

THE WELL-BEING OF FAMILIES LIVING WITH AUTISM SPECTRUM DISORDER IN QATAR



DIFI

معهد الدوحة الدولي للأسرة
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CONTRIBUTORS

This report was prepared by: Naomi V. Ekas, PhD, Assistant Professor, Department of Psychology, Texas Christian University, USA; Abdallah M. Badahdah, PhD, Director, Family Research Division, Doha International Family Institute, Qatar; and Azza O. Abdelmoneium, PhD, Senior Lead Researcher, Doha International Family Institute, Qatar.

Staff from DIFI, namely, Gilla M. Camden, Research and Grant Specialist; Mohamed I. Mahgoub, Lead Researcher; and Aisha J. Al Sultan, Researcher, also contributed to this publication.

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DOHA INTERNATIONAL FAMILY INSTITUTE (DIFI)

The Doha International Family Institute (DIFI), a member of Qatar Foundation for Education, Science and Community Development (QF), was established in 2006. The Institute works to strengthen the family through the development and dissemination of high-quality research on Arab families, encouraging knowledge exchange on issues relevant to the family and making the family a priority for policy makers through advocacy and outreach at the national, regional and international levels. Among the Institute's most important initiatives are the Annual Conference on the Family and the OSRA Research Grant in collaboration with the Qatar National Research Fund, an annual research grant which encourages research related to the Arab family and family policy. The Institute has special consultative status with the United Nations Economic and Social Council (ECOSOC).

To know more about the Doha International Family Institute, please visit www.difi.org.qa.

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FOREWORD

With the increased prevalence of Autism Spectrum Disorder (ASD) globally over the past fifty years, and the diagnosis of an estimated 1 in 160 children worldwide (World Health Organization, 2017), today more and more families are embarking on the daunting and challenging journey that **precedes** a child's autism diagnosis. A child's autism does not occur in a vacuum, but is rather accompanied by a range of communication challenges, misunderstandings of social cues, and a lack of emotional understanding that significantly impacts every member of the family. Thus, families of children with autism can often feel overwhelmed and undersupported. In addition, as parents adjust to life after diagnosis and focus their time and resources on the needs of their child with autism, the ensuing stress may have lasting negative effects on their marriage, other children, finances, and personal as well as familial relationships.

Yet, research has shown that empowering the families of children with autism throughout and following the critical diagnostic process can equip them with tools to cope better with newfound challenges, and ultimately facilitate successful family adaptation. Hence, by conducting the first comprehensive qualitative study in Qatar on the perceptions and experiences of families of children with autism, the Doha International Family Institute is aiming to contribute to the achievement of the goals of the Qatar National Autism Plan 2017-2021. Specifically, by giving a voice to families of children with autism in Qatar, this study highlights their challenges and unmet needs to allow us to better inform strategies and programs aimed at immediate and long-term family empowerment.

By addressing critical gaps in research on the challenges faced by parents of children with autism in Arab countries and on the psychological well-being of families with children with autism, this study delves into the unique experiences of such families in Qatar to identify the challenges for parents and the impact on their psychological well-being, as well as assistive protective factors for counteracting negative effects. In an effort to contribute to the improvement of the lives of families of children with autism not only in Qatar but also in the larger Arab region, this study offers empirically-based recommendations for shaping policies that best support these families and allow each family member to thrive and reach their full potential.



Noor Al Malki Al Jehani
Executive Director
Doha International Family Institute

EXECUTIVE SUMMARY

Autism is a lifelong neurodevelopmental disorder that affects approximately 1% of children worldwide. Children with autism have difficulties in social interactions and communication and often engage in repetitive behaviors or have restricted interests (American Psychiatric Association, 2013). As a result of their child's autism diagnosis, parents of children with autism often experience increased stress and poorer psychological well-being. Moreover, relationships within the family (e.g., marital relationship) may be negatively impacted. Addressing the needs of family members, particularly parents, is critical, as decades of research have shown that parents' psychological well-being can affect the way that parents interact with their children. These interactional patterns can, in turn, impact children's development in many of the areas that are affected by autism, including the social and emotional, language, and cognitive domains.

The government of Qatar has recently taken steps to address the needs of children with autism and their families. The overarching aim of the Qatar National Autism Plan is to improve the lives of individuals with autism and their families. The six pillars of the National Autism Plan are designed to address the needs of individuals with autism and their families in areas such as raising awareness about autism, receiving early diagnosis, and accessing treatment and education. Once these needs are met, it is likely that the families of children with autism in Qatar can flourish. However, there are likely to be other challenges and unmet needs that the National Autism Plan does not address, and it was with this in mind that this first comprehensive study of families of children with autism in Qatar was undertaken.

1. Aims and Methodology

This study has three primary aims: 1) to identify the challenges that families of children with autism in Qatar face; 2) to examine the psychological well-being of parents of children with autism; and 3) to make recommendations for improving the lives of families of children with autism.

To accomplish these goals, a multimethod study was conducted in which a total of 20 mothers and fathers of children with autism were interviewed about their experiences raising a child with autism. Based on the themes that emerged from these parent interviews, a survey was developed and completed by 42 mothers and fathers of children with autism. This survey gathered demographic information and data on parents' needs related to their child with autism, child behavior problems, parents' psychological well-being (life satisfaction, parenting stress, perceived parenting competence, and romantic relationship satisfaction), social support, and coping strategies.

2. Qualitative Findings

Our thematic analysis of the parent interviews revealed six main challenges that parents of children with autism face:

Service providers

Parents reported numerous challenges regarding services in Qatar, starting from the moment they first suspect that something is not quite right with their child's development. Frustrations with the diagnostic process were common, with parents reporting difficulties in getting medical professionals to provide diagnoses in a timely manner. Parents were also concerned about the long wait lists to access government-provided therapy services in Qatar, and about the quality of these services. Finally, parents reported difficulties accessing inclusive education for their children.

Social support

Parenting a child with autism can be an isolating experience. Parents reported being unable to go out with their friends or enjoy public activities in the way they used to do before their child's diagnosis. Many parents wished they could have some type of respite care in order to enjoy time with their spouses, but they were concerned about finding someone able to take care of their child.

Autism awareness

Some parents reported that a lack of awareness about autism, as well as not knowing what the early signs of autism are, had prevented them from seeking a diagnosis earlier. Parents' lack of awareness included not knowing the typical developmental milestones in the first few years of life. This knowledge is critical to ensuring that children with autism receive an early diagnosis and early treatment. Another challenge is the lack of autism awareness in the community. Parents reported being shunned and having to deal with people commenting about their child's behavior and their parenting skills when out in public with their child with autism. This can lead to parents not taking their child out in public with them anymore.

Finances

The financial burden associated with raising a child with autism was also a challenge for parents. Several families reported paying for private therapies because the wait list for the government-provided services was too long, or they felt that the services were not working for their child. The majority of families we interviewed reported that the mother took leave from her employment in order to provide care to the child with autism. This creates additional stress in the family, as fathers are then solely responsible for providing financial support to the family.

Family environment

In addition to the challenges that parents face, the entire family system is also impacted by a diagnosis of autism in the family. Some parents discussed that their marriage was negatively impacted by not having time to spend together as a couple, or feeling that their spouse was not supportive. The dynamics of sibling relationships may also be impacted, with the unaffected sibling (i.e., sibling who does not have autism) feeling jealous of the attention that their sibling with autism receives, or being embarrassed by their sibling's behavior.

The future

Many parents recognized that services are improving for young children with autism, but they are concerned about what will happen when their child becomes an adult. Parents were especially worried about whether their child would be able to live independently and have employment opportunities. A challenge that was commonly reported was not knowing about the types of services available for adults with autism and their families. A troubling thought for many parents was how their child would be cared for when the parents are no longer able to provide care.

