2013; Bonanno et al., 2015; Garmezy, 1987; Luthar et al., 2000; Masten, 2011), religious coping (e.g., Haworth et al., 1996; McIntosh et al., 1993; Tarakeshwar & Pargament, 2001) and social support (e.g., Dunn et al., 2001; Ramisch, 2010; Sanders & Morgan, 1997; SimanTov & Kaniel, 2011; Stuart & McGrew, 2009) are associated with lower levels of parental stress, anxiety and depression (See chapter 4 & 5). Given that the participant sample in this study is relatively understudied and that the majority of previous research on parental mental health associated with caring for an autistic

child is predominantly conducted in Western countries, it is important to note that the proposed associations between the factors affecting parental mental health mentioned throughout the literature are also evident in parents of autistic children in Saudi Arabia. This could potentially suggest that despite the variation in cultural contexts, there are several facets to parental experiences caring for an autistic child that could be considered as universal.

Although this study found a significant association between increased levels of challenging child behaviour, ASC symptom severity, affiliate stigma and increased levels of parental stress, anxiety and depression, further statistical analyses have shown affiliate stigma to be the only significant predictor of mental health issues in this participant sample. These findings give credence to previous studies which suggest that affiliate stigma acts as a significant contributor to stress, anxiety and depression in parents of children with ASC (Mak & Cheung, 2008; Corrigan & Watson, 2002; Crabtree 2007; Green 2007; Gray 2002; Falk et al., 2014; Papadopoulos et al. 2018). Moreover, previous studies have also indicated that parents of autistic children are more likely report higher levels of mental health issues in comparison to parents of non-autistic children and parents of children diagnosed with other developmental conditions (Estes et al., 2013; Herring et al., 2006; Illias, Cornish, Kummar, Park, & Golden, 2018; Lecavalier, Leone, & Wiltz, 2006; Osborne & Reed, 2009; Tomanik, Harris, & Hawkins, 2004). Since this link has been it has been well established in the literature that caregivers of autistic children are at a higher risk of developing mental health issues in comparison to the general population (Da Pasz & Wallander, 2017; Zablotzky et al., 2013; Sander & Morgan, 1997). It is important to note that when parents experience mental health issues, the children they are caring for are also at a higher risk of experiencing mental health issues as well as potential delays in their overall development (Osbourne et al., 2008; Dykens et al., 2014).

Moreover, given that individuals from different cultures around the world have varied perceptions towards mental health in general, including developmental conditions such as autism, it is essential to look at how autism is understood and managed by parents in population samples from cultures that are somewhat understudied. Parents' perceptions regarding their child's developmental condition among different cultural groups has been a focal point in recent literature (Daudji et al., 2011; Diken, 2006; García, Pérez, & Ortiz, 2000; Kermanshahi et al., 2008; Masasa, Irwin-Carruthers, & Faure, 2005) with some studies highlighting the idea that developmental conditions are perceived differently in every culture. Furthermore, these varying perceptions tend to shape parental perceptions towards their children as well as the time and resources these parents were willing to invest in terms of their child's treatment, education and social inclusion. As such, a cultural understating of ASC is essential. According to Groce (1999), individuals with disabilities are not usually limited by their impairments but more so by the cultural interpretation of their condition. As such, it is important to understand what is normative within a particular culture with regards to developmental conditions such as autism as parents from different cultural contexts may be impacted differently by their child's condition (Santos & Mccollum, 2007). Despite the majority of studies emphasizing the potential of a causal link between child characteristics (challenging child behaviour and ASC symptom severity) and parental mental health issues, this study, with a participant sample from Saudi Arabia, found the experiences of affiliate stigma associated with autism to be the only predictor of parental mental health issues.

Seeing as parents of autistic children are particularly vulnerable to experiencing affiliate stigma (Mak & Cheung, 2008), whereby the public's negative attitudes towards the autistic child and parent becomes internalized by the parent, it is important to explore how affiliate stigma affects parents of autistic children from different cultural backgrounds, especially in parts of the world where mental health problems such as anxiety and depression

also remain highly stigmatized (Papadopoulos, 2016). According to Samadi and McConkey (2011), there is a dire need for further research about the stigma faced by parents of children with ASC to be conducted in developing countries as the bulk of existing research on stigma is mostly limited to parents of children with ASC from Western countries. As such, there is a gap in the literature with regards to experiences of affiliate stigma amongst parents of autistic children from Arab countries including Saudi Arabia. Therefore, one of the aims of this study was to explore the relationship between parental mental health and affiliate stigma among parents of autistic children in Saudi Arabia. Research by Papadopoulos, Foster and Caldwell (2013) found that collectivist cultures were more likely to stigmatize individuals who deviate from the social norms compared to individualistic cultures. Seeing as Saudi Arabia is considered to be a collectivist culture, the impact of affiliate stigma on parents of autistic children could therefore be particularly relevant in understanding their overall experiences of caring for an autistic child.

Although some development has been made in Saudi Arabia in terms of mental health awareness, the Saudi Arabian society still tends to marginalize individuals with disabilities and developmental conditions for several reasons including as the lack of awareness and knowledge about the condition itself and the idea of shame associated with having mental health issues or disability (Al-Jadid, 2014). Despite there being no existing studies on affiliate stigma experienced by parents of autistic children in Saudi Arabia, the results from this study show that the majority of parents reported having experienced high levels of affiliate stigma which predicted their high levels of stress, anxiety and depression. The results from this study could potentially provide professionals and future researchers with a better understanding of the stress, anxiety and depression that Saudi Arabian parents experience caring for their autistic child. This study could also help to inform care providers of the potential effects that affiliate stigma has on parents which could improve the quality of care they provide. Considering the

importance of parental mental health in terms of supporting their child with ASC, culturally informed interventions targeting affiliate stigma, parental stress, anxiety and depression is necessary in order to ensure the overall wellbeing of both child and parent.

The analysis of parental mental health associated with caring for an autistic child should usually be considered from a more complex perspective that go beyond bivariate relationships seeing as these relationships may be explained or modified by other variables as well. The results from this study indicated that affiliate stigma was the only significant predictor of mental health issues in parents of autistic children in this participant sample from Saudi Arabia, therefore, this study aimed to explore the impact of resilience, religious coping and social support on the relationship between affiliate stigma and parental mental health.

Across all three of the mediation models the variable of religious coping did not seem to have a significant impact on the relationship between affiliate stigma and parental stress, anxiety or depression. Despite a number of studies showing that religious coping is a form of adaptive coping that alleviates parental stress, anxiety and depression (Kim & Esquivel, 2011; Pargament, Tarakeshwar, Ellison, & Wulff, 2001) and acts as a buffer against stressors such as challenging child behaviour and social stigma (Friedrich et al., 1988), religious coping did not have a significant impact on the relationship between affiliate stigma, stress, anxiety or depression. Religious coping as an adaptive coping mechanism has only recently gained more attention in the field of parental mental health (Folkman et al., 2004). Despite the benefits of religious coping being well documented for both psychological and physical outcomes (Koenig et al., 2001, Larson et al., 2003, Seybold et al., 2001), its function as a resource for coping remains understudied. Although some studies have emphasized the potential for religious coping to act as a buffer against mental health issues, other studies have postulated that religious coping can neither be regarded as a problem-focused nor emotion-focused type of coping (Tamres et al., 2002). Moreover, studies by Cook et al. (1997) and Hudek-Knežević



(1999) interpret the low factor loadings of religious coping with other forms of coping as an attribute of a distinctive and independent coping strategy. Studies of a comparative nature that explore the dynamics of a family with a child diagnosed with a disability in ethnic contexts typically cite religious coping and spirituality as a salient coping strategy that positively impacts family adjustment (Duvdevany & Vudinsky, 2005; Khamis, 2007; Skinner, Correa, Skinne, & Bailey, 2001; Tarakeshwar & Pargament, 2001; Allen & Marshall, 2010; Feudtner, Haney & Dimmers, 2003; Schneider & Mannell, 2006). However, a study by Hastings et al. (2005) found that religious coping was associated with higher levels of depression in parents of autistic children from the UK. Although a discrepancy like this could be associated with the variation in culture, it does suggest that more research is needed in the context of parental mental health and religious coping. Additionally, a literature review conducted by Pearce (2005) found that only four studies have examined religious coping as a mediator between stressors and caregiver mental health (Abernethy et al., 2002; Fitchett et al., 1999; Tix and Frazier, 1998). In three of these four studies, religious coping did not act as a significant mediator even after controlling for other psycho-social mediators. The one study by Chang et al. (1998) indicated that religious coping mediated the effect between the stressor and caregiver distress. Religious coping has been selected as a potential mediator in this study due to its cultural significance considering the participant sample recruited in this study. Despite it being negatively associated with parental stress, anxiety and depression, it did not mediate the relationship between affiliate stigma and stress, anxiety or depression. Thus, it is evident that more research is needed to determine whether religious coping may have a different impact on the relationship between affiliate stigma and parental mental health or whether other unexplored variables could be influencing this relationship.

Although studies have highlighted the critical role perceived social support plays in helping parents of autistic children cope with higher levels of stress, anxiety and depression

(e.g., Tehee et al., 2009; Ekas et al., 2010; Lovell et al., 2012; Weiss et al., 2013; Mackintosh et al., 2012; Vohra et al., 2014; Bailey, Wolfe, & Wolfe, 1994; Dunn et al., 2001; Gallagher & Whiteley, 2012; Gray & Holden, 1992; Hare, Pratt, Burton, Bromley, & Emerson, 2004; McCallion, Janicki, & Kolomer, 2004; Weiss, 2002; Luther, Canham & Young-Cureton, 2005; Schilling, Gilchrist, & Schinke, 1984), in line with these studies, the results in this study found that social support mediated the relationship between affiliate stigma and parental depression, however, it did not mediate the relationship between affiliate stigma and stress or anxiety. Studies exploring the role of social support as a mediator consistently report the buffering effect social support has against parental stress, specifically support from friends, family and a partner. Typically, higher levels of perceived social support have been associated with lower levels of distress in parents of children with ASC (Lindsey & Barry, 2018). Results from this study show social support mediating the relationship between affiliate stigma and depression. Although these findings support previous studies that suggest that social support acts as a protective factor against depressive symptoms (Benson & Karlof, 2009; Weiss et al., 2012) however a significant impact was not found when it came to the outcomes of stress and anxiety in this study. This could potentially be explained by the participant sample size or the presence of other unidentified factors influencing the relationships between affiliate stigma, parental stress and anxiety. Seeing as previous studies have suggested that parent's perception of autism and how they provide support for their child are significantly influenced by their cultural background (Gona, Newton, Rimba, Mapenzi, Kihara, Van de Vijver, et al., 2015; Mandell & Novak, 2005; Mire, Gealy, Kubiszyn, Burrige, & Goin-Kochel, 2015; Ponde & Rousseau, 2013), it is important to explore the dynamics of perceived social support amongst an understudied population sample such as Saudi Arabia in order to gain a better understanding on how caring for an autistic child in other parts of the world can have an influence on family functioning and parental psychological wellbeing (Bayat, 2007).

Since resilience has recently emerged as a growing field of interest, particularly in research revolving around parents of children with ASC, it was selected as a potential mediator in order to explore its impact on stress, anxiety and depression in parents of children with ASC from Saudi Arabia. Although research has found that parents of children diagnosed with autism who score highly on resilience scales tend to report lower levels of parenting stress, anxiety and depression and are more adept at managing the challenges of caring for their child (Hayes & Watson, 2013; Bekhet, Johnson, & Zauszniewski, 2012), there are no known quantitative studies to date exploring resilience in parents of autistic children in Saudi Arabia. In line with previous studies, resilience significantly mediated the relationship between affiliate stigma and parental anxiety as well as the relationship between affiliate stigma and parental depression. However, it did not have any significant effect on the relationship between affiliate stigma and stress. Resilience is generally regarded as a dynamic process whereby an individual has the ability to effectively recover from stressful situations (Smith et al., 2010). In the parenting or care-providing context, resilience is considered as the ability of a parent or caregiver to bounce-back from a stressful situation deriving from the context of care-providing without compromising their mental health (Fernández-Lansac et al., 2012, Lin et al., 2013). Therefore, resilience can be regarded as a dynamic process as opposed to static one indicating that parents of autistic children could potentially be helped to increase their levels of resilience in order to alleviate symptoms of stress, anxiety and depression. Some studies have even shown that highly resilient parents tend to have a positive overview of the caring process and is sometimes seen as an opportunity for personal growth (Fernández-Lansac & Crespo, 2011; Heiman, 2002; Bayat, 2007, Phelps et al., 2009).