3. Survey Findings

The surveys that parents completed also provided a rich body of information for understanding parents' unmet needs with respect to their child with autism, and how these impact their psychological well-being. From the survey data, we were also able to identify individual and environmental factors that could improve the lives of parents of children with autism.

Unmet needs

Many of the needs that parents reported in the survey were similar to the challenges they discussed in the interviews. However, the survey items included aspects of raising a child with autism that were not assessed during the interviews. Consistent with the interviews, parents reported unmet needs with respect to service providers in Qatar. One area of need that was not revealed in the interviews was in the area of mental health. Parents, particularly fathers, reported needing counseling.

Social support also emerged as an unmet need for parents of children with autism. Parents were particularly in need of instrumental social support, which consists primarily of having someone who can take care of their child and provide respite care. With respect to autism awareness, parents reported needing information about how to interact and play with their child with autism. They also needed to learn more about other conditions (e.g., ADHD, depression, anxiety, epilepsy) with which their child might be diagnosed. Financial needs consisted of needing assistance with paying for their child's therapies, paying for respite care and babysitters, and loss of employment for mothers who need to stay home to care for their child. Finally, parents reported needing help managing aspects of the family environment, including how to manage household tasks, how to solve problems as a family, and how to support other family members.

Psychological well-being

Parental psychological well-being is multifaceted and consists of "feeling good" in various domains. The survey we administered assessed parents' general satisfaction with their lives, their parenting-related stress, their perceived competence as parents, and the quality of their romantic relationships with their spouses. In general, parents reported average levels of life satisfaction; however, there was considerable variation in their levels of life satisfaction. Parents who reported greater social support needs were

more likely to report low levels of life satisfaction, higher levels of parental stress, and lower romantic relationship satisfaction. Another factor related to parental psychological well-being was the severity of children's behavior problems (e.g., aggression, temper tantrums, etc.). Parents of children with greater behavior problems also reported lower life satisfaction, greater parental stress, and lower perceived competence as a parent.

Protective factors

Given that raising a child with autism is stressful and can negatively impact parental psychological well-being, we explored whether there were characteristics of the parent (coping strategies) or their environment (receipt of social support) that could help to buffer, or protect against, this stress. Parents who reported high levels of social support were less affected by their child's behavior problems. In addition, parents who were able to utilize adaptive coping strategies were also doing better. Examples of adaptive strategies include distraction, planning, acceptance, reframing, and religious coping. Identifying these protective factors is an important first step in developing parent-focused intervention programs to improve parental well-being.

4. Recommendations

To improve the lives of families of children with autism, we make the following recommendations:

- Children should not have to wait so long to receive a diagnosis of autism, and there should be more and better communication with parents throughout the process. Similarly, the process of seeking services for children with autism should be simplified, and greater access made easier for families. All children should be able to receive services, ideally at a young age.
- To reduce the financial burden on families, and the stress associated with needing financial assistance, all families should have access to government-provided services of the highest quality, delivered by well-trained therapists. In addition, the process of seeking paid leave for mothers who choose to stay home to provide full-time care for their child should be simplified.
- Community awareness about autism should be increased. Public awareness campaigns should aim to teach community members about the causes of autism, the symptoms of autism, and the behaviors that children with autism might exhibit.
- Parents should have access to multifaceted social support services that include both instrumental and emotional forms of support. Given the unique needs of fathers, we recommend that separate groups be established that are fathers only.
- In addition to social support, parents should be provided with mental health services that directly address the stress that they are experiencing.
- Parents should be taught coping skills to deal with the stress associated with raising a child with autism.

CHAPTER ONE: BACKGROUND AND RATIONALE FOR STUDY

1.1. Autism Spectrum Disorder

Autism is a neurodevelopmental disorder characterized by difficulties in social communication (e.g., expressive language, eye contact, social interaction, etc.) and engagement in restricted and repetitive behaviors (e.g., repetitive hand and body movements, interest in unusual objects, etc.). Autism typically develops early in childhood and persists throughout the lifespan. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) (American Psychiatric Association, 2013) now classifies children on a continuum according to the level of support needed (i.e., from Level 1: requiring support to Level 3: requiring very substantial support).

The worldwide prevalence of autism is estimated to be 1 in 160 children (Elsabbagh et al., 2012). In the United States, however, the prevalence rate is 1 in 68 children (Centers for Disease Control and Prevention (CDC), 2014), which was a 30% increase over a two-year period. In the United Kingdom, the prevalence rate is approximately 1% (Buescher, Cidav, Knapp, & Mandell, 2014). Autism appears to be more prevalent in males than in females, with a ratio ranging from 4:1 to 3:1 (Messinger et al., 2015). The prevalence rate in many low- and middle-income countries is unknown, and in Arab countries there have been only limited studies examining prevalence rates. A study of toddlers in Beirut and Mount Lebanon found a prevalence rate of 1 in 66 children (Chaaya, Saab, Maalouf, & Boustany, 2016). In the United Arab Emirates, the prevalence of children diagnosed with pervasive developmental disorders (using DSM-IV criteria) was 29 per 10,000 (Eapen, Mabrouk, Zoubeidi, & Yunis, 2007), whereas in the Sultanate of Oman the prevalence rate of autism was found to be 1.4 per 10,000 (Al-Farsi et al., 2011). In Bahrain, a prevalence rate of 4.3 per 10,000 was found with a male to female ratio of 4:1 (Al-Ansari & Ahmed, 2013). There are no known studies examining the prevalence rate of autism in Qatar; however, we might expect a rate similar to those of other Arab countries. Overall, there appear to be discrepancies in the rates found between Western and Arab countries. The lower rates of autism in Arab countries may be due to difficulties accessing diagnostic services, a lack of trained professionals to conduct diagnostic services (e.g., clinical child psychologists, child psychiatrists, developmental pediatricians), less awareness about autism, and cultural differences in reporting child difficulties. Nonetheless, a growing number of parents in Arab countries find themselves raising a child with autism.

1.2. Family Challenges

Parents in Western countries report a variety of challenges as a result of parenting a child with autism. From the first concerns about their child's development, parents report difficulties navigating the healthcare system and receiving services for their child, and problems with the education system (e.g., receiving services in school, developing individualized education plans, etc.). There is also a considerable financial

strain associated with raising a child with autism, ranging from costs associated with medical services and therapies to payment for private schools or home aid workers (Buescher et al., 2014). Parents often report feelings of frustration because they know that the needs of the family are not being met (e.g., access to services, receipt of quality services) (Montes, Halterman, & Magyar, 2009). Other challenges include feeling unable to go out in public due to their child's behavior, losing friends, and being treated badly by strangers (Myers, Mackintosh, & Goin-Kochel, 2009). Parents of children with autism may also experience stigma as a result of their child's disability (Chan & Lam, 2017).

Research examining challenges faced by parents of children with autism in Arab countries is also limited. In Egypt, Zaki and Moawad (2016) found that nearly two-thirds of mothers reported poor awareness regarding autism, which may impact the ability to seek services. Jordanian parents of children with autism reported issues with having to rely on multiple providers for their child's care, the financial burden of services, the availability of services, and the degree of collaboration between parents and providers (Al Jabery, Arabiat, Al Khamra, Betawai, & Abdel Jabbar, 2014). In the Sultanate of Oman, 60% of families reported that they were unhappy with the services their child received (Al-Farsi et al., 2013). Parents living in the West Bank were found to face financial challenges and discrimination and stigma from family members and the community, as well as difficulties handling their child's behavior (Dababnah & Parish, 2013). Notably, in the only study of parents of children with autism in Qatar, parents reported dissatisfaction with the length of time it took to receive services (Kheir et al., 2012).

The challenges that parents of children with autism face may negatively impact their quality of life and their psychological well-being (Kuhlthau et al., 2014). Studies have consistently demonstrated that mothers of children with autism report elevated levels of parental stress compared to mothers of typically developing children and mothers of children with other developmental disabilities (Dabrowska & Pisula, 2010). Mothers of children with high-functioning autism also reported decreased well-being, such as greater depressive symptomatology and higher levels of anxiety compared to mothers of typically developing children (Lee, 2009). These increased depressive symptoms were found to predict lower levels of family functionality for mothers of children with autism (Jellett, Wood, Giallo, & Seymour, 2015). Moreover, mothers of children with autism reported lower levels of family cohesion and adaptability compared to normative data from the general population (Higgins, Bailey, & Pearce, 2005). Finally, the stigma that some parents report experiencing is often associated with negative outcomes, including depression, anxiety, and increased caregiver burden (Chan & Lam, 2017). Some of the factors associated with poor well-being include the severity of the child's autism symptoms (Ekas & Whitman, 2010), the presence of comorbid child behavior problems (Ekas & Whitman, 2010), a lack of social support, and feelings of social isolation (Boyd, 2002).

1.3. Family Challenges in Arab Countries

Research conducted in Arab countries is generally consistent with that carried out in the West. For example, Lebanese mothers of children with autism reported signifi-

cantly lower standards of well-being and less social support compared to mothers of typically developing children (Obeid & Daou, 2015). Similarly, mothers of children with autism in Jordan reported high levels of stress and lower quality of life (Dardas, 2014). In Saudi Arabia, parents of children with autism reported significantly higher symptoms of depression and anxiety compared to parents of typically developing children (Almansour, Alateeq, Alzahrani, Algeffari, & Alhomaïdan, 2013). In Qatar specifically, Kheir et al. (2012) found that parents of children with autism had mental health scores similar to those of parents of typically developing children, but their health-related quality of life scores were significantly lower. Unfortunately, there has been little research in Arab countries on the effect of raising a child with autism on family-level functioning. Indeed, a careful search of the literature revealed no studies examining family-level characteristics such as family cohesion or the quality of the marital relationship, both of which are known to be impacted in Western families. For parents in Arab countries a variety of factors were associated with decreased well-being, including awareness about autism (Zaki & Moawad, 2016), child behavior problems (Ahmad & Dardas, 2015; Obeid & Daou, 2015), parents' age and income (Dardas & Ahmad, 2014), and discrimination and stigma (Dababnah & Parish, 2013).

1.4. Protective Factors

Although raising a child with autism presents challenges for parents and is associated with impaired well-being, there are considerable individual differences, and many parents do not report mental health problems. Researchers have therefore focused on identifying factors that predict better well-being. Among parents of children with autism in the United States, the presence of a strong social support network (partner, friends, and extended family) was a robust predictor of positive outcomes (Ekas, Lickenbrock, & Whitman, 2010). The coping strategies that parents employed were also found to predict outcomes. Notably, parents who were able to reframe the situation in a positive light, or find benefit in their child's diagnosis, reported better outcomes (Ekas, Timmons, Pruitt, Ghilain, & Alessandri, 2015). Studies have also examined the role of religion/spirituality and found positive associations with parents' well-being (Ekas, Whitman, & Shivers, 2009). Certain parental characteristics, such as hope and hardiness, have also been shown to be associated with improved well-being (Ekas, Pruitt, & McKay, 2016). The identification of factors that promote better well-being is important for the development of intervention and prevention programs for families of children with autism.

There is a growing literature examining coping strategies and their association with well-being in parents of children with autism in Arab countries. For example, in Jordan and Lebanon the use of positive reappraisal coping was associated with lower levels of psychological distress for parents of children with autism (Obeid & Daou, 2015; Rayan & Ahmad, 2016). On the other hand, the use of disengagement coping was associated with poor well-being (Obeid & Daou, 2015). Fortunately, positive reappraisal coping was found to be the most commonly used coping strategy for parents in Jordan (Dardas, 2014). In the West Bank, Dababnah and Parish (2013) found religious coping to be an effective strategy for some parents. Taken together, these studies suggest

that there are mechanisms that can be targeted for intervention with Arab parents of children with autism. However, there are no studies examining these associations among Qatari parents.

1.5. Objectives

Research examining the well-being of parents of children with autism is predominantly conducted in Western countries, such as the United States, Canada, and the United Kingdom. Although studies have been conducted in Arab countries in recent years, the results are inconclusive and only one study has been conducted in Qatar. In order to address this critical gap in our understanding of the psychological well-being of families of children with autism, this study adopted a multimethod approach, to accomplish two primary aims: 1) to identify factors that families of children with autism in Qatar report as challenging; and 2) to examine the extent to which these factors are associated with parental psychological well-being. We also explored whether there are protective factors that may help to buffer the stress of raising a child with autism.

1.6. Research Questions

The overarching aim of the current project is to understand the experiences of families of children with autism living in Qatar. With this general aim in mind, the following specific objectives were pursued: 1) to identify the factors that parents of children with autism report as challenging; 2) to examine the ways in which parents' psychological well-being is impacted when they are raising a child with autism; 3) to identify protective factors that may buffer the negative effects of raising a child with autism; and 4) to make recommendations to shape policies aimed at improving the lives of families of children with autism.

1.7. Methodology Overview

The aims of the current project were achieved using multiple methods. Given the lack of existing research on parents of children with autism in Qatar, we first developed a qualitative interview protocol and conducted interviews with mothers and fathers of children with autism. A thematic analysis of the interviews was then carried out and used to inform the development of a survey that was administered to mothers and fathers of children with autism.

1.8. Qualitative Methods

1.8.1. Participants

A total of 20 parents of children with autism, recruited through Shafallah and Renad, were interviewed (four fathers and five mothers from Shafallah, and seven mothers and four fathers from Renad). All participants were Qatari nationals.

1.8.2. Methods

The interview questions were developed on the basis of preliminary conversations with Qatari parents and service providers who interact with families on a day-to-day basis. In addition, two focus groups consisting of four parents each were conducted to assist with the development of the interview questions. These informal conversations elicited important information regarding the experiences of families of children with autism. This information, together with the existing research on the experiences of parents of children with autism in other parts of the world, was used to create a semi-structured interview protocol with open-ended questions. The interview questions were carefully reviewed to ensure cultural appropriateness. This portion of the study received IRB approval from Qatar University. Interviews were conducted in the parent's preferred location (i.e., Shafallah or Renad), were conducted in Arabic, and were audio-recorded for later transcription. Interviews lasted approximately 30-45 minutes.

1.8.3. Analysis

Transcripts of the interviews were evaluated by members of the research team in order to identify the common themes that emerged across parents.

1.8.4. Limitations

The parents interviewed were diverse in terms of the ages of their children and the severity of their children's autism symptoms. Unfortunately, the small sample size limited the ability to conduct analyses taking into account children's ages and severity of symptoms. It is likely that the experiences of parents with younger children were markedly different from those of parents with older children (Duarte, Bordin, Yazigi, & Mooney, 2005). In addition, previous research suggests that the challenges associated with raising more severely impaired children with autism are greater and more stressful (Ekas & Whitman, 2010). Nonetheless, the in-depth information collected provides us with information about families living in Qatar, which is critical for making policy recommendations that can be implemented in Qatar.