Although resilience in parents of autistic children is still an emerging field with no known studies conducted on this topic in Saudi Arabia to date, results from this study show that it is an important factor to consider when exploring the relationship between affiliate

stigma and parental mental health. In the Saudi Arabian society, stigma associated with autism is still extremely prevalent (Alenazi et al., 2020) (See chapter 1 & 3). Consequently, parents of autistic children tend to socially isolate both themselves and their children as a result of the negative experiences they face. However, not all parents share such similar negative experiences, and it is therefore imperative to highlight how protective factors such as resilience impact parental experiences of caring for a child with autism in Saudi Arabia in order to help mental health care providers, pediatricians and autism specialists intervene with parents in order to support their child's development and also reinforce their resilience and overall wellbeing (Bravo-Benítez et al., 2019).

There are currently a very limited number of studies on the experiences of parents of autistic children in Saudi Arabia. Despite this, Saudi Arabia, similar to other countries around the world has been seeing an increase in the prevalence of ASC cases (Al-Gadani, El-Ansary, Attas, & Al-Ayadhi, 2009; Alqahtani, 2012; Al-Salehi, Al-Hifthy, & Ghaziuddin, 2009). It is important to note that although data on the prevalence of ASC and any factors associated with it in Saudi Arabia are very limited, the increase in the number of diagnosed ASC cases also means that more parents of autistic children will potentially require support. The outcomes of this study can be considered as a response to the call to increase the quantity and quality of scientific studies focused on parents of autistic children within the cultural context of Saudi Arabia (Sulaimani & Gut, 2019). Moreover, although somewhat culturally challenging, public awareness campaigns to reduce autism stigma is an important factor to consider in order for parents of autistic children to feel more socially supported and reduce the level of affiliate stigma they may experience (Sulaimani & Gut, 2019). The results from this study could potentially provide professionals and future researchers with a clearer understanding of the experiences that Saudi Arabian parents have when caring for their autistic child. This study

could also help in informing care providers of the beneficial effects protective factors have on parental mental health which could improve the quality of care they deliver.

There are several limitations to note in this study. Firstly, the scales used in this study are self-report measures which can be subject to social desirability biases. Secondly, quantitative data using a Likert-scales are only able provide close-ended information and does not explain why a participant chose those specific responses (Creswell & Clark, 2007). Thirdly, the size of the sample, the geographical specificity and the overrepresentation of gender in the participant sample may limit the generalizability of the results. In order to address some of the cultural concerns regarding the discussion of mental health, this study utilized the anonymized survey method, whereby parents of autistic children would be more likely to take part in the study. Despite the online survey method being convenient and easily accessible, it is possible that participants were limited to those with access to the internet. Even so, results from this study could help enrich what little quantitative data that exists on parental mental health and the protective factors associated with it in Saudi Arabia and also contribute to the development of effective intervention methods that are relevant for parents of autistic children in Saudi Arabia.

### **Conclusion**

According to Abidin (1990) the need for dynamic multivariate models that could potentially inform research on the interplay of factors that affect parental mental health and child outcomes is crucial. Attempting to explore how certain factors interact with each other and consequently affect parents of autistic children in different parts of the world is an important step in that direction as opposed to assuming that the mere diagnosis of ASC is enough to warrant mental health issues in parents. This study aimed to investigate which factor predicted the most stress, anxiety and depression in parents of autistic children from Saudi Arabia and which other factors alleviated them. This study looked at the impact of a number

of factors on parental mental health and found affiliate stigma to be the main source of stress, anxiety and depression in parents of children with ASC. Moreover, this study found resilience to be an important factor that influences the relationship between affiliate stigma and parental anxiety and depression. Furthermore, social support also was shown to be an important factor to some extent which explains the relationship between affiliate stigma and depression in parents of autistic children in Saudi Arabia.

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## **Discussion**

### **Summary of Key Findings**

The overarching aim of this thesis was to explore how parents of autistic children in Saudi Arabia perceive and cope with their child's condition. This thesis sought to investigate the factors that contribute to the high levels of stress, anxiety and depression typically reported by parents of children with ASC in previous studies, and to explore whether there are certain factors that alleviate the aforementioned mental health issues. Throughout the chapters, the relationship between the following factors were explored (stress, anxiety, depression, challenging child behaviour, autism symptom severity, affiliate stigma, resilience, religious coping and social support). The results in this thesis have shown that, in line with previous studies the majority of participants reported high levels of stress, anxiety and depression well above the cut off score (chapter,2,3,4,5,6).

According to a large number of previous studies (e.g., Seltzer et al., 2001; Tomanik et al., 2004; Herring et al., 2006; Lecavalier et al., 2006; Osborne and Reed, 2009; Estes et al., 2013), the main factor leading to the development of mental health issues in parents of autistic children is the child's challenging behaviour. However, it is important to note that challenging behaviours are also commonly observed and recorded in other childhood disorders and are not specifically unique to children with ASC. As such, guided by the literature, chapter 2 aimed to explore whether the most commonly mentioned factor (challenging child behaviour) pertaining to parental mental health issues also applied in a different population sample. The results from this study found that the majority of parents reported high levels of challenging child behaviour with results well above the cut-off score. This study found that an increase in challenging child behaviour was associated with parental stress, anxiety, and depression. However, the results in chapter 2 found that despite the association, challenging child behaviour did not predict any of the parental mental health issues. On the other hand, another relatively significant number of

studies suggest that ASC symptom severity is also a primary predictor of a parental mental health issues (e.g., Charnsil & Bathia, 2010; Yeo & Lu, 2012; Athari et al., 2013; Wisessathorn et al., 2013; Ilias et al., 2016). As such, chapter 2 also aimed to investigate whether this association can also be seen in parents of autistic children from Saudi Arabia. In line with previous studies, results indicated that ASC symptom severity was linked to parental stress, anxiety and depression. Seeing as both challenging child behaviour and ASC symptom severity were both linked to parental mental health issues, further statistical analyses were conducted, and those results indicated that the link between ASC symptom severity and parental mental health problems was the only one that maintained significance. The combination of findings in this study alluded to other potential factors at play considering that challenging child behavior did not significantly predict any parental mental health outcomes explored in this study (i.e., stress, anxiety, depression). To further explore the high levels of reported parental mental health issues, chapter 3 aimed to explore the relationship between stress, anxiety, depression, autism symptom severity and affiliate stigma in parents of autistic children in Saudi Arabia.

Research has suggested that parents of autistic children often report encountering various forms of stigmatization related to their child's condition (Mitter et al., 2019). Consequently, these parents tend to experience high levels of stress, anxiety and depression associate with the experience of stigma (Crabtree, 2007; Green, 2007; Gray, 2002; Papadopoulos et al., 2018). Presently, there are no studies conducted on parents of children with ASC in Saudi Arabia which explore the effects of affiliate stigma on parental mental health. Despite the lack of literature on the topic, as hypothesized, the majority of participants in this study reported experiencing high levels of affiliate stigma, stress anxiety and depression. Moreover, in line with the literature and as predicted it was found that increased levels of affiliate stigma were associated with increased levels of stress, anxiety and depression. The study also found that increased levels of ASC symptom severity were also related to higher

levels of affiliate stigma. Although the majority of parents in this study reported experiencing increased levels of affiliate stigma, in accordance with the literature, this study found that parents of children with Level 3 Autism tended to report higher levels of affiliate stigma in comparison to parents of children diagnosed with Level 2 Autism. Thus, it can be suggested that parents of children with more ASC symptom severity tend to experience stigma more frequently (Farrugia, 2009). In chapter 3 it was also found that both autism symptom severity and affiliate stigma were associated with parental anxiety. Interestingly, further statistical analyses revealed that affiliate stigma was the only significant factor predicting parental anxiety. Although there are currently no existing studies on affiliate stigma experienced by parents of autistic children in Saudi Arabia, results from this study indicate that the majority of parents reported having experienced high levels of affiliate stigma which predicted their high levels of stress, anxiety and depression. It is well established that stigma towards mental health conditions contributes to the delay in intervention, diagnosis and acceptance of ASC. Results from chapter 3 show that the majority of participants are clearly facing high levels of distress for this reason, as such it is important to highlight the need for Saudi Arabia to tackle the issue of mental health stigma and for future research to investigate this factor in other parts of the world.

Although the majority of parents reported high levels of stress, anxiety, depression and affiliate stigma, not all parents reported levels above the general population mean. As such this study sought to explore the factors commonly mentioned in the literature that are associated with lower levels of reported mental health issues in parents of autistic children. As such, chapter 4 aimed to investigate the relationship between stress, anxiety, depression, resilience and religious coping in parents of autistic children in Saudi Arabia. A growing number of studies have shown that religious coping is a form of adaptive coping that alleviates parental stress, anxiety and depression (Kim & Esquivel, 2011; Pargament, Tarakeshwar, Ellison, &

Wulff, 2001) and acts as a buffer against stressors such as difficult child behaviour and stigma (Friedrich et al., 1988). Although some studies suggest that higher levels of religious coping lower the rates of mental health issues in parents of children with autism, this field of research remains largely understudied despite it being an integral part of daily life in many cultures. As such, one of the aims of this study was to gain a better understanding of the impact that religious coping has on the mental health of parents of autistic children from Saudi Arabia where religiosity is central to everyday life. As predicted, higher levels of religious coping were associated with lower levels of stress, anxiety and depression. The results from this study supported findings from various studies which suggest that religious coping can be considered as a buffer against stress, anxiety and depression (Haworth et al., 1996; McIntosh et al., 1993; Tarakeshwar and Pargament, 2001). Previous research has also suggested that parents of children diagnosed with ASC who score highly on resilience scales are more likely to report lower levels of stress, anxiety and depression and are more adept at managing the challenges of caring for a child diagnosed with autism (Hayes & Watson, 2013; Bekhet, Johnson, & Zauszniewski, 2012). However, to date, there have been no studies conducted on the impact resilience has on the mental health of parents of autistic children in Saudi Arabia. As such, chapter 4 aimed to explore whether this factor also played a significant role in a different population sample. As predicted, this study showed that increased levels of resilience were associated with lower levels of stress, anxiety and depression. Although results from this study found an association between higher levels of resilience and religious coping with lower levels of parental stress, anxiety and depression, further statistical analyses indicated that resilience was the only main predictor of lower levels of stress, anxiety and depression in parents of autistic children in Saudi Arabia. Since there is a dearth in empirical studies on the resilience of parents of children with ASC in Saudi Arabia as well as the majority of studies on this specific population sample focusing on the negative aspects of caring for a child with ASD,

this study aimed to address these gaps in the literature by exploring how protective factors such as resilience and religious coping can potentially reframe a parent's perception positively and mitigate parental mental health issues.

Seeing as social support is the most frequently reported factor reported by parents of children with ASC that helps them cope with daily stressors associated with caring for their child (e.g., Meadan, Halle, & Ebata, 2010; Luther, Canham, & Cureton, 2005; Pepperell, Paynter, & Gilmore, 2018; Zaidman et al., 2017), chapter 5 incorporated this factor to assess whether it also acted as a buffer against mental health issues in parents of autistic children in Saudi Arabia. As predicted, a high levels of perceived social support were shown to be associated with lower levels of stress, anxiety and depression. Moreover, as hypothesized, social support from a spouse was the only predictor of lower levels of both stress and anxiety. However, contrary to the hypothesis, this study found that perceived social support from neither friends, family nor spouse predicted the lower levels of depression. It can be suggested from the findings in chapter 5 that although most of the research on social support for parents of children with ASC has been conducted in Western countries (Button, Pianta, & Marvin, 2001; Figueiredo & Costa, 2009), this study found similar results with this participant sample whereby social support is significantly associated with lower levels of mental health issues in parents of autistic children from Saudi Arabia. The results from chapter 5 also support findings from several previous studies regarding the type of informal social support perceived as most effective. This study indicated that although high levels of social support from either friends, family and spouse were significantly related to lower levels of stress, anxiety and depression, further statistical analyses revealed that high levels of perceived social support from a spouse was the only significant predictor of lower levels of stress and anxiety. Such findings can sometimes be attributed to cultural differences to some extent, especially where stigma attached to mental health issues are prevalent. For example, some studies have shown that participants



tended to report their family members being unhelpful and showing no support, often even hesitating to interact with their autistic child. These findings highlight the lack of understanding of ASC amongst some family members which consequently leaves parents feeling socially isolated and largely unsupported. The idea that parents of children with ASC place an importance on spousal support can be explained by the idea that when it comes to managing a child with ASC, spousal support can be considered as an immediate form of response which is not usually available when it comes to support from family and friends (Burrell, Ives & Unwin, 2017). Moreover, in a society that is rife with stigma associated with ASC, which can also extend to the parents of an autistic child, it is likely that social support from a spouse would prove to be the most effective seeing as the spouse is usually also the parent of the autistic child who experiences the reality of their child's condition as well and therefore hold a more genuine perception of the situation. The overall findings from chapter 5 highlighted the important role social support plays in the lives of parents of autistic children in Saudi Arabia and also sheds light on the intricacies of the types of informal support they tend to rely on.