Another limitation is that we only interviewed parents. The family system in Qatar is not limited to the immediate family but also includes extended family, such as grandparents, aunts, uncles, and cousins. Interviews with siblings and grandparents would likely highlight different challenges and perspectives which are also important in the development of family-focused interventions and policies.

1.9. Quantitative Methods

1.9.1. Participants

A total of 42 parents (35 mothers and seven fathers) of children with autism were surveyed. Participants were recruited through Shafallah. The majority (85%) of parents were married and reported having had at least a university education (59.6%). Over

50% of the parents reported a household income greater than 20,000 riyals. All participants were Qatari nationals.

1.9.2. Methods

The themes that emerged from the qualitative inquiry informed the development of the survey. Once constructs had been selected, a search for well-validated measures was conducted, with an emphasis on selecting measures with validated Arabic translations. When Arabic translations were not available, a native English speaker who was fluent in Arabic translated the measures. The following constructs were measured in this study: demographic variables, family needs, coping strategies, parenting stress, life satisfaction, social support, sense of parenting competence, child behavior problems, and romantic relationship satisfaction. IRB approval was obtained, and parents completed and returned a paper version of the survey, which was designed to be completed within 30 minutes.

1.9.3. Analysis

We first compiled descriptive information on the demographics of the parents (e.g., gender, age, household income, and education) and the children (gender and age). Next, we examined the associations between the constructs of interest in the study. Linear regression analyses were performed to examine whether constructs of interest predicted parent outcomes (e.g., stress and relationship satisfaction). Finally, moderation analyses were conducted to examine whether certain factors (e.g., coping strategies and social support) helped to buffer the stresses associated with raising a child with autism.

1.9.4. Limitations

Given the time constraints of the study, we were unable to include all of the constructs that we wished to measure. For example, we initially wanted to examine sibling relationships, but were unable to include those measures in the survey. However, our focused survey provides the first set of quantitative data collected from parents of children with autism in Qatar. Given the lack of previous research on this population in Qatar, it is our hope that our endeavor has introduced parents to the research process and provided a foundation for future studies in Qatar.

Another limitation is that the project only included Qatari nationals residing in Doha. Qatari nationals only comprise one-eighth of the total population of Qatar (Al-Hendawi, Khair, & Keller, 2017). Thus, the views presented in this report represent only a small segment of the population. Further research is needed to examine the experiences and needs of expatriates living in Qatar.

CHAPTER TWO: INSIGHTS OF MOTHERS AND FATHERS OF CHILDREN WITH AUTISM

This chapter presents the results of the thematic analysis of the interviews conducted with Qatari mothers and fathers of children with autism. The analysis showed that mothers and fathers of children with autism identified six areas in which they experience challenges. These include: 1) difficulties with service providers; 2) lack of social support; 3) lack of awareness about autism in the community; 4) financial difficulties; 5) marital and family disruptions; and 6) fears about their children's future. Each of these areas is discussed in detail below.

2.1. Difficulties with Service Providers

A common challenge for parents of children with autism is navigating the complexity of the service provider system (Siklos & Kerns, 2007). This includes obtaining the initial diagnosis for their child, finding therapy providers for their child, seeking medical providers who can care for their child's unique needs, and working with the education system to ensure their child receives a quality education. Families in Arab countries, including Qatar, have commonly reported dissatisfaction with the services they receive (Al Jabery et al., 2014; Al-Farsi et al., 2013; Kheir et al., 2012). This dissatisfaction may translate into increased stress and mental problems among parents of children with autism.

One challenge that several parents discussed was the diagnostic process in Qatar. Parents were specifically troubled by the amount of time that it took to get their child's diagnosis. For example, Umm Amir spoke of the length of time between when she first noticed there was something not quite right with her child's development and when the diagnosis of autism was first given:

I didn't notice anything wrong with him until he was one year and eight months old. I noticed that he didn't respond to me. You would call out to him but he wouldn't respond, not like other children. I said, 'No, maybe it is like Ahmed, his brother, who started speaking late.' So I didn't worry about it. I thought maybe it was normal, so I went and took him to a doctor in Doha Clinic. I think he was the first person to discover it, as he didn't make eye contact, which is something that I didn't notice. He is the one who told me about it and asked me to take him to a pediatrician because he doesn't make eye contact. At that time, I didn't know what that meant, so I took him to one doctor and then another and another and then Rumeilah [Hospital]¹. They said that he might have autism, but they didn't confirm it. He was little. In Rumeilah, for half an hour, two days, there was speech therapy, and half an hour for behavioral therapy, but it wasn't effective. This was when he was a little over two years old. At three years old, they confirmed that he is autistic.

¹ Rumeilah Hospital is a member of Hamad Medical Corporation.

Another parent spoke of her frustration in trying to get the appropriate services for her son. Umm Muhammad reported difficulties with the length of the wait lists in Qatar, and having to turn to private institutions for support:

When we left the doctor's, my husband and I decided that our son had to take a step forward. Of course, I started by taking my son's report to Roua Center¹ in regard to his integration, and they said, 'He can't be integrated.' I asked, 'Why, when in Rumeilah they said that he can be integrated? Rumeilah Hospital's report says that he needs a teacher, so how are you saying no?' They said that they don't have the staff, but I work as a nurse in a school and I can see that they have staff. They said, 'Go and work with him at home and we will get back to you when we have the staff.'

Delays in diagnosis and treatment are troubling for parents, given that research consistently shows that early intervention is crucial for children with autism (Howlin, Magiati, & Charman, 2009). Parents expressed concern that a lack of access to this care was responsible for their child's lack of improvement and continued delayed development:

You see what early intervention can do? My son, because he was big, not little, and the intervention was not early enough, his problem is that he doesn't speak, is aggressive, and hyperactive.

With regard to education and integration, we are truly suffering. In the association, we are trying to change that. Our kids are getting older and we know about the places. I want my son to have a solid foundation, right, and then to be integrated. But from my experience, I was taking him there without any foundation or staff... I advise them about early intervention because integration is all about a solid foundation from the start – not integrating him after four years.

Although some parents are able to obtain services for their children, they are concerned about the quality of care that their children receive. Several parents reported that they felt their child was not being supervised properly. This is a common concern reported by parents, and education systems in some countries have experienced reports of abuse and neglect by teachers and therapists. Umm Amir discussed the issues she experienced with her son:

I did use to take him to one of the centers, but it caused problems. I chose to take him out because the last time he was in a center, he was bitten by a girl! The second time, after she bit him, I told them to pay attention. The third time, I found that they had put Pampers on him, when he was used to going to the bathroom. But that's it. I couldn't take it anymore. For God's sake, the boy was regressing and getting worse.

¹ "Roua" is an Arabic word meaning "vision." Roua Center is part of the Ministry of Education and Higher Education in Qatar, and offers assessment, advice and support for students with special needs.

In addition to concerns about the quality of teachers, parents in Qatar often rely on domestic workers or nannies to take care of their children when they are not in school or therapy. Unfortunately, many of these domestic workers are not trained in how to manage the behavior of children with autism. Several parents expressed concerns about their domestic workers using inappropriate tactics to handle their children's behavior. Domestic workers are typically hired to assist with household duties such as cooking and cleaning. Thus, it may be too much to expect them also to be able to manage the special needs of a child with autism.

Many of the concerns expressed by the parents in this study are similar to those expressed in other parts of the world. Nonetheless, these parental concerns are serious and have important implications for children's development, and also for the health of the family. Indeed, the Qatar National Autism Plan appears poised to address these critical issues. Notably, the Plan aims to improve diagnostic services and ensure that children with autism have access to appropriate interventions and services. In addition, it also addresses parents' concerns about access to educational services by recommending that children with autism should, when possible, be placed in regular classrooms. When implemented, these improvements in the provision of services will likely translate into improvements in parents' mental health and overall family functioning.

2.2. Lack of Social Support

When faced with stressful or challenging situations, many adults turn to others to provide instrumental support (e.g., babysitting, helping with chores, etc.) and/or emotional support (e.g., listening, providing advice, etc.). Among parents of children with autism, research has consistently found that social support from friends, family, and spouse is associated with better mental health outcomes (Boyd, 2002). Unfortunately, many parents also report feeling isolated because their friends and family don't understand what they are experiencing (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). This sense of isolation can lead to feelings of loneliness and increased depression symptoms (Ekas et al., 2016). Parents interviewed for this report spoke of needing respite care for their children and feeling that they couldn't visit friends or family because of their child's behavior. Some mothers reported struggling to get support from their husbands. Umm Muhammad shared how she doesn't feel like her husband supports her:

Honestly, he doesn't withhold his support. Sometimes he provides 50 percent support and sometimes his mood changes and he says, 'My son is normal. Don't sit around making a big deal out of nothing. Our son is normal. Let him go along normally.' He isn't able to accept that our son has needs, special needs.

To address these feelings of isolation, some mothers have joined an informal association in Doha, and have reported it to be very helpful to be around other mothers who share similar experiences:

Joining the association really helped me and made me stronger. Now, I love getting together with them in any meeting. Then, a few of us mothers got together and made another association through the Weyak Mental Health Friends Association. We get together now and again at restaurants and we say, 'Excuse us, we don't want to talk about our children or anything' – except when we include our kids.

2.3. Lack of Awareness about Autism in the Community

The increased prevalence of autism has resulted in more awareness about autism across the world (Dillenburger, Jordan, McKerr, Devine, & Keenan, 2013). Unfortunately, although people state that they “have heard about autism,” there is considerable progress to be made in helping people to understand what autism is. Many people in the community do not know what the symptoms of autism are and have persistent, incorrect beliefs about the causes of autism (Hebert & Koulouglioti, 2010). One father, Abu Reema, described his own lack of awareness about what autism is:

I went online, although I am bad with research, but I did some research to look up her case and what is autism. In general, I go online and offline and I learnt that autism is an illness for children, the child becomes alone and isolated and it has many forms – this is what I understood about it.

Many parents described going out in public with their child and being stared at because of their child's behavior. In some cases, parents reported that they stopped going out because of this. For example:

Abdulla doesn't go out a lot, because if he goes out he is coming and going. His problem is that at the playground they are not willing to understand that there are children with special needs. One lady came from the playground and said that Abdulla had to leave the playground.

Another mother, Haya, reported the following:

When I go out, my daughter suffers until now because no one respects her rights. She has to go out and play. If she screams, some stare and I usually tell them that she has special needs.

Parents also reported being told that they were bad parents because of their children's behavior out in public:

Some people look at her or walk away from her. I am a human, not an angel; of course I will be hurt. I am a father, and it hurts to see my daughter's situation like this.

The girl was sitting and maybe screamed twice or three times, and an old man got up, maybe in his fifties or sixties, and said, 'You are not able to raise your daughter well.'

In addition to experiencing remarks from adults, parents also reported that other children have made negative comments about their child with autism:

At school, his siblings told me that the kids say he is crazy. So I corrected the idea they had, and told them he is from the People of Paradise, and they shouldn't let him go and open the door because he will run, and they really did work together so that he couldn't go out the door.

I was disappointed, other children say he is crazy or insane.

Public awareness is critical to moving toward acceptance of disability and reducing stigma in society. Dissemination of research about the causes of autism can also help to dispel some existing myths (e.g., blaming vaccines or poor parenting). Public awareness is also critical to ensure that parents identify early signs of autism when their child is very young. Early identification is the key to early diagnosis and early intervention. The Qatar National Autism Plan cites awareness (parental, public, and professional) as one of the core themes to be addressed. As noted in this report, parents find this lack of awareness to be a concern. Although not mentioned in the National Autism Plan, increasing awareness will also likely yield improvements in parents' lives by reducing the feelings of social isolation and stigma they experience on a daily basis.

2.4. Financial Difficulties

Raising a child with autism can be a large financial burden for families. In the United States, it is estimated that the lifetime financial cost of a child with autism is 3.2 million dollars (Ganz, 2007). Parents are often responsible for paying for therapy, medical treatments, and private education services. Even in countries that provide universal healthcare, the costs can be exorbitant (Järbrink & Knapp, 2001). Although services are available at no cost to families in Qatar, many of the families discussed the financial costs associated with seeking private services because the wait lists were too long for receiving government services. Abu Mohammad, a father, mentioned these concerns several times in his interview:

I tried with my efforts and his mother, we took him to a special educational center, he stayed with them for about six months because the fees were a bit hard for me to pay. I went to a number of centers and didn't find any benefit! But the center that we are enrolled at, I started to feel something in Mohammad because it has been a month, and a month with transportation costs 5,000 riyals, it is too much.

Often, the demands of raising a child with autism can result in one parent having to quit their job in order to provide support to their child. In Qatar, several mothers reported taking leave of absence from their jobs to care for their children. One father, Abu Hamad, described the difficulties that obtaining this leave of absence has created for their family:

My wife has worked as an employee until now. She applied for leave according to the national law regarding care because she needs to take care of him. So she applied, of course, at the ministry where she is working, and she spoke with the legal advisors, and they said that his condition is not very delayed and the law allows for a five-year paid leave because of his condition. So, because of this, they said she can apply for two years, and they requested a number of reports. How can his condition not qualify for five years? I don't know, but we said, 'Okay, no problem, two years are good.' After two years, if they don't renew it, then we can apply for a second time and they may give it in installments, according to the legal advisor.

The financial difficulties associated with raising a child with autism can put considerable strain on parents and the family. Research has shown that parents who report greater financial burdens also report higher levels of mental health problems (Harper, Dyches, Harper, Roper, & South, 2013). This financial burden also has a negative impact on the quality of the parents' marital relationship (Harper et al., 2013). The financial concerns these parents reported are consistent with those reported by parents in other Middle Eastern locations, such as Jordan (Al Jabery et al., 2014) and the West Bank (Dababnah & Parish, 2013). The financial burden for Qatari parents could be eased by addressing parents' other concerns regarding access to care and education. By shortening wait times and ensuring that all children are able to receive quality treatment, it is likely that this perceived financial burden will decrease.

2.5. Marital and Family Disruptions

The challenges that parents face raising a child with autism can also negatively impact the larger family system. This can include the relationship between the parents, the relationship between siblings, the parent-child relationship (including impacting the parents' relationship with their non-autistic children), and relationships with extended family members. For example, in the United States, the divorce and separation rate for parents of children with autism steadily increases as the child ages (Hartley et al., 2010). Parents who remain married often report lower levels of relationship satisfaction as a result of raising a child with autism (Hartley et al., 2010).

As discussed above (see 2.2. Lack of Social Support), some mothers in Qatar reported feeling that their husbands were not supportive. Other parents reported feeling that there was not enough time to spend with their spouse, and feeling they couldn't take time to deal with their marital relationship because their child demanded so much time.

Many parents discussed sibling dynamics. The sibling relationship is a unique, lifelong relationship that has a large impact on all aspects of children's development (Brody, 1998). Unfortunately, when one child in the family has autism this can disrupt the sibling relationship and also impair the relationship between the parents and the non-affected siblings (i.e., the children in the home without an autism diagnosis).