Seeing as results chapters 2,3,4 and 5 have indicated that significant relationships between all the factors explored are present. Chapter 6, guided by the double ABC-X model, sought to explore how all the variables (stress, anxiety, depression, challenging child behaviour, affiliate stigma, autism symptom severity, resilience, religious coping and social support) interact with each other and the impact they have on the mental health of parents of autistic children in Saudi Arabia. Previous studies have highlighted the need for research to incorporate a more holistic approach when exploring parental mental health associated with caring for a child with a developmental condition in order to simultaneously explore the influence on a variety of relevant factors on parental mental health. There are several studies which have suggested that future research should adopt the multi-dimensional approach of the double ABC-X model in their studies in order to gain a more integrated understanding of the

factors influencing parental mental health associated with caring for an autistic child. Upon the recommendations regarding the future directions of previous studies, chapter 6 was framed within the double ABC-X model to explore the factors that influence parenting stress, anxiety and depression in a sample of parents of autistic children from Saudi Arabia. In summary, the double ABC-X model enables the analysis of the relationships between several variables simultaneously using multiple indicators which provides a clearer and more realistic picture of the experiences of parents of autistic children. Although the use of the double ABC-X model has been seen in recent studies looking at parental experiences caring for a child with autism (Manning et al., 2011), to date, there are no existing studies that have employed the double ABC-X model when exploring parental experiences of ASC in Saudi Arabia. In chapter 6 it was found that in line with previous research, the majority of participants reported high levels of stress, anxiety and depression (e.g., Dabrowska & Pisula, 2010; Estes et al., 2013; Hayes & Watson, 2013; Wang et al., 2011; Dykens & Lambert, 2013; Weiss, 2002; Stein et al., 2011; Kuusikko-Gauffin et al., 2013; Falk et al., 2014). Also, in support of previous research, high levels of challenging child behaviour, autism symptom severity and affiliate stigma were associated with high levels stress, anxiety and depression (e.g., Estes et al., 2013; Ilias et al., 2016; Papadopoulos et al., 2018). Moreover, resilience, religious coping and social support were negatively associated with stress, anxiety and depression (e.g., Hayes & Watson, 2013; Tarakeshwar & Pargament, 2001; Siman-Tov & Kaniel, 2011). Considering that the participant sample in this study is relatively understudied and that the majority of previous research on parental mental health associated with caring for a child with ASC is mainly conducted in Western countries, it is important to note that the proposed associations between the factors affecting parental mental health mentioned throughout the literature are also seen in parents of autistic children in Saudi Arabia. This suggests that despite the variation in cultural contexts,

there are several facets to parental experiences caring for an autistic child that could be considered as universal.

On the other hand, in spite of the correlational nature of the variables explored, this study found affiliate stigma to be the only significant predictor of stress, anxiety and depression in this participant sample. Although there are no existing studies on affiliate stigma experienced by parents of autistic children in Saudi Arabia, the results from this study indicate that most parents reported high levels of affiliate stigma which predicted the high levels of stress, anxiety and depression. When exploring the factors that pertain to lower levels of stress, anxiety and depression in this participant sample from Saudi Arabia, the variable of religious coping did not seem to have any significant impact on the relationship between affiliate stigma and parental mental health. Thus, it is evident that more research is needed to determine whether religious coping may have a different impact on the relationship between affiliate stigma and parental mental health or whether other unexplored variables could be influencing this relationship. The results from chapter 6 also found that social support mediated the relationship between affiliate stigma and parental depression, however, it did not mediate the relationship between affiliate stigma and stress or anxiety. This could potentially be explained by the participant sample size or the presence of other unidentified factors influencing the relationships between affiliate stigma, parental stress and anxiety. Moreover, considering the prevalence of stigma associated with ASC in Saudi Arabia, it is possible that social support for this group of parents is not very effective in relieving psychological distress or that they are unable to effectively utilize social support for fear of the stigma associated with their child's condition or their own mental health issues. Although resilience in parents of autistic children is still an emerging field, presently there are no known quantitative studies exploring resilience in parents of autistic children in Saudi Arabia. In line with previous studies, resilience significantly mediated the relationship between affiliate stigma and parental anxiety as well as

the relationship between affiliate stigma and parental depression. However, it did not have any significant effect on the relationship between affiliate stigma and stress. Results from chapter 6 highlight that it is an important factor, if not the most important factor, that explains the relationship between affiliate stigma and better parental mental health.

In summary, this thesis found that affiliate stigma was the key predictor of mental health issues in parents of autistic children with ASC in Saudi Arabia, and that resilience was the main significant predictor of lower levels of mental health issues. In contrast to the trending notions in the literature, this thesis found that parental stress, anxiety and depression in this participant sample were not directly related to factors associated with their autistic child, but rather to factors linked to external conditions and internal resources (i.e., stigma and resilience).

### **Theoretical and Methodological Implications**

This research project yielded several significant theoretical and methodological implications. First, the current trend within the relevant research on parental mental health associated with caring for a child with ASC suggest that the analysis of parental outcomes should be considered from a more complex perspective that goes beyond bivariate relationships, seeing as these relationships may be explained or modified by other variables as well. However, studies exploring the various underlying mechanisms of this dynamic are notably scarce and the specific potential predictors and mediators of parental mental health issues linked to caring for a child with ASC remain somewhat overlooked cross-culturally and largely inconclusive. There are very few studies which have explored the ability of multiple variables to simultaneously predict stress, anxiety and depression in parents of children with ASC (Falk et al., 2014) with the majority of studies exploring only one or two factors. This thesis, guided by the double ABC-X model, employed nine variables to assess parental mental

health in terms of caring for an autistic child in Saudi Arabia and the findings proved to be significant and complimentary to the majority of suggestions in the relevant literature.

Second, in an attempt to generate a clearer understanding of what factors may be predictive of parental stress, anxiety and depression in parents of children with ASC and which factors alleviate these issues, each of these mental health outcomes were measured in isolation. The majority of previous studies have either combined parental stress, anxiety and depression as a single outcome variable or have measured only a single outcome variable, predominantly stress (e.g., Al-Kandari et al., 2017; Lai, Goh, Oei, & Sung, 2015; McAuliffe, Cordier, Vaz, Thomas, & Falkmer, 2017; Twoy, Connolly, & Novak, 2007) which has created a gap in the literature in terms of research with a specific focus on how each factor may impact each mental health outcome individually. Studies which explore each factor and its effect on specific mental health constructs independently, such as the studies in this thesis, can be regarded as being potentially impactful in portraying a more accurate experience of parents of children with ASC. Importantly, there are almost no existing studies conducted with a participant sample from the Middle East which have explored a multitude of variables collectively in the same study despite research suggesting the significance of their impact on parental mental health. This thesis is the first of its kind which has employed a relatively large number of variables and attempted to adapt the double ABC-X model in a severely understudied population sample. The findings from this thesis imply that models such as the double ABC-X are also applicable cross-culturally.

Third, this thesis serves to open a path and provide a foundation for research in an area where very limited data exists. Finding relevant literature on parental experiences of caring for a child with ASC in Saudi Arabia was very difficult and there were doubts on whether participants would willingly take part in the studies. As such, this research project made an attempt to address the gap in the literature and potentially prove that the likelihood of

conducting more future research on parental mental health associated with caring for an autistic child in Saudi Arabia can be successful. Although this thesis confirmed that the relationships between the variables (stress, anxiety, depression, challenging child behaviour, autism symptom severity, affiliate stigma, resilience, religious coping and social support) do exist, and that the double ABC-X model is also applicable in a participant sample from Saudi Arabia, future research should also explore this relationship using longitudinal research methods as well as a larger sample size and perhaps use more statistical modelling procedures with other variables that are may also impact parental mental health.

### **Cross-cultural Similarities and Differences**

Recently, studies exploring the experiences of parents of autistic children has expanded and extended across different cultures. There has also been a substantial amount of evidence in previous studies indicating that parents of autistic children consistently report high levels of stress, anxiety and depression (Hayes & Watson, 2013). However, since not much is known about the underlying factors that may lead to or protect against the decline in parental mental health, this thesis sought to identify and explore how these factors contribute to or alleviate parental mental health issues associated with caring for a child with ASC in Saudi Arabia.

Taking into consideration the impact cultural views have on parental mental health as well as intervention seeking behaviours (Daley, 2002; Mandell & Novak, 2009; Bernier et al., 2010), research studies with participant samples from differing cultural backgrounds are essential for a more evolving and all-inclusive understanding of the varying parental experiences of caring for a child with ASC. Research on parental stress, anxiety and depression associated with caring for an autistic child in Saudi Arabia is significantly limited. This could be attributed to the lack of existing data on ASC in the region as well as the negative cultural perceptions and stigma attached to mental health in general. This is the first research project of

its kind which has explored factors such as stress, anxiety, depression, challenging child behavior, autism symptom severity, affiliate stigma, resilience, religious coping and social support in a participant sample in the Middle East. The main finding in this research project was the unequivocal impact affiliate stigma had on parental mental health in Saudi Arabia. As mentioned before, affiliate stigma is not a common issue for parents of autistic children in Western countries, however it is clear that it is a major distressing factor amongst parents of autistic children from Saudi Arabia. Such findings highlight the multi-faceted and idiosyncratic nature of parental experiences caring for an autistic child that are sometimes significantly impacted by the cultural context.

Intrestingly, although culture plays a key role in creating differences in parental experiences caring for an autistic child, this thesis found that resilience, similar to a large number of studies conducted in the West, was the most significant factor that protects against parental stress, anxiety and depression despite religious coping and social support being explored in parallel, which at face value may be considered more culturally relevant factors. Although caring for an autistic child can be a unique experience for many parents in different countries around the world, this study showed that despite there being certain cultural factors which set parental experiences apart, there are also other factors that are shared.

### **Parent Characteristics and Child Characteristics**

The majority of research on parental experiences caring for a child with ASC typically focuses on the negative aspects while the positive impact of this caregiving experience remains overlooked to some extent. Most studies suggest that parental mental health issues stem from child characteristics, these suggestions fail to offer an accurate framework of the experiences of the parents (Hastings, Kovshoff, Ward et al., 2005). Not all parents caring for a child with ASC report such high levels of mental health issues (Abidin, 1992; Pozo & Sarriá, 2014). Some

studies have suggested that while there are certain factors that do contribute to parental mental health issues, these factors are also impacted by the parents' own psychological characteristics (Boyce, Behl, Mortensen, & Akers, 1991; Bristol, 1984; Hastings & Johnson, 2001). Various studies have also highlighted the importance of these parent-centered variables acting as protective factors which alleviate the experiences of stress, anxiety and depression. Moreover, the research on the positive aspects of caring for conditions has been increasing (e.g., Blacher & Baker, 2007; Hastings & Taunt, 2002; Hastings, Kovshoff, Ward et al., 2005; Potter, 2016), however there are hardly any studies of the same nature with a participant sample from Saudi Arabia. As such, this thesis made an attempt to incorporate a reasonable number of variables that included both child and parent characteristics based on the double ABC-X model.

According to Abidin's (1992) ecological and systemic approach to family relations, stress in parents is usually a result of characteristics that are present in both the child and the parent. Accordingly, a parent's perception of their internal resources can act as potential mediator between events caused by a stressor and the level of stress. Thus, it can be suggested that the cognitive appraisal of an event caused by a stressor along with the utilization of a coping mechanism are the main factors by which parental stress can be conceptualized. Given the importance of this evaluative processes, it can be suggested that parental health issues are not necessarily directly linked to caring for an autistic child but can often depend on the parent's evaluative processes (Pastor et al., 2015). This notion was clearly seen in the results of this thesis where parental stress, anxiety and depression were not predicted by child related characteristics (challenging behaviour, autism symptom severity) but by societal and parental factors (affiliate stigma and resilience).

In contrast with the overwhelming amount of studies indication that child characteristics serve as main predictors of parental mental health issues, to some extent it is clear in this thesis that the internalization of societal perceptions of ASC by parents in this



participant sample is a more distressing factor compared to the child's actual characteristics. Moreover, this thesis implies that parental internal characteristics (resilience) are more effective than external resources (social support) in protecting against stress, anxiety and depression. From the results in this research project, it can be implied that although there is an association between parental mental health issues and child characteristics (challenging behaviour and autism symptom severity), stress, anxiety and depression in this participant sample are not directly associated with the autistic child but with the parent's internalization of negative societal perceptions and the ability for them to bounce-back from such negative experiences.

### **Practical Implications**

There are several practical implications which can be informed by this thesis. Firstly, the results from this study could provide professionals and future researchers with a better understanding of parental mental health associated with caring for a child in Saudi Arabia. This thesis could also help in informing family intervention providers of the potential effects that affiliate stigma has on parental mental health which could improve the quality of intervention they deliver. Considering the importance of parental mental health in terms of raising a child with ASC, culturally informed interventions targeting affiliate stigma, parental stress, anxiety and depression is somewhat necessary in order to ensure the overall wellbeing of both child and parent.

Given that resilience emerged as the most significant factor associated with lower levels of mental health issues, specialists in the region may assist parents in fostering positive parenting behaviours by creating programs that target developing parental characteristics such as resilience and other types of adaptive coping resources. The findings from this thesis may also benefit family intervention specialists in identifying high levels of affiliate stigma in

parents of autistic children as the results of the internalized stigma can be detrimental to the overall wellbeing of parents which may consequently lead to negative parenting behaviours.

Another clear implication in this thesis is that an increase in ASC awareness should be a priority in Saudi Arabia seeing as mental health issues in parents from this participant sample were predicted by affiliate stigma. Also, seeing as social media platforms have become increasingly accessible to everyone including parents of autistic children in Saudi Arabia, specialists could advise these parents to connect with relevant online groups as a means of accessible social support which can also help to foster positive attitudes towards their child and alleviate feelings of social isolation.

Finally, The results from this research project could serve as a stepping-stone by contributing to the limited existing quantitative research on parental stress, anxiety and depression in Saudi Arabia and also contribute to the development of effective intervention methods and coping mechanisms that are culturally relevant for parents of children with ASC. These findings are important seeing as it is well established that parental mental health has a direct impact on the child. When parents face mental health issues, they can become less responsive to their child's needs and negatively impact the quality of care they deliver. This notion has important practical implications for future research and intervention services as it could promote a shift from interventions that target the removal of child related stressors to interventions that assist parents in the skills needed to tap into their internal resources to overcome daily challenges while also helping them perceive their child's condition in a positive manner.

## **Limitations, Recommendations for Future Research and Conclusion**

### **Limitations**

There are several limitations to note in this thesis. First, the measures used in this survey were self-report measures which could be can sometimes be prone to social desirability biases. Second, the geographical specificity and the gender composition of the participants creates limits generalizability of the results. Due to the overrepresentation of gender in this research project, the ability to generalize the findings to fathers is limited. Research on the experiences of fathers as primary caregivers of children with developmental conditions is extremely scare and additional studies are of great need in that area. Although survey responses from fathers or autistic children in Saudi Arabia would have been ideal, given the cultural traditions and restraints, the fact that all participants in this study were mothers of autistic children came as no surprise. Although the majority of studies on parental experiences caring for an autistic child are generally comprised of a small participant sample, one of the limitations in this study could also be attributed to this study's sample size. This could be due to the recruitment method or the indirect method of communication. Seeing as the recruitment material was first sent to a few support groups for parents of autistic children in Saudi Arabia, there is a chance that a considerable number of mothers who participated in this study were from these support group and they may already hold positive perceptions towards their situation which could create potential bias in the sample. In order to address some of the cultural concerns regarding the discussion of mental health issues, this thesis used the anonymized survey method in hopes that parents of children with ASC will be more likely to take part. However, it is a possible that the participants were restricted to those with access to the internet.

### **Recommendations for Future Research**

There are several recommendations for future research based on the thesis limitations. Firstly, it is recommended that future research build on this research project and examine other potential variables predicting and alleviating parental mental health issues caring for a child

with ASC. Also, future research should also look into the positive aspects of caring for an autistic child and the variables associated with it (e.g., positive reframing, locus of control, post-traumatic growth) as this area in research is still relatively limited, especially in the Middle East. Seeing as this thesis has shown that the double ABC-X model can be applicable in this participant sample from Saudi Arabia, future studies should incorporate a larger number of parents of autistic children including fathers and parents who are not associated with any formal organization or parent support group in order to increase the likelihood of generalizability. Seeing as this is the first research project of its kind to utilize the double ABC-X model, explore parental mental health outcomes as separate domains and incorporate a multitude of variables, it is recommended that future research replicate this study in order to determine the validity and reliability of the findings in this study. An increase in research in this area with a participant sample from Saudi Arabia could also provide more data and suggest more actions needed to be taken in order to better help autistic children and their parents in that region. Finally, it is recommended that future research exploring parental mental health associated with caring for an autistic child, not only in Saudi Arabia, employ a more holistic approach and use a variety of variables and analysis the interplay between them in order to gain a more realistic understanding of the experiences these parents have.

## **Conclusion**

This thesis aimed to explore the factors associated with mental health issues in parent of autistic children in Saudi Arabia as well as the protective factors that alleviate them. As such, this thesis explored how challenging child behaviour, autism symptom severity, affiliate stigma, social support, religious coping and resilience impacted parental stress, anxiety, depression. The studies in this thesis found that parental mental health issues were significantly predicted by affiliate stigma and that individual resilience played a major role in explaining

lower levels of mental health issues in this participant sample. Seeing as mental health issues in parents from Saudi Arabia were not directly linked to their autistic child, the findings from this research project highlight the importance of understanding how parent-specific factors can protect against parental mental health issues as opposed to focusing on the negative relationships between parental outcomes associated with child-specific factors. This is especially important as parenting skills can have significant implications for child outcomes and in order for parents to provide the best quality of care for their autistic child, their own mental health should also be taken into account.

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# Appendices

## Appendix A- Ethical Approval Letter



### Application Details

Ethics Reference 2019-0889  
Title of Project Stress, Anxiety and Depression in Parents of Children with Autism in Saudi Arabia  
Lead Researcher Renad Yassin  
Academic Supervisor Lesley Allinson, Niko Kargas  
Committee Human Ethics Committee (PR)  
Date of Ethical Opinion 31 October 2019

### Favourable Opinion

Thank you for your submission, on behalf of the committee and I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form and supporting documentation.

The favourable ethical opinion provided is conditional to the following requirements:

#### 1. Commencement of the research

- 1.1 Risk Assessment: In accordance with H&S policy and guidance, a risk assessment must be completed or existing risk assessment reviewed/updated before data collection commences. A copy of the risk assessment should be retained with your research data.
- 1.2 It is assumed that the research will commence within 12 months of the date of the favourable ethical opinion.
- 1.3 If the research does not commence within 12 months of the favourable opinion being issued, the lead applicant (and academic supervisor for student research) should send a written explanation for the delay. A further written explanation should be sent after 24 months if the research has still not commenced.
- 1.4 If the research does not commence within 24 months, the REC may review its opinion.

#### 2. Duration of favourable opinion

- 2.1 The favourable ethical opinion of the REC for a specific research study applies for the duration of the study, as detailed in your application (or any subsequent amendments).

#### 3. Amendments

- 3.1 If it is proposed to make an amendment to the research, the lead applicant (authorised by the academic supervisor for student research) should submit an amendment to the REC by accessing the original application form on LEAS and creating an amendment form.

#### 4. Monitoring

- 4.1 Research Ethics Committees may review a favourable opinion in the light of progress reports and any developments relevant to the study. The lead applicant and academic supervisor (for student research), is responsible for ensuring the research remains scientifically sound, safe, ethical, legal and feasible throughout its duration. The lead applicant and academic supervisor (for student research) should submit a progress report to the REC 13 months after the date on which the favourable opinion was given. Annual progress reports should be submitted thereafter.
- 4.2 Progress reports should be completed and submitted using the forms in LEAS.

#### 5. Conclusion or early termination of the research

- 5.1 The Lead Applicant should complete the End of Study Form in LEAS once the study has completed. It is also their responsibility to inform the Committee of early termination of the project or if the work is not completed.

#### 6. Long Term Studies

- 6.1 The lead applicant and academic supervisor (for student research) is responsible for ensuring that the study procedures and documentation are updated in light of legislative or policy changes and also for reasons of good practice (e.g. standards for supporting documentation). This should be documented in the progress report to the REC (see above) and, where necessary, an amendment (see above) should be submitted to the REC. The REC may review its opinion in light of legislative changes or other relevant developments.

Additional guidance may be found at [here](#)

### Statement of Compliance

The Committee is constituted in accordance with the University of Lincoln [Research Ethics policy](#) and [E-QMS SOP E-01 Ethics Committee Operations](#).

Yours Sincerely

A handwritten signature in black ink, appearing to read "David Mullineaux".

Professor David Mullineaux

## Appendix B- Participant Information Sheet, Consent Form and Debrief (English)

### Participant Information Sheet/Information about the research (Draft version 1.0: 24/10/2019)



**Title of Study:** Stress, Anxiety and Depression in Parents of Children with Autism in Saudi Arabia

**Name of Researcher(s):** Renad Yassin

I'd like to invite you to take part in my research study. Joining the study is entirely up to you. Before you decide, I would like you to understand why the research is being done and what it would involve for you. This information sheet will help you decide whether you would like to take part in this study, my contact details can be found below should you have any questions you would like to ask before taking part in this study. I suggest this should take about 30 minutes. Please feel free to talk to others about the study if you wish.

#### **What is the purpose of the study?**

This PhD research project aims to explore factors associated with stress, anxiety and depression in parents of children diagnosed with Autism in Saudi Arabia. According to previous research, parenting a child diagnosed with Autism can be more challenging than parenting a typically developing child and children with other conditions. This project could potentially help us better understand what contributes to parental experiences of stress, anxiety and depression associated with caring for a child diagnosed with Autism and what factors help alleviate these mental health outcomes. Through this online survey, this research will investigate the effects of social support, religious coping, social stigma and child's challenging behaviour on parental experiences of stress, anxiety and depression in Saudi Arabia specifically.

Different cultures around the world have different perceptions towards mental health, including developmental disabilities such as Autism. Through this survey, this PhD research project aims to look at how Autism is understood and managed by parents in Saudi Arabia since research on parents of children with Autism in Saudi Arabia is very limited. The results from this study could help Autism specialists and other researchers in the field get a true representation and understanding of parental experiences raising a child with Autism in Saudi Arabia.

#### **Why have I been invited?**

You are being invited to take part because you are a parent of a child diagnosed with Autism in Saudi Arabia. We are inviting 100 participants like you to take part.

#### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part, you will be able to return to this information sheet at any time throughout the survey. You will also be asked to complete a consent form on the next page should you decide to take part in this online survey study. If you decide to take part, you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

#### **What will happen to me if I take part?**

It should take you approximately 30 minutes to complete this online survey should you decide to take part. You will be taken to a consent form page before the survey begins. In the survey, you will be asked to answer questions on your personal experiences with stress, anxiety, depression, social support, religious coping and your child's challenging behaviour. Afterwards, you will be taken to a debrief page where you can also find links that can help you access support in your area should you need it. If you begin to feel distressed at any point in the survey, you are free to exit the page or skip to the debrief page where you can use one of the provided support links. No identifiable data will be collected and all your responses will be anonymised and securely stored on the university OneDrive in a password protected file. Only the researcher and research supervisors will have access to it.

#### **Expenses and payments**

You will not be paid to participate in the study.

#### **What are the possible disadvantages and risks of taking part?**

The questions in this survey cover topics such as stress, anxiety, depression, stigma, religious coping, social support and challenging child behaviour. It is recommended that you do not take part in this study if you feel that questions on the topics mentioned may cause you any form of distress.

**What are the possible benefits of taking part?**

Although there are no direct personal benefits to participating, you will, however, be taking part in a research the aims to better understand parental mental health associated with caring for a child with Autism, particularly in Saudi Arabia where research on the subject is extremely limited.

I do not know what the exact outcomes of the study, however, should you wish to obtain a summary of the findings, you can email me or my supervisors and a copy of the findings will be sent to you when the research project is finished (contact details found at the end of this page). Your email will be stored on the University OneDrive until the summary is sent, then subsequently deleted.

**Will my taking part in the study be kept confidential?**

All your data will be anonymised and no personal or identifiable data will be collected. We will follow ethical and legal practice and all information about you will be handled in confidence.

**Privacy notice**

The University of Lincoln is the lead organisation for this study and will be the data controller for this study. This means that we are responsible for looking after your information and using it properly. The university's Research Participant Privacy Notice <https://ethics.lincoln.ac.uk/research-privacy-notice/> will explain how we will be using information from you in order to undertake this study.