Research has shown that some siblings have higher levels of mental health problems (Rodrigue, Geffken, & Morgan, 1993). There may be several reasons for this, including the parents not spending enough time with the non-affected children or because a non-affected sibling takes on the role of a "protector" for their sibling with autism (Tomeny, Barry, Fair, & Riley, 2017). This is not the typical role of a sibling, and can create additional stress for the non-affected sibling. Many parents are aware of these issues and report that they are unable to spend as much time with the non-affected sibling as they would like (Howlin, 1988).

One mother, Umm Amir, described how the siblings in her home were quite helpful with her son with autism, but that they were sometimes embarrassed or didn't want to have him around:

Honestly, my daughter Hala, who is his sister, she is the one that helps me. As for Ahmad (her other son), sometimes he feels sad about it, sometimes he says, 'Mom, don't bring him to school. Mom, he is bothering me...'

Another mother, Umm Muhammad, discussed similar issues with sibling relationships in her family, and mentioned that the non-affected siblings may feel some jealousy:

My youngest son really makes him lose his temper, because he takes things from his hand and Muhammad starts to react, and I am worried that he will yell at him and hit him. When his siblings are at school in the morning, he stays with his little brother, Yousef... So there remains some jealousy and contention.

Although not discussed extensively by the parents in these interviews, the role of the extended family is also critical. This is particularly true in a Middle Eastern country, where the extended family (e.g., grandparents, aunts, uncles, cousins) play an active role in children's development. Many of the parents interviewed said the grandparents were quite supportive and understanding about their grandchildren's autism diagnosis. However, one father (Abu Reema) mentioned that his parents felt sorry for his daughter, perhaps reflecting a lack of awareness about autism:

Because we lived with it, and they (the parents) were still sorry when they see the girl, for example when she goes to my father's house twice or three times a week they feel sorry for her, but we lived with it.

The quality of relationships in the family system is an important determinant of both parent and child outcomes (Bronfenbrenner, 1986). The concerns that Qatari parents cited are similar to those of parents in other countries and suggest that further attention needs to be given to the family unit. For example, respite care is one easy solution to allow couples to spend time alone and is shown to be beneficial to parents' mental health (Harper et al., 2013). Other research has shown that programs designed for

non-affected siblings to engage in activities with their peers, including peers who also have siblings with autism, are effective in increasing the non-affected siblings' well-being (Naylor & Prescott, 2004).

2.6. Fears about the Future of the Child with Autism

It is quite common for parents of children with autism to worry about their child's future (Ogston, Mackintosh & Myers, 2011). Children with autism vary in the level of support they require. Those who require little support are able to attend university, hold jobs, and raise a family. Conversely, those who require a high level of support may require continual support to function on a daily basis. There are some children, however, who may need a moderate level of support with respect to daily living skills (e.g., cooking, cleaning, and taking medication), but are able to attend university and work. Parents often express concerns about how their child's support needs will be met when the parent is unable to provide care, whether due to the parent's advancing age or as a result of the parent's death. Indeed, one study found that parents of children with autism reported higher death anxiety (i.e., fear of death) compared to parents of typically developing children. This heightened death anxiety was associated with poorer psychological well-being (Cox, Eaton, Ekas, & Van Enkevort 2015).

Qatari parents expressed similar concerns. Worry about who would take care of their child seemed to be a common concern among parents of adolescents and young adults. This may be a function of the parents' advancing age and increasing thoughts about their own mortality. Indeed, one father of a younger child was unaware that there would not be services available for his child later in life.

Another concern that parents spoke about was the lack of employment opportunities for their adult child. Parents were concerned about the lack of services available for their adult children and how their children would spend their days. One mother emphasized the importance of continuing to encourage and foster independence skills; however, she was also worried about the lack of opportunity for this (e.g., no services to assist adults with finding jobs or job training). The same mother also spoke about the stigma surrounding the types of jobs that might be available for her son. Specifically, she was concerned that the community would look at her family negatively if her son was working in a service position usually reserved for non-Qataris.

Worldwide, there is a distinct lack of services aimed at the growing number of adults with autism. It seems easy to forget that the children currently being diagnosed with autism will eventually become adults. Thus, communities must be prepared to accommodate these children as they "age out" of the educational system and traditional services. In addition, there is a growing number of individuals receiving a diagnosis of autism in adulthood (Brugha et al., 2011). However, there is little service provision for these adults. Given parents' concerns about their aging children, communities must also plan for providing care for adults with autism when their parents are no longer able to do so.

CHAPTER THREE: UNMET NEEDS AND PROTECTIVE FACTORS FOR PARENTS OF CHILDREN WITH AUTISM

This chapter presents the results of the survey data collected from Qatari mothers and fathers of children with autism. This part of the study was guided by several overarching aims: 1) to describe the challenges that parents identified as problematic using quantitative data collected from surveys; 2) to identify factors that predict parental psychological well-being; for the purpose of this report, psychological well-being covers parental life satisfaction, parenting stress, perceptions of parenting competence, and romantic relationship quality; and 3) to identify protective factors that may help to buffer the negative impact of raising a child with autism.

3.1. Family Needs

In the interviews parents identified a variety of challenges associated with raising a child with autism. These ranged from difficulties with service providers to feeling a lack of social support. The survey administered in this study included items designed to assess these challenges quantitatively.

3.1.1. Service provider needs

During the interviews, many parents expressed concern with the length of time it took to receive a diagnosis of autism. On average, parents first noticed something was not quite right about their child's development at approximately 21 months of age. It took about three months for parents to discuss their concerns with a healthcare professional. Children were nearly three years of age (35 months) when they received an official diagnosis from a medical professional. Thus, parents spend, on average, 14 months navigating the healthcare system in Qatar. These months are often filled with stress and uncertainty. In addition, this is a period of missed opportunities for their children to receive important early intervention services. On a positive note, the time between parents first noticing problems and receiving a diagnosis was much shorter for a second child (approximately seven months). This is likely because these parents knew the early signs of autism and could compare behaviors with those of their first child diagnosed with autism. In addition, these parents also knew how to access resources because they had gone through the process already. It is also possible that medical professionals are more likely to take parents' concerns seriously when they know there is a family history of autism. Although the amount of time that parents report waiting is similar to that in other countries (Wiggins, Baio, & Rice, 2006), it still remains one of the most stressful times for parents.

As discussed in Chapter Two, parents frequently mentioned growing frustration with long wait lists at service providers, and not feeling that their children's needs were being adequately met within the education system. As part of the survey, parents answered questions about their needs with respect to information and support in

relation to their child with autism. The level of need ranged from “no need” to “a little need” to “a lot of need.” Mothers and fathers reported “a little” to “a lot of” need with respect to professional support. Needing professional support includes needing to meet with their child’s teacher or therapist as well as needing professional counseling for their own mental health needs. When we compared these two items, we found that parents were reporting a greater need to meet with a counselor (psychologist, social worker, or psychiatrist). This suggests that parents may be aware of the impact that the stress associated with raising a child with autism has on their mental health. Perhaps more interestingly, mothers and fathers reported similar levels of professional support needs. There tends to be considerable stigma surrounding mental health issues in men, and men are less likely to receive mental health services (World Health Organization, 2002). This may be especially accentuated in Arab countries, where male gender roles are strictly adhered to (Fakhr El-Islam, 2008). Although parents are reporting these needs, this study does not have any data on whether parents have sought the services of a professional counselor. Given these needs, it may be important for medical professionals to address parents’ mental health concerns during and after the diagnostic process.