**What will happen if I don't want to carry on with the study?**

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. As your participation is anonymous it will not be possible to withdraw your data once submitted, as I have no way of identifying you.

**Where will my data be stored?**

The data obtained from the study will be stored securely on the university OneDrive in a password protected file. Only the researcher and research supervisors will have access to it. The data from this study *may* be put in an Open Access repository.

**What will happen to the results of the research study?**

The results in this research will be used in my PhD project and will be made available upon project completion in approximately 27 months. If you would like to obtain a finalized copy of the PhD project or a summary of the findings, you are welcome to send an email to my or my supervisors (see contact details below) and a copy will be sent to you upon project completion and approval. There will be no identifiable data collected in this survey and since your responses are anonymised they may be shared with other researchers or made available in online data repositories in the future.

**Who is organising and funding the research?**

This research is being organised by the University of Lincoln.

**Who has reviewed the study?**

All research conducted by the University of Lincoln is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests.

**What if there is a problem?**

If you have a concern about any aspect of this study, you should ask to speak to the researcher or research supervisors, who will do their best to answer your questions. The researcher and research supervisors' contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting [ethics@lincoln.ac.uk](mailto:ethics@lincoln.ac.uk).

If you feel that we have let you down in relation to your information rights then please contact the Information Compliance team by email on [compliance@lincoln.ac.uk](mailto:compliance@lincoln.ac.uk) or by post at Information Compliance, Secretariat, University of Lincoln, Brayford Pool, Lincoln, LN6 7TS. You can also make complaints directly to the Information Commissioner's Office (ICO). The ICO is the independent authority upholding information rights for the UK. Their website is [ico.org.uk](http://ico.org.uk) and their telephone helpline number is 0303 123 1113.

**Further information and contact details**

Renad Yassin [16637585@students.lincoln.ac.uk](mailto:16637585@students.lincoln.ac.uk)

Dr Niko Kargas [NKargas@lincoln.ac.uk](mailto:NKargas@lincoln.ac.uk) Tel: +44 152288726

Dr Lesley Allinson [lallinson@lincoln.ac.uk](mailto:lallinson@lincoln.ac.uk)



Project ID: 0889



### CONSENT TO PARTICIPATE IN RESEARCH

**Title of Project: Stress, Anxiety and Depression in Parents of Children with Autism in Saudi Arabia**

**Name of Researcher: Renad Yassin**

Please initial box

1. I confirm that I have read the information sheet dated (01/01/2020) (version 2.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected. I understand that should I withdraw then the information collected so far may not be erased and that this information may still be used in the project analysis. ☐
3. I understand that individuals from the University of Lincoln may look at research data collected during the study, to ensure that the study is conducted appropriately. I give permission for these individuals to have access to my data; I understand that no personal details will be collected. ☐
4. I agree to take part in the above study. ☐

**\*Note to reviewer:** This consent form will be a tick box consent form as part of the Qualtrics survey

## Participant Debrief Sheet



(Draft Version 1.0: 24/10/2019)

**Title of Study:** Stress, Anxiety and Depression in Parents of Children with Autism in Saudi Arabia

**Name of Researcher:** Renad Yassin

I'd like to thank you for taking part in this research study. This research will provide crucial information and broaden our understanding of parental mental health associated with caring for a child diagnosed with Autism.

### What was the aim of the study?

This PhD research project aims to explore factors associated with stress, anxiety and depression in parents of children diagnosed with Autism in Saudi Arabia. Through this online survey, this research attempted to investigate the effects of social support, religious coping, social stigma and child's challenging behaviour on parental experiences of stress, anxiety and depression in Saudi Arabia specifically. This research could help us understand how Autism is perceived and managed by parents in Saudi Arabia since research on parents of children with Autism in Saudi Arabia is very limited.

### Questions and withdrawing

If you have any further questions about the study, please feel free to ask the researcher before you finish or alternatively contact the researcher or their supervisors at any time on [16637585@students.lincoln.ac.uk](mailto:16637585@students.lincoln.ac.uk), [NKargas@lincoln.ac.uk](mailto:NKargas@lincoln.ac.uk), [lallinson@lincoln.ac.uk](mailto:lallinson@lincoln.ac.uk)

Since you have submitted your data anonymously then it will not be possible to withdraw your data, as we will be unable to identify your responses.

### Further help and support

If you have any ethical concerns regarding the current research, your treatment as a participant or your involvement in the study please feel free to contact [ethics@lincoln.ac.uk](mailto:ethics@lincoln.ac.uk).

If you have been affected by any of the issues raised by taking part in this study the following organisations may be able to provide help and advice:

Prince Salman Centre for Disability Research – [www.kscdr.org.sa](http://www.kscdr.org.sa)

Saudi Psychological Counselling Hotline – 920033360

Saudi Psychiatric Association – <http://www.saudipsych.org>

The Saudi Autism Society – <http://saaautism.org>

Jeddah Autism Centre – <http://www.jacenter.org/>

### Contact Details of Researcher and Supervisors

Renad Yassin [16637585@students.lincoln.ac.uk](mailto:16637585@students.lincoln.ac.uk)

Dr Niko Kargas [NKargas@lincoln.ac.uk](mailto:NKargas@lincoln.ac.uk) Tel: +44 1522 886726

Dr Lesley Allinson [lallinson@lincoln.ac.uk](mailto:lallinson@lincoln.ac.uk)



## Appendix C- Participant Information Sheet, Consent Form and Debrief (Arabic)



### ورقة معلومات المشارك / معلومات حول البحث

(الإصدار النهائي 2.0 01/01/2020)

عنوان الدراسة: الضغط النفسي والقلق والاكتئاب لدى والدي أطفال التوحد في المملكة العربية السعودية

اسم الباحثة: رناد ياسين

أرغب في دعوتك للمشاركة في دراستي البحثية. الانضمام إلى الدراسة أمر متروك لك تمامًا. قبل أن تقرر ، أود منك أن تفهم سبب إجراء البحث وما يتضمنه البحث. ستساعدك ورقة المعلومات هذه في تحديد رغبتك في المشاركة في هذه الدراسة أم لا ، يمكن العثور على تفاصيل الاتصال الخاصة بي أدناه إذا كانت لديك أي أسئلة ترغب في طرحها قبل المشاركة في هذه الدراسة. هذا الاستبيان سيستغرق حوالي 30 دقيقة. لا تردد في التحدث إلى الآخرين حول الدراسة إذا كنت ترغب في ذلك.

#### ما هو الغرض من الدراسة؟

يهدف مشروع بحث الدكتوراه هذا إلى استكشاف العوامل المرتبطة بالضغط النفسي والقلق والاكتئاب لدى والدي أطفال التوحد في المملكة العربية السعودية. وفقًا للأبحاث السابقة ، يمكن أن تكون رعاية الطفل المصاب بالتوحد أكثر صعوبة من الطفل ذو نمو طبيعي أو أطفال ذوي احتياجات خاصة أخرى. يمكن أن يساعدنا هذا المشروع بشكل أفضل في فهم ما يساهم في تجارب الوالدين من الضغط النفسي والقلق والاكتئاب المرتبط برعاية طفل مشخص بالتوحد وما هي العوامل التي تساعد على تخفيف نتائج الصحة النفسية السلبية لدى الأوين. من خلال هذا الاستبيان عبر الإنترنت ، سوف يطري هذا البحث أفكار حول الدعم الاجتماعي ، والتكيف الديني ، والوصمة الاجتماعية وسلوك الطفل الصعب من خلال تجارب الوالدين مع الضغط النفسي والقلق والاكتئاب في المملكة العربية السعودية على وجه التحديد.

للتقافات المختلفة حول العالم تصورات مختلفة تجاه الصحة العقلية ، بما في ذلك الإعاقات التطورية مثل التوحد. من خلال هذا الاستبيان ، يهدف مشروع بحث الدكتوراه هذا إلى النظر في كيفية فهم التوحد وإدارتهما من قبل الآباء والأمهات في المملكة العربية السعودية ، حيث أن البحث عن والدي الأطفال المصابين بالتوحد في المملكة العربية السعودية محدود للغاية. يمكن أن تساعد نتائج هذه الدراسة أخصائي التوحد والباحثين الآخرين في هذا المجال في الحصول على فهم حقيقة خبرات الوالدين الذين يربون طفلًا مشخص بالتوحد في المملكة العربية السعودية.

#### لماذا دعيت لهذا الاستبيان؟

تم دعوتك للمشاركة لأنك والد أو والدة لطفل مصاب بالتوحد في المملكة العربية السعودية. نحن نود ان ندعو 100 مشارك مثلك للمشاركة في الاستبيان.

#### هل يجب علي المشاركة؟

الأمر متروك لك لتقرر إذا كنت ستشارك أم لا. إذا قررت المشاركة ، فستتمكن من العودة إلى ورقة المعلومات هذه في أي وقت خلال الاستبيان. سيطلب منك أيضًا إكمال نموذج الموافقة على الصفحة التالية في حال اقرار المشاركة في الدراسة الاستبائية عبر الإنترنت هذه. إذا قررت المشاركة ، فلا يزال بإمكانك الانسحاب في أي وقت ودون إبداء سبب. هذا لن يؤثر على حقوقك القانونية.

#### ماذا سيحدث لي إذا شاركت؟

يستغرق حوالي 30 دقيقة لإكمال هذا الاستبيان عبر الإنترنت إذا قررت المشاركة. سيتم نقلك إلى صفحة نموذج الموافقة قبل بدء الاستبيان. سيطلب منك الإجابة على الأسئلة المتعلقة بتجاربك الشخصية من خلال الضغط النفسي والقلق والاكتئاب والدعم الاجتماعي التكيف الديني

والسلوك الصعب عند طفلك. بعد ذلك ، سيتم نقلك إلى صفحة استخلاص المعلومات حيث يمكنك أيضًا العثور على روابط يمكن أن تساعدك في الوصول إلى الدعم في منطقتك إذا احتجت إليها. إذا بدأت تشعر بالقلق في أي وقت في الاستبيان ، فأنت حر في الخروج من الصفحة أو الانتقال إلى صفحة الاستعلامات حيث يمكنك استخدام أحد روابط الدعم المقدمة. لن يتم جمع أي بيانات شخصية منك ، وسيتم إخفاء هويتك وتخزينها بشكل آمن في OneDrive الجامعي في ملف محمي بكلمة مرور. الباحث والمشفرون على الأبحاث هم وحدهم الذين يمكنهم الوصول إليها.

#### المصروفات والمدفوعات

لن يتم الدفع لك للمشاركة في الدراسة.

#### ما هي المخاطر المحتملة للمشاركة؟

تغطي الأسئلة الواردة في هذا الاستبيان موضوعات مثل الضغط النفسي والقلق والاكتئاب والوصم والتكيف الديني والدعم الاجتماعي وتحديات سلوك الطفل. يوصى بعدم المشاركة في هذه الدراسة إذا شعرت أن الأسئلة حول الموضوعات المذكورة قد تسبب لك أي شكل من أشكال الضيق.

#### ما هي فوائد المشاركة؟

على الرغم من عدم وجود فوائد شخصية مباشرة للمشاركة ، إلا أنك ستشارك في بحث يهدف إلى تحسين فهم الصحة العقلية الوالدية المرتبطة برعاية طفل مصاب بالتوحد ، خاصة في المملكة العربية السعودية حيث تكون الأبحاث حول هذا الموضوع محدودة للغاية .

لا أدري ما هي النتائج الدقيقة للدراسة ، ومع ذلك ، إذا كنت ترغب في الحصول على ملخص للنتائج ، فيمكنك إرسال بريد إلكتروني إلى أو المشرفين على وسيتم إرسال نسخة من النتائج إليك عند الانتهاء من مشروع البحث ( تفاصيل الاتصال الموجودة في نهاية هذه الصفحة). سيتم تخزين بريدك الإلكتروني على University OneDrive حتى يتم إرسال الملخص ، ثم يتم حذف بريدك الإلكتروني لاحقًا.

#### هل تبقى مشاركتي في الدراسة سرية؟

سيتم إخفاء هويتك عن بياناتك ولن يتم جمع أي بيانات شخصية. سنتبع الممارسات الأخلاقية والقانونية وسيتم التعامل مع جميع المعلومات المتعلقة بك بسرية تامة.

#### إشعار الخصوصية

تعد جامعة لينكولن المؤسسة الرائدة في هذه الدراسة وستكون وحدة التحكم في البيانات لهذه الدراسة. هذا يعني أننا مسؤولون عن رعاية معلوماتك واستخدامها بشكل صحيح. سيوضح إشعار خصوصية المشاركين في الجامعة من <https://ethics.lincoln.ac.uk/research-privacy-notice> كيف سنستخدم المعلومات منك من أجل إجراء هذه الدراسة.

#### ماذا سيحدث إذا لم أكن أرغب في متابعة الدراسة؟

مشاركتك طوعية ولديك الحرية في الانسحاب في أي وقت ، دون إبداء أي سبب ، ودون أن تتأثر حقوقك القانونية. نظرًا لأن مشاركتك مجهولة ، فلن يكون من الممكن سحب بياناتك بمجرد إرسالها ، حيث ليس لدي أي وسيلة لتحديد هويتك.

#### أين سيتم تخزين بياناتي؟

سيتم تخزين البيانات التي تم الحصول عليها من الدراسة بشكل آمن في جامعة OneDrive في ملف محمي بكلمة مرور. الباحث والمشفرون على الأبحاث هم وحدهم الذين يمكنهم الوصول إليها. يمكن وضع البيانات من هذه الدراسة في مستودع الوصول المفتوح.

#### ماذا سيحدث لنتائج الدراسة البحثية؟

سيتم استخدام النتائج في هذا البحث في مشروع الدكتوراه الخاص بي وسيتم إتاحتها عند الانتهاء من المشروع في حوالي 27 شهرًا. إذا كنت ترغب في الحصول على نسخة نهائية من مشروع الدكتوراه أو ملخص للنتائج ، فنحن نرحب بك لإرسال بريد إلكتروني إلى أو المشرفين (انظر تفاصيل الاتصال أدناه) وسيتم إرسال نسخة إليك بعد الانتهاء من المشروع و موافقته. لن يتم جمع أي بيانات محددة في هذا الاستبيان وبما أن إجاباتك مجهولة المصدر فقد تتم مشاركتها مع باحثين آخرين أو إتاحتها في مستودعات البيانات عبر الإنترنت في المستقبل.

#### من يقوم بتنظيم وتمويل البحث؟

يتم تنظيم هذا البحث من قبل جامعة لينكولن.

#### من قيم هذه الدراسة؟

يتم فحص جميع البحوث التي أجرتها جامعة لينكولن من قبل مجموعة مستقلة من الناس ، تسمى لجنة أخلاقيات البحث ، لحماية اهتماماتك

#### ما إذا كان هناك مشكلة؟

إذا كنت لديك مخاوف بشأن أي جانب من جوانب هذه الدراسة ، يجب عليك أن تطلب التحدث إلى الباحث أو المشرفين على البحوث ، الذين سيبدلون قصارى جهدهم للإجابة على أسئلتك. ترد تفاصيل الاتصال الخاصة بالباحث والمشرفين على البحوث في نهاية ورقة المعلومات هذه. إذا كنت لا تزال غير سعيد وترغب في تقديم شكوى رسميًا ، يمكنك القيام بذلك عن طريق الاتصال بـ [ethics@lincoln.ac.uk](mailto:ethics@lincoln.ac.uk).

إذا كنت تشعر بأننا خذلناك فيما يتعلق بحقوق المعلومات الخاصة بك ، فالرجاء الاتصال بفريق الامتثال للمعلومات عن طريق البريد الإلكتروني على [response@lincoln.ac.uk](mailto:response@lincoln.ac.uk) أو عن طريق البريد في Information Compliance ، سكرتارية ، جامعة لينكولن ، Brayford Pool ، Lincoln ، LN6 7TS.

يمكنك أيضًا تقديم شكوى مباشرة إلى مكتب مفوض المعلومات ICO. (ICO) هي السلطة المستقلة التي تدعم حقوق المعلومات في المملكة المتحدة. موقع الويب الخاص به هو [ico.org.uk](http://ico.org.uk) ورقم خط المساعدة الخاص بهاتفهم هو 1113 123 0303.

#### مزيد من المعلومات وتفاصيل الاتصال

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## Appendix D- Study Measures (English)

### Demographic Questions

- 1-Are you a parent of a child diagnosed with Autism Spectrum Disorder? (Yes/No)
- 2-Your child's gender: \_\_\_\_\_
- 3-Age of child: \_\_\_\_\_
- 4-Your gender: \_\_\_\_\_
- 5-Your age: \_\_\_\_\_
- 6-Nationality: \_\_\_\_\_
- 7-Please indicate your level of education: (Some high school/no diploma, High school graduate or equivalent, Some university/no degree, Bachelor's degree, Higher education degree, technical/vocational training)

### Depression, Anxiety and Stress Scale: DASS- 21

(Lovibond, S.H. & Lovibond, P.F. (1995). *Manual for the Depression Anxiety & Stress Scales*. (2nd Ed.) Sydney: Psychology Foundation.)

Please read each statement and select a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement. The rating scale is as follows: 0 Did not apply to me at all 1 Applied to me to some degree, or some of the time 2 Applied to me to a considerable degree or a good part of time 3 Applied to me very much or most of the time

- 1-I found it hard to wind down (0 1 2 3)
- 2-I was aware of dryness of my mouth (0 1 2 3)
- 3-I couldn't seem to experience any positive feeling at all (0 1 2 3)
- 4-I experienced breathing difficulty (e.g. Breathlessness in the absence of physical exertion) (0 1 2 3)
- 5-I found it difficult to work up the initiative to do things (0 1 2 3)
- 6-I tended to over-react to situations (0 1 2 3)
- 7-I experienced trembling (e.g. in the hands) (0 1 2 3)
- 8-I felt that I was using a lot of nervous energy (0 1 2 3)
- 9-I was worried about situations in which I might panic and make a fool of myself (0 1 2 3)
- 10-I felt that I had nothing to look forward to (0 1 2 3)
- 11-I found myself getting agitated (0 1 2 3)
- 12-I found it difficult to relax (0 1 2 3)
- 13-I felt down-hearted and blue (0 1 2 3)
- 14-I was intolerant of anything that kept me from getting on with what I was doing (0 1 2 3)
- 15-I felt I was close to panic (0 1 2 3)
- 16-I was unable to become enthusiastic about anything (0 1 2 3)
- 17-I felt I wasn't worth much as a person (0 1 2 3)
- 18-I felt that I was rather touchy (0 1 2 3)
- 19-I was aware of the action of my heart in the absence of physical exertion (0 1 2 3)
- 20-I felt scared without any good reason (0 1 2 3)
- 21-I felt that life was meaningless (0 1 2 3)

### Child's Challenging Behavior – CCBS (Version 2)

(Bourke-Taylor, H.M., Law, M., Howie, L., & Pallant, J.F., 2013)

At times, all children and teenagers behave in challenging ways. The following statements relate to your child's behavior at home. Please read each statement and select the most appropriate category representing your level of agreement.

- 1-My child never has tantrums (Strongly Agree/Agree/Disagree/Strongly Disagree)
- 2-My child aggravates others (Strongly Agree/Agree/Disagree/Strongly Disagree)
- 3-My child is never aggressive and violent towards others (Strongly Agree/Agree/Disagree/Strongly Disagree)
- 4-My child does not mind when I leave them at home with another adult while I go out (Strongly Agree/Agree/Disagree/Strongly Disagree)
- 5-My child can be stubborn and uncooperative (Strongly Agree/Agree/Disagree/Strongly Disagree)
- 6-I am able to manage the most challenging and difficult behaviours effectively on my own at home (Strongly Agree/Agree/Disagree/Strongly Disagree)
- 7-My child is happy and content at home most of the time (Strongly Agree/Agree/Disagree/Strongly Disagree)
- 8-My child follows the family routine easily (Strongly Agree/Agree/Disagree/Strongly Disagree)
- 9-My child copes well with disruptions to the family routine (Strongly Agree/Agree/Disagree/Strongly Disagree)

### Affiliate Stigma Scale

(Mak, W. W. S. and R. Y. M. Cheung (2008). *Affiliate stigma among caregivers of people with intellectual disability or mental illness. Journal of Applied Research in Intellectual Disabilities*, 21, 532-545.

Below are some sentences related to your life as a caregiver of child with intellectual disability such as autism. There are no right or wrong answers. Please read each sentence carefully then choose the option which best represents your opinion.

- 1-I feel inferior because I have a family member with an intellectual disability (Strongly Disagree/ Disagree/ Agree/Strongly Agree)

- 2-I avoid communicating with my family member who has an intellectual disability. (Strongly Disagree/ Disagree/Agree/Strongly Agree)
- 3-Other people would discriminate against me if I was with a family member who has an intellectual disability. (Strongly Disagree/ Disagree/Agree/Strongly Agree)
- 4-I feel emotionally disturbed because I have a family member with an intellectual disability. (Strongly Disagree/ Disagree/Agree/Strongly Agree)
- 5-I do not dare to tell others that I have a family member with an intellectual disability. (Strongly Disagree/ Disagree/Agree/Strongly Agree)
- 6-My reputation is damaged because I have a family member with an intellectual disability. (Strongly Disagree/ Disagree/Agree/Strongly Agree)
- 7-The behavior of my family member with an intellectual disability is embarrassing. (Strongly Disagree/ Disagree/Agree/Strongly Agree)
- 8-I avoid going out with my family member who has an intellectual disability. (Strongly Disagree/ Disagree/Agree/Strongly Agree)
- 9-People's attitudes towards me are negative when I am with my family member who has an intellectual disability. (Strongly Disagree/ Disagree/Agree/Strongly Agree)
- 10-I feel helpless about having a family member with an intellectual disability. (Strongly Disagree/ Disagree/Agree/Strongly Agree)
- 11-I reduce contact with my friends and relatives because I have a family member an intellectual disability. (Strongly Disagree/ Disagree/Agree/Strongly Agree)
- 12-Having a family member with an intellectual disability has a negative impact on me. (Strongly Disagree/ Disagree/Agree/Strongly Agree)
- 13-I feel sad because I have a family member with an intellectual disability. (Strongly Disagree/ Disagree/Agree/Strongly Agree)
- 14-When I am with my family member who has an intellectual disability, I keep a relatively low profile. (Strongly Disagree/ Disagree/Agree/Strongly Agree)
- 15-Having a family member with an intellectual disability makes me think that I am incompetent compared to other people. (Strongly Disagree/ Disagree/Agree/Strongly Agree)
- 16-I worry that other people will find out I have a family member with an intellectual disability. (Strongly Disagree/ Disagree/Agree/Strongly Agree)
- 17-I reduce interacting with my family member who has an intellectual disability. (Strongly Disagree/ Disagree/Agree/Strongly Agree)
- 18-Having a family member with an intellectual disability makes me think that I am less than others. (Strongly Disagree/ Disagree/Agree/Strongly Agree)
- 19-I feel that I am under great pressure because I have a family member with an intellectual disability. (Strongly Disagree/ Disagree/Agree/Strongly Agree)
- 20-I do not dare to participate in activities related to intellectual disability lest other people suspect I have a family member with an intellectual disability. (Strongly Disagree/ Disagree/Agree/Strongly Agree)
- 21-Having a family member with mental illness/intellectual disability makes me lose face. (Strongly Disagree/ Disagree/Agree/Strongly Agree)
- 22-I reduce contact with my neighbors because I have a family member with an intellectual disability. (Strongly Disagree/ Disagree/Agree/Strongly Agree)

#### **Gilliam Autism Rating Scale- Third Edition (GARS-3)**

(Gilliam, J. E. (2014). *Gilliam Autism Rating Scale—Third Edition (GARS-3)*)

On a scale of 0 to 3, rate the following items in terms of how adequately the item describes the individual's behavior. Select the number that best describes your observations of the person's typical behavior under ordinary circumstances (i.e., most places, with people they are familiar with, and in usual daily activities). If you are uncertain about how to rate an item, delay the rating and observe the person for a 6-hour period to determine rating.