Parents also reported needing between “a little” and “a lot of” support from their community. Community services include such things as meeting with other parents who have children with autism and accessing medical and dental services for their child. These reported needs mirror the responses parents provided during the interviews (see Chapter Two). As previously discussed, parents expressed considerable frustration and difficulties with getting appointments with medical professionals. Notably, parents worried about finding dentists and doctors who would be able to manage their child’s behavior. Some children with autism are hypersensitive to different sensations (American Psychiatric Association, 2013). Thus, some children may find the bright lights of a hospital or the sound of a dentist’s drill to be extremely upsetting. Other children may not like to be touched, which presents difficulties when a doctor needs to conduct an examination, or they need to have their blood drawn. It is critical that medical professionals have training in what autism is and how they can adapt their treatment to better meet the needs of this population. From examining the responses of mothers and fathers, it appears that mothers report greater needs with respect to finding dentists and labs/x-ray centers that will understand their child’s autism. Mothers tend to be more involved with their child’s medical care (Gray, 2003), including finding providers and taking their child to appointments. Therefore, it is logical that they would be reporting greater needs. It may be beneficial for autism service centers to compile a list of resources for parents. This could include medical and dental professionals who are trained in providing services to children with autism. It may also be important to take one step back and encourage medical professionals to receive additional training in how to provide services to children with autism.

3.1.2. Social support needs

Social support consists of instrumental (e.g., having someone assist you with daily needs) and emotional (e.g., having someone to talk to) support. During the interviews, parents reported feeling isolated from their friends and not having people they

could turn to for help. Surprisingly, parents reported only “a little need” for emotional support from friends and family (e.g., having friends to talk to, talking to family about concerns). Mothers and fathers were similar in their emotional support needs with one exception: fathers reported higher needs with respect to having friends to talk to. Male friendships are typically characterized by shared activities as opposed to the emotional disclosures that exemplify female friendships (Aukett, Ritchie, & Mill, 1988). Fathers of children with autism may not feel like they have an outlet for sharing their feelings surrounding their child’s disability. One way to meet emotional support needs is by attending parent support meetings. Parents report that talking to other parents of children with autism is the most beneficial outlet (Boyd, 2002). In Qatar there is a parent association; however, it is composed primarily of mothers. Fathers may benefit from support groups that consist only of fathers. Several communities in the United States have implemented father groups, and they report them to be quite helpful.

In addition to needing emotional support, parents also reported needing instrumental support. Indeed, the need for instrumental support was greater than the need for emotional support, and this was consistent across mothers and fathers. Instrumental support consists of finding babysitters or respite care, finding daycare programs for children, and finding childcare later in the day (after most day programs have ended). The need for childcare was commonly cited during the interview part of this study. Moreover, parents expressed concern about finding individuals who were qualified to care for their child. Currently, parents often rely on domestic workers to assist with childcare, but the domestic workers have not received training with respect to managing autistic behaviors. The receipt of instrumental support is associated with better mental health outcomes for parents of children with autism and is a need that can be readily addressed through the implementation of formal respite care programs. Research has found that even small amounts of respite care are associated with improvements in parents’ mental health (Harper et al., 2013). Respite care allows parents to take a psychological breather, and is also an opportunity for parents to reconnect romantically or for parents to spend one-on-one time with non-affected siblings.

3.1.3. Need for awareness and understanding of autism

There is a need for greater awareness about autism in Arab countries. For example, in Egypt, Zaki and Moawad (2016) found that nearly two-thirds of mothers reported poor awareness regarding autism, which may impact the ability to seek services. Community awareness of autism is increasing; however, many community members lack awareness regarding the behavior of children with autism. This lack of awareness, combined with the stigma surrounding autism, leads mothers to report feeling isolated. For example, mothers in the United States have reported feeling like they can no longer go out in public because others do not understand their child’s behavior (Dunn et al., 2001). As previously discussed, the parents interviewed for this report also mentioned feeling that greater awareness is needed, and that others don’t understand their child’s disability.

Many parents of children with autism struggle to understand their child’s disability.

This can include not knowing how their child will develop (e.g., “Will my child use language in the future?”). It might also include a lack of awareness about how to play with their child, how to teach their child, or how to deal with their child’s behavior. Parents in Qatar reported needing between “a little” and “a lot of” information surrounding these issues. Parents’ greatest needs revolved around how to interact with (play with and teach) their child with autism. Mothers’ needs in these areas were greater than those of fathers. This may be because mothers are often the primary caregiver and may spend more time interacting with their child. It is critical for parents to have this knowledge, as it can affect their parenting behavior. For example, if a parent is unsure of how to interact with their child it may lead to them disengaging from their child or engaging in an intrusive way. Parent-child play is essential for typically developing children’s social, emotional, and cognitive development (Ginsburg, 2007). Research also shows that the quality of parenting behavior is an important determinant of language development in children with autism (Baker, Messinger, Lyons, & Grantz, 2010). Thus, it is important for the child’s development for parents to be armed with awareness and knowledge about effective ways to parent their child with autism. In addition, parents would also benefit from a better sense of self-efficacy as parents, which in turn could translate into better psychological well-being for them.

Parents also struggle to find general information about autism and about the resources and services available for their child. Parents in Qatar reported “a lot of need” regarding information both about the services that are currently available for their child and about those that will be available in the future. The greatest need identified was for information about the services their child with autism might receive in the future. This is consistent with the interviews, where parents reported worries and concerns about their child’s future. Specifically, parents were concerned about whether there would be programs available for their child after they finished school or became too old for the existing therapy programs. Parents also worried about the availability of vocational training and employment for their adult children. Mothers reported greater needs than fathers, particularly with respect to needing information about services currently available for their child.

Perhaps reflecting the lack of knowledge and awareness about autism, parents also reported needing information about other conditions or disabilities that their child with autism might have. A large percentage of children with autism will have a comorbid (i.e., co-occurring) psychiatric or medical condition. Common comorbid medical conditions include epilepsy and gastrointestinal issues. As many as 38% of children with autism have a co-occurring intellectual disability (Centers for Disease Control and Prevention (CDC), 2014). With respect to psychiatric disorders, as many as 70% of children with autism receive a diagnosis of anxiety, depression, or ADHD (Simonoff et al., 2008). In addition, some children with autism display aggressive behaviors toward themselves and others (American Psychiatric Association, 2013). These comorbid conditions can not only affect the effectiveness of treatments that children receive but may also influence the types of treatments that are recommended for them. Children with a comorbid diagnosis of ADHD may need medication and psychotherapy to treat the symptoms of ADHD. Treating the symptoms of ADHD is critical, as it then allows therapists to begin treating the behaviors related to autism. For example, the inatten-

tion associated with ADHD may inhibit the child’s ability to pay attention to their ABA (Applied Behavior Analysis) therapist during sessions. An adolescent with depression may lack interest and motivation in engaging with teachers and peers, which may exacerbate their social interaction difficulties. Finally, a comorbid intellectual disability may influence the types of educational programs and therapies that are offered to a child. Parents should be aware of the possible comorbid conditions that their child with autism may have. This awareness is important for several reasons: 1) parents may be alert to the red flag symptoms of the comorbid condition (e.g., hyperactivity and inattention for ADHD, lack of interest and sadness for depression); 2) parents may be more likely to ask medical professionals for assessments for comorbid conditions; and 3) parents can seek the services that might be most beneficial for their child’s unique constellation of diagnoses.

3.1.4. Financial needs

The financial burden of raising a child with autism is significant. Parents may have increased expenses associated with their child’s autism-related therapies (e.g., ABA, speech therapy, occupational therapy, physical therapy, etc.), their child’s associated medical conditions, and their child’s associated psychiatric conditions. Some parents have an additional financial burden of paying for private educational services because the public education system is not meeting their child’s needs. Another financial burden often reported by the parents we interviewed is that one parent may need to stop working in order to provide care for their child. Overall, parents reported needing “a little” to “a lot of” financial assistance. The greatest needs related to paying for therapy, paying for respite care/babysitting, and a lack of employment. Fathers reported slightly higher levels of need for financial assistance, except in the domain of employment. This may be because mothers in Qatar are more likely than fathers to stop working after their child’s diagnosis, with the financial burden then being shifted on to fathers. This financial burden could be reduced through greater access to high-quality government-provided autism services.