(0- Not at all like the individual, 1- Not much like the individual, 2- Somewhat like the individual, 3- Very much like the individual)

- 1-If left alone, the majority of the individual's time will be spent in repetitive or stereotyped behaviors (0 1 2 3)
- 2-Is preoccupied with specific stimuli that are abnormal in intensity (0 1 2 3)
- 3-Stares at hands, objects, or items in the environment for at least 5 seconds (0 1 2 3)
- 4-Flicks fingers rapidly in front of eyes for periods of 5 seconds or more (0 1 2 3)
- 5-Makes rapid lunging, darting movement when moving from place to place (0 1 2 3)
- 6-Flaps hands or fingers in front of face or at sides (0 1 2 3)
- 7-Makes high-pitched sounds (e.g., eee-eee-eee-eee) or other vocalizations for self-stimulation (0 1 2 3)
- 8-Uses toys or objects inappropriately (e.g., spins cars, takes action toys apart) (0 1 2 3)
- 9-Does certain things repetitively, ritualistically (0 1 2 3)
- 10-Engages in stereotyped behaviors when playing with toys or objects (0 1 2 3)
- 11-Repeats unintelligible sounds (babbling) over and over (0 1 2 3)
- 12-Shows unusual interest in sensory aspects on play materials, body parts or objects (0 1 2 3)
- 13-Displays ritualistic or compulsive behaviors (0 1 2 3)

- 14-Does not initiate conversations with peers or others (0 1 2 3)
- 15-Pays little or no attention to what peers are doing (0 1 2 3)
- 16-Fails to imitate other people in games or learning activities (0 1 2 3)
- 17-Doesn't follow other's gestures to look at something (e.g., when other person nods head, points or uses other body language cues) (0 1 2 3)
- 18-Seems indifferent to other person's attention (doesn't try to get, maintain or direct the other person's attention) (0 1 2 3)
- 19-Shows minimal expressed pleasure when interacting with others (0 1 2 3)
- 20-Displays little or no excitement in showing toys or objects to others (0 1 2 3)
- 21-Seems uninterested in pointing out things in the environment to others (0 1 2 3)
- 22-Seems unwilling or reluctant to get others to interact with them (0 1 2 3)
- 23-Shows minimal or no response when others attempt to interact with them (0 1 2 3)
- 24-Displays little or no reciprocal social communication (e.g., doesn't voluntarily say "bye-bye" in response to another person saying "bye-bye" to them) (0 1 2 3)
- 25-Doesn't try to make friends with other people (0 1 2 3)
- 26-Fails to engage in creative, imaginative play (0 1 2 3)
- 27-Shows little or no interest in other people (0 1 2 3)
- 28-Responds inappropriately to humorous stimuli (e.g., doesn't laugh at jokes, cartoons, funny stories) (0 1 2 3)
- 29-Has difficulty understanding jokes (0 1 2 3)
- 30-Has difficulty understanding slang impressions (0 1 2 3)
- 31-Has difficulty identifying when someone is teasing (0 1 2 3)
- 32-Has difficulty understanding when they are being ridiculed (0 1 2 3)
- 33-Has difficulty understanding when causes others to dislike them (0 1 2 3)
- 34-Fails to predict probable consequences in social events (0 1 2 3)
- 35-Doesn't seem to understand that people have thoughts or feelings different from them
- 36-Doesn't seem to understand that the other person doesn't know something (0 1 2 3)
- 37-Needs an excessive amount of reassurance if things are changed or go wrong (0 1 2 3)
- 38-Becomes frustrated quickly when they cannot do something (0 1 2 3)
- 39-Temper tantrums when frustrated (0 1 2 3)
- 40-Becomes upset when routines are changed (0 1 2 3)
- 41-Responds negatively when given commands, requests or directions (0 1 2 3)
- 42-Has extreme reactions (e.g., cries, screams, tantrums) in response to loud, unexpected noise (0 1 2 3)
- 43-Temper tantrums when doesn't get their way (0 1 2 3)
- 44-Temper tantrums when told to stop doing something they are enjoying (0 1 2 3)
- \*Is the individual mute? (Yes/No) – if your answer is YES, do not complete next 2 subscales\* (If yes, Qualtrics survey will not show the following questions)
- 45-Uses exceptionally precise speech (0 1 2 3)
- 46-Attaches very concrete meanings to words (0 1 2 3)
- 47-Talks about a single subject excessively (0 1 2 3)
- 48-Displays superior knowledge or skill in specific subjects (0 1 2 3)
- 49-Displays excellent memory (0 1 2 3)
- 50-Shoes an intense, obsessive interest in specific intellectual subjects (0 1 2 3)
- 51-Makes naïve remarks (unaware of reaction produced in others) (0 1 2 3)
- 52-Repeats (echoes) words or phrases verbally or with signs (0 1 2 3)
- 53-Repeats words out of context (repeats words or phrases heard at an earlier time) (0 1 2 3)
- 54-Speaks (or signs) with flat tone, affect (0 1 2 3)
- 55-Uses "yes" and "no" inappropriately. Say "yes" when asked if they want an aversive stimulus or says "no" when asked if they want a favorite toy or treat (0 1 2 3)
- 56-Uses "he" or "she" instead of "I" when referring to self (0 1 2 3)
- 57-Speech is abnormal in tone, volume or rate (0 1 2 3)
- 58-Utters idiosyncratic words or phrases that have no meaning to others (0 1 2 3)

#### **Brief Resilience Scale (BRS)**

(Smith, B. W., Dalen, J., Wiggins, K., Tooley, E., Christopher, P., & Bernard, J. (2008). *The brief resilience scale: assessing the ability to bounce back. International journal of behavioral medicine, 15*(3), 194-200.

Please respond to each item by selecting the most appropriate response (1-Strongly Disagree, 2-Disagree, 3-Neutral, 4-Agree, 5-Strongly Agree)

- 1-I tend to bounce back quickly after hard times (1 2 3 4 5)
- 2-I have a hard time making it through stressful events (1 2 3 4 5)
- 3- It does not take me long to recover from a stressful event (1 2 3 4 5)
- 4-It is hard for me to snap back when something bad happens (1 2 3 4 5)
- 5-I usually come through difficult times with little trouble (1 2 3 4 5)
- 6-I tend to take a long time to get over set-backs in my life (1 2 3 4 5)

#### **Multidimensional Scale of Perceived Social Support (MSPSS)**

(Zimet, Dahlem, Zimet & Farley, 1988)

We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Select the "1" if you Very Strongly Disagree	Select the "2" if you Strongly Disagree
Select the "3" if you Mildly Disagree	Select the "4" if you are Neutral
Select the "5" if you Mildly Agree	Select "6" if you Strongly Agree
Select the "7" if you Very Strongly Agree	

- 1-There is a special person who is around when I am in need. (1 2 3 4 5 6 7)
- 2-There is a special person with whom I can share my joys and sorrows. (1 2 3 4 5 6 7)
- 3-My family really tries to help me. (1 2 3 4 5 6 7)
- 4-I get the emotional help and support I need from my family. (1 2 3 4 5 6 7)
- 5-I have a special person who is a real source of comfort to me. (1 2 3 4 5 6 7)
- 6-My friends really try to help me. (1 2 3 4 5 6 7)
- 7-I can count on my friends when things go wrong. (1 2 3 4 5 6 7)
- 8-I can talk about my problems with my family. (1 2 3 4 5 6 7)
- 9-I have friends with whom I can share my joys and sorrows. (1 2 3 4 5 6 7)
- 10-There is a special person in my life who cares about my feelings. (1 2 3 4 5 6 7)
- 11-My family is willing to help me make decisions. (1 2 3 4 5 6 7)
- 12-I can talk about my problems with my friends. (1 2 3 4 5 6 7)

**Brief Arab Religious Coping Scale (BARCS)**

(Amer, M., Hovey, J. D., Fox, C. M., & Rezcallah, A. (2008). Initial development of the brief Arab religious coping scale (BARCS). *Journal of Muslim Mental Health*, 3, 69-88.)

Please read each statement carefully and select how often you have engaged in the following behaviors when you have experienced a stressful situation or problem.

(0 = not used at all/ does not apply 1 = used sometimes 2 = used often 3 = used always)

- 1) I prayed for strength. (0 1 2 3)
- 2) I looked for a lesson from God in the situation. (0 1 2 3)
- 3) I got help from religious leader/s. (0 1 2 3)
- 4) I recalled a passage from a religious text (e.g., Bible, Qur'an). (0 1 2 3)
- 5) I attended events at the church/ mosque/ temple. (0 1 2 3)
- 6) I put my problem in God's hands. (0 1 2 3)
- 7) I increased my prayers to God. (0 1 2 3)
- 8) I attended religious classes (e.g., Bible study, Islamic halaqa) (0 1 2 3)
- 9) I tried to make up for my mistakes. (0 1 2 3)
- 10) I asked God for a blessing. (0 1 2 3)
- 11) I used a religious story to help solve the problem. (0 1 2 3)
- 12) I shared my religious beliefs with others. (0 1 2 3)
- 13) I donated time to a religious cause or activity. (0 1 2 3)
- 14) I looked for love and concern from the members of my church/ mosque/ temple. (0 1 2 3)
- 15) I prayed to get my mind off my problem/s. (0 1 2 3)



## Appendix E- Study Measures (Arabic)

- 1- هل أنت والد/ة لطفل مصاب باضطراب طيف التوحد؟ (نعم / لا)
- 2- جنس طفلك: \_\_\_\_\_
- 3- عمر الطفل: \_\_\_\_\_
- 4- جنسك: \_\_\_\_\_
- 5- عمرك: \_\_\_\_\_
- 6- الجنسية: \_\_\_\_\_
- 7- يرجى الإشارة إلى مستواك التعليمي: (بعض المدارس الثانوية / بدون دبلوم ، خريج ثانوي أو ما يعادلها ، بعض الجامعات / لا يوجد درجة ، درجة البكالوريوس ، درجة التعليم العالي ، التدريب التقني / المهني

على مقياس من 0 إلى 3 ، صنف العناصر التالية من حيث مدى وصف العنصر لسلوك طفلك. حدد الرقم الذي يصف بشكل أفضل ملاحظتك عن السلوك المعتاد لطفلك في ظل الظروف العادية (مثل معظم الأماكن ، والأشخاص الذين يعرفونهم ، وفي الأنشطة اليومية المعتادة). إذا كنت غير متأكد من كيفية تصنيف عنصر ما ، فقم بتأخير التقييم ومراقبة طفلك لمدة 6 ساعات لتحديد التصنيف.

0-ليس على الإطلاق مثل الفرد ، 1- ليس مثل الفرد ، 2- يشبه الفرد إلى حد ما ، 3- يشبه الفرد جدًا

1. إذا تلاك الطفل لوحده يقضي معظم الوقت يكرر نفس السلوك و الانفعال
2. يشغل دائما بتصرفات غير طبيعية و باستمرار
3. يحدق و يركز نظره على يديه مثلا او الشيء نفسه لمدة تزيد عن خمس ثواني
4. يحرك اصابعه بسرعة امام وجهه لأكثر من خمس ثواني
5. ينطلق بسرعة من مكان لأخر
6. يرفرف يديه و اصابعه على جانبيه او امام وجهه
7. يصدر اصوات عالية ليحفز نفسه
8. يستخدم الالعاب بطريقة غير مألوفة، يلف عجل السيارات في دوائر او يفككها
9. يقوم بأشياء بتكرار او روتين محدد
10. يمارس سلوكيات غير طبيعية عند التعامل مع الاشياء او الالعاب
11. يكرر اصوات غير مفهومة باستمرار
12. يظهر اهتمام غير طبيعي بالالعاب الحسية اوبعض اعضاء الجسم
13. لديه سلوكيات لا يستطيع مقاومتها و يتبعها في كل نشاط
14. يبادر بالتحدث مع اصدقائه او الآخرين
15. ينتبه لمل يفعله اصدقائه
16. يستطيع ان يقلد الآخرين في اللعب و النشاط التعليمي
17. يتبع الاشارات التي يقوم بها الآخرون مثلا الاشارات اليدوية او حركة الرأس او الجسم
18. يهيمه مقاصد الآخرين او يحاول ان يفهم او يعرف ما يقصده الآخرين
19. يظهر سعادته عندما يتعامل مع الآخرين
20. يكون متحمس عندما يعرض العابه على الآخرين
21. يشير الى الاشياء في محيط الآخرين
22. يقبل بأن يتعامل مع الآخرين
23. يتجاوب مع الآخرين اذا حاولوا التواصل معه
24. يتبادل مع الآخرين التعامل الاجتماعي، يرد على من يقول له "مع السلامة" مثلا
25. يحاول ان يصادق احد
26. يستعمل خياله في اللعب
27. يظهر اي اهتمام بالآخرين
28. يتجاوب بطريقة طبيعية اثناء المزاح كأن يضحك على النكتة او الرسوم المتحركة او القصص المضحكة
29. يستوعب النكت او المزاح
30. يفهم المصطلحات او الجمل العامة
31. يعرف اذا كان احد يمازحه
32. يعرف اذا ما كان احد يسخر منه
33. يدرك ما الذي يجعل الناس لا تحبه
34. يستطيع ان يتوقع ما يحدث في المناسبات الاجتماعية
35. يدرك بان الآخرين لديهم افكارهم و مشاعرهم التي تختلف
36. يعرف بان الآخرين قد لا يعرفون بعض الامور
37. يحتاج الى الكثير من التهدة اذا ما حدث اي تغيير او شيء خاطئ
38. يشعر بالفهر سريعا اذا لم يستطيع فعل شيئا ما
39. يعاني من نوبات غضب اذا تضايق
40. يغضب اذا تغير الروتين
41. يكون سلمي عندما توجه له تعليمات او طلبات
42. يصرخ و يبكي اذا سمع صوت عاليا فجأة
43. يغضب شديدا اذا لم يحصل على ما يريد
44. تأتبه نوبات غضب شديدة اذا طلب منه ان يتوقف عن عمل شيء هو متمتع به
45. هل طفلك ابكم؟
46. طريقة كلامه محددة جدا



47. كلماته لها معنى محدد
48. يتحدث عن موضوع واحد باستمرار
49. هو متميز و متفوق في موضوع معين
50. لديه ذاكرة جيدة
51. يظهر اهتمام كبير و متواصل في موضوع فكري/علمي معين
52. يقول ملاحظات غير مناسبة و لا يعرف كيف يمكن ان يكون تأثيرها و ردة فعلها عند الاخيرين
53. يكرر باستمرار كلمات او جمل مع اشارات
54. يكرر كلمات عشوائية يكون قد سمعها سابقا
55. يتكلم بدون اي نعمة او تعبير في الصوت
56. يجيب بنعم او لا دون ان يفرق بينهما
57. يستخدم الضمائر بشكل صحيح
58. كلامه غير طببي من ناحية علو الصوت او السرعة
59. يقول كلمات و جمل ليس لها معنى

في بعض الأحيان ، يتصرف جميع الأطفال والمراهقين بطرق صعبة. العبارات التالية تتعلق بسلوك طفلك في المنزل. يرجى قراءة كل بيان واختيار أنسب فئة تمثل مستوى موافقتك. (أوافق بشدة / أوافق / أعارض / أعارض بشدة)

- 1- طفلي لا يعاني من نوبات غضب
- 2- طفلي يزج الآخرين
- 3- طفلي ليس عدوانيًا وعنيفًا تجاه الآخرين أبدًا
- 4- طفلي لا يمانع عندما أتركه في المنزل مع شخص بالغ آخر أثناء الخروج
- 5- يمكن لطفلي أن يكون عنيدًا وغير متعاون
- 6- أنا قادر على إدارة أكثر السلوكيات صعوبة وصعوبة بشكل فعال في المنزل
- 7- طفلي سعيد وراض في المنزل معظم الوقت
- 8- طفلي يتبع روتين الأسرة بسهولة
- 9- يتأقلم طفلي جيدًا مع الاضطرابات في روتين الأسرة

فيما يلي بعض الجمل المتعلقة بحياتك كمقدم رعاية لطفل يعاني من إعاقة ذهنية مثل التوحد. لا توجد اجابات صحيحة أو خاطئة. يرجى قراءة كل جملة بعناية ثم تحديد الخيار الأفضل الذي يمثل رأيك. (لا أوافق بشدة / لا أوافق / أوافق / أوافق بشدة)

- 1- أشعر بالنقص لأن أحد أفراد عائلتي يعاني من إعاقة ذهنية
- 2- أتجنب التواصل مع أحد أفراد عائلتي من ذوي الإعاقة الذهنية.
- 3- يميز الناس ضدي إذا كنت مع أحد أفراد عائلتي من ذوي الإعاقة الذهنية.
- 4- أشعر باضطراب عاطفي لأن أحد أفراد عائلتي يعاني من إعاقة ذهنية.
- 5- لا أجرؤ على إخبار الآخرين بأن لدي أحد أفراد عائلتي من ذوي الإعاقة الذهنية.
- 6- تضررت سمعي لأن لدي أحد أفراد عائلتي من ذوي الإعاقة الذهنية.
- 7- سلوك أحد أفراد عائلتي من ذوي الإعاقة الذهنية محرج.
- 8- أتجنب الخروج مع أحد أفراد عائلتي من ذوي الإعاقة الذهنية.
- 9- مواقف الناس تجاهي سلبية عندما أكون مع أحد أفراد عائلتي المصاب بإعاقة ذهنية.
- 10- أشعر بالعجز تجاه أحد أفراد الأسرة من ذوي الإعاقة الذهنية.
- 11- قلل من التواصل مع أصدقائي وأقاربي لأن لدي أحد أفراد عائلتي من ذوي الإعاقة الذهنية.
- 12- وجود أحد أفراد الأسرة من ذوي الإعاقة الذهنية له أثر سلبي علي.
- 13- أشعر بالحزن لأن لدي أحد أفراد الأسرة من ذوي الإعاقة الذهنية.
- 14- عندما أكون مع أحد أفراد عائلتي المصاب بإعاقة ذهنية ، فإنني أبقي بعيدًا عن الأنظار نسبيًا.
- 15- وجود أحد أفراد الأسرة من ذوي الإعاقة الذهنية يجعلني أعتقد أنني غير كفء مقارنة بالآخرين.
- 16- أخشى أن يكتشف الآخرون أن لدي أحد أفراد عائلتي من ذوي الإعاقة الذهنية.
- 17- أقوم بتقليل التفاعل مع أحد أفراد عائلتي من ذوي الإعاقة الذهنية.
- 18- وجود أحد أفراد الأسرة من ذوي الإعاقة الذهنية يجعلني أعتقد أنني أقل من الآخرين.
- 19- أشعر أنني تحت ضغط كبير لأن لدي أحد أفراد عائلتي من ذوي الإعاقة الذهنية.
- 20- لا أجرؤ على المشاركة في الأنشطة المتعلقة بالإعاقة الذهنية حتى لا يشك الآخرون في أن لدي أحد أفراد الأسرة من ذوي الإعاقة الذهنية.
- 21- وجود فرد من الأسرة يعاني من مرض عقلي / إعاقة ذهنية يجعلني أفقد الوجه.
- 22- أقوم بتقليل الاتصال بجيراني لأن لدي أحد أفراد الأسرة من ذوي الإعاقة الذهنية

يرجى الرد على كل عنصر عن طريق تحديد الإجابة الأكثر ملاءمة (1-لا أوافق بشدة ، 2-لا أوافق ، 3-محايد ، 4-أوافق ، 5-أوافق بشدة)

- 1- أميل إلى الارتداد بسرعة بعد الأوقات الصعبة
- 2- أجد صعوبة في الخروج من الأحداث المجهدة
- 3- لا يستغرق الأمر وقتًا طويلاً للتعا في من حدث مرهق
- 4- من الصعب علي العودة عندما يحدث شيء سيء
- 5- عادة ما أواجه الأوقات الصعبة مع القليل من المتاعب
- 6- أميل إلى قضاء وقت طويل في التغلب على النكسات في حياتي

اقرأ كل بيان بعناية. وضح ما تشعر به حيال كل عبارة.  
 حدد "1" إذا كنت لا توافق بشدة ، حدد "2" إذا كنت لا توافق بشدة  
 حدد "3" إذا كنت غير موافق بدرجة معتدلة ، حدد "4" إذا كنت محايدًا  
 حدد "5" إذا كنت توافق بشكل معتدل ، حدد "6" إذا كنت توافق بشدة

حدد "7" إذا كنت توافق بشدة

- 1- يوجد شخص مميز موجود في الجوار عندما أحتاج.
- 2- هناك شخص مميز يمكنني مشاركة أفراحه وأحزاني معه.
- 3- عائلتي تحاول مساعدتي حقًا.
- 4- أحصل على المساعدة العاطفية والدعم الذي أحتاجه من عائلتي.
- 5- لدي شخص مميز هو مصدر الراحة الحقيقي لي.
- 6- أصدقائي يحاولون حقًا مساعدتي.
- 7- يمكنني الاعتماد على أصدقائي عندما تسوء الأمور.
- 8- أستطيع التحدث عن مشاكلي مع عائلتي.
- 9- لدي أصدقاء أشاركهم أفراحهم وأحزاني.
- 10- هناك شخص مميز في حياتي يهتم بمشاعري.
- 11- عائلتي مستعدة لمساعدتي في اتخاذ القرارات.
- 12- أستطيع التحدث عن مشاكلي مع أصدقائي.

يرجى قراءة كل عبارة بعناية وتحديد عدد المرات التي شاركت فيها في السلوكيات التالية عندما واجهت موقفًا أو مشكلة مرهقة.  
(0 = غير مستخدم على الإطلاق / لا ينطبق 1 = يستخدم أحيانًا 2 = يستخدم غالبًا 3 = يستخدم دائمًا)

- (1) صليت من أجل القوة.
- (2) بحثت عن درس من الله في الموقف.
- (3) حصلت على مساعدة من رجل ديني.
- (4) تذكرت مقطعًا من نص ديني
- (5) حضرت المناسبات في المسجد
- (6) أضعت مشكلتي بين يدي الله.
- (7) زدت صلاتي إلى الله.
- (8) حضرت دروسًا دينية (على سبيل المثال الحلقة الإسلامية)
- (9) حاولت الاستغفار
- (10) طلبت من الله بركة
- (11) استخدمت قصة دينية للمساعدة في حل المشكلة
- (12) شاركت معتقداتي الدينية مع الآخرين.
- (13) تبرعت بالوقت لقضية أو نشاط ديني.
- (14) بحثت عن الحب والاهتمام من أعضاء مسجدي
- (15) صليت لأبعد عقلي عن مشكلتي

يرجى قراءة كل عبارة وتحديد رقم 0 أو 1 أو 2 أو 3 والذي يشير إلى مدى انطباق العبارة عليك خلال الأسبوع الماضي. لا توجد إجابات صحيحة أو خاطئة. لا تضيق الكثير من الوقت في أي بيان. مقياس التصنيف على النحو التالي: 0 لم ينطبق علي على الإطلاق 1 تم تطبيقه علي إلى حد ما ، أو في بعض الأحيان 2 تم تطبيقه علي بدرجة كبيرة أو جزء كبير من الوقت 3 تم تطبيقه علي كثيرًا أو أكثر من الوقت

- 1- وجدت صعوبة في الاسترخاء
- 2- كنت على علم بجفاف فمي
- 3 - لا أستطيع أن أشعر بأي شعور إيجابي على الإطلاق
- 4- عانيت من صعوبة في التنفس (مثل ضيق التنفس في حالة عدم وجود مجهود بدني)
- 5- وجدت صعوبة في العمل على المبادرة للقيام بالأشياء
- 6- أميل إلى المبالغة في رد الفعل تجاه المواقف
- 7- شعرت بارتجاف (على سبيل المثال في البدين)
- 8- شعرت أنني أستهلك الكثير من الطاقة العصبية
- 9- كنت قلقة بشأن المواقف التي قد أصاب بالذعر وأخذت نفسي
- 10- شعرت أنه ليس لدي ما أتطلع إليه
- 11- وجدت نفسي مضطربًا
- 12- وجدت صعوبة في الاسترخاء
- 13 - شعرت بالحزن والأرق
- 14- كنت غير متسامح مع أي شيء يمنعني من متابعة ما كنت أفعله
- 15- شعرت أنني على وشك الذعر
- 16- لم أستطع التحمس لأي شيء
- 17- شعرت أنني لا أساوي كثيرًا كشخص
- 18- شعرت بأنني حساس نوعًا ما
- 19- كنت على علم بعمل قلبي في غياب المجهود البدني
- 20- شعرت بالخوف دون سبب وجيه
- 21- شعرت أن الحياة لا معنى لها



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الموافقة على المشاركة في البحث

عنوان المشروع: الضغط النفسي والقلق والاكتئاب لدى والدي اطفال التوحد في المملكة العربية السعودية

اسم الباحث: رناد ياسين

1. ادرك أن مشاركتي طوعية وأنني حر في الانسحاب في أي وقت دون إبداء أي سبب ، دون أن تتأثر حقوقي القانونية . ☐
2. أدرك أنه في حالة انسحابي ، فإن المعلومات التي تم جمعها حتى الآن قد لا يتم محوها وأن هذه المعلومات قد تظل مستخدمة في تحليل المشروع. ☐
3. أفهم أن الأفراد من جامعة لينكولن قد يبحثون في بيانات البحوث التي تم جمعها أثناء الدراسة ، لضمان إجراء الدراسة بشكل مناسب. أسمح لهؤلاء الأفراد بالوصول إلى بياناتي ؛ أنا أفهم أنه لن يتم جمع أي تفاصيل شخصية ☐
4. اوافق على المشاركة في هذا الاستبيان ☐