3.1.5. Family needs

The quality of the family environment can affect outcomes for all members of the family. A positive family environment is characterized by high levels of positive emotional expressiveness, low levels of parental control, and low levels of conflict (Moos & Moos, 1994). Families with these qualities will often have better problem-solving skills and feel they are on a team working together. Having a child with a disability, including autism, may disrupt the quality of the family environment. Parents in this study reported needing “a little” help with managing aspects of the family environment. This included needing help discussing problems, deciding who will do household chores and take care of the children, and deciding what types of recreational activities to do. Parents’ greatest need was with respect to family members supporting one another during difficult times. This last need was more pronounced for mothers. Addressing this need is critical, as research on families of children with autism shows that greater family cohesion and a more positive family environment are associated with better psychological well-being for parents (Ekas et al., 2016).

3.1.6. Summary

The unmet needs of parents of children with autism in Qatar as recorded through the survey questionnaire are strikingly similar to the challenges that parents reported in the interviews (see Chapter Two). The survey data, however, provides information about specific areas of challenge within the larger domains that parents discussed in the interviews. It appears that parents need assistance with finding services for their child, including services that are outside the domain of treating their child's autism symptoms (e.g., doctors, dentists, etc.). Parents also need support to meet their own needs, including needing respite care, financial assistance, and mental health counseling. Parents also need guidance with respect to managing family routines and knowledge about how to support other family members.

3.2. Parents' Psychological Well-Being

Psychological well-being is a multifaceted construct that generally includes high levels of "feeling good" and low levels of "feeling bad." Psychological well-being can encompass multiple domains of an individual's life, including mental health, life satisfaction, and relationships with others (e.g., parent-child relationships, and romantic relationship). Research consistently shows that parents of children with autism experience significantly lower levels of psychological well-being than parents of typically developing children and parents of children with other developmental disabilities (Lee, 2009). There are various factors that influence a parent's psychological well-being. The family needs discussed above are one such factor that can impact parental well-being. For example, parents who feel unsupported may experience greater parenting stress and feel less competent as parents. Another factor is the severity of the child's autism symptoms and co-occurring behavioral problems. Indeed, previous research has found that behavior problems are a predictor of parental well-being above and beyond the child's core autism symptoms (Ekas & Whitman, 2010). For this report, we examined several aspects of parents' psychological well-being: 1) their general satisfaction with their lives; 2) well-being related to their role as a parent (parenting stress and sense of competence as a parent); and 3) the quality of their relationship with their spouse.

3.2.1. Life satisfaction

Overall, parents reported levels of life satisfaction that are considered average in comparison to the general population (Diener, Emmons, Larsen, & Griffin, 1985). That is, parents are generally satisfied with most areas of their life, but there may be some areas where they would like to see some improvement. Although the "average" level of life satisfaction suggests parents were generally satisfied, there was individual variability in parents' responses. Out of a total of 40 parents, there were two parents who reported being "extremely dissatisfied" with their lives, and four parents reported being "dissatisfied" with their lives. A total of eight parents reported being "slightly below average" in life satisfaction, whereas 10 parents were in the "average" range of life satisfaction. Of particular note, 12 parents reported being "above average" in life

satisfaction and four parents were "highly satisfied" with their lives. This variability suggests that a majority of parents feel they are accomplishing their life goals and are satisfied with their life circumstances.

Our next step was to examine the factors associated with life satisfaction among parents of children with autism in Qatar. We concentrated on the family needs identified above, and the child's behavior problems. Parents who reported needing more emotional support also reported lower levels of life satisfaction. As previously discussed, many children with autism have co-occurring behavior problems. These can include behaviors such as hitting others, having temper tantrums, not helping others, not sharing with others, not listening to adults, having trouble making friends, and hyperactivity and inattention. We found that Qatari parents of children with greater behavior problems reported lower life satisfaction.

3.2.2. Parenting-related well-being

A central part of an individual's identity is their role as a parent. Some parents experience stress in relation to parenting their child, and this stress is generally heightened among parents of children with autism (Lee, 2009). Qatari parents reported feeling elevated levels of general distress in their parenting role. This generalized distress includes feeling unsupported, depressed, conflicted, and restricted in their role as a parent. On average, parents scored 32 out of a possible 55 points on this measure. Parents also reported feeling dissatisfied with their interactions with their child (average score: 32 out of 55 possible points). Parents' greatest stress surrounded their perceptions of how difficult their child was to take care of (average score: 40 out of 60 possible points). Mothers and fathers reported comparable levels of parenting stress.

Parents who reported greater emotional support needs also reported higher levels of general distress related to parenting and less satisfaction with interactions with their child with autism. Similarly, a greater need for instrumental support (e.g., needing childcare) was found in parents who reported that their child's behavior was more difficult to manage. Greater need for financial assistance was also associated with parents feeling less satisfied with their interactions with their children and reporting their children as being more difficult to deal with. Qatari parents who reported that their child had more behavior problems also reported greater general parenting distress, less satisfaction with their interactions with their child, and feelings that their child's behavior was hard to manage.

Another component of parenting is the extent to which the parent feels competent in their role as a parent. This includes feeling that parenting is a manageable and rewarding task. Parents with a high sense of parenting competence report low levels of frustration as a parent, and feel that they can solve any problems that arise with respect to their child. Mothers and fathers reported similar levels of perceived parenting competence. Contrary to expectations, parents' needs were unrelated to their sense of parenting competence. However, when children had more behavior problems, the parents reported lower levels of parenting competence.

3.2.3. Romantic relationship well-being

Research in the United States has found that the divorce and separation rate for parents of children with autism is higher than for the general population, and the risk of separation or divorce increases as the child ages (Hartley et al., 2010). Among parents who remain married, the levels of relationship satisfaction are lower than for parents of typically developing children (Hartley et al., 2010). We found that Qatari mothers and fathers reported similar levels of relationship satisfaction. Parents' reported relationship satisfaction was negatively impacted by the need for emotional and instrumental support. Surprisingly, the amount of behavior problems the child displayed was unrelated to the parents' reporting of relationship satisfaction.

3.2.4. Summary

These findings are consistent with previous research in non-Arab countries that the receipt of social support (emotional and instrumental) is associated with better psychological well-being among parents of children with autism (Boyd, 2002). This suggests that the benefits of social support may be universal across countries. Moreover, the negative impact of financial burden on psychological well-being was also similar to that found in the United States. Children's behavior problems emerged as a consistent factor impacting multiple domains of parental psychological well-being.

3.3. Protective Factors

There is often considerable individual variability in the psychological well-being of parents of children with autism. As discussed above, although the group of Qatari parents in this study reported average levels of life satisfaction overall, there were some parents reporting high levels of dissatisfaction and some reporting high levels of satisfaction. "Resilience" refers to the ability to maintain high levels of psychological well-being in the face of stress. Thus, a parent of a child with autism may be considered resilient if they report high levels of life satisfaction when their child has high levels of behavior problems. Of particular interest to researchers is to identify the innate characteristics or environmental supports that these individuals have that help to promote better psychological well-being (or act as a buffer against the negative effects of stress). These are referred to as "protective factors," and can include personality characteristics or ways of thinking (e.g., optimism, hopeful thinking, coping strategies, etc.) as well as the broader environmental context (e.g., social support). The purpose of identifying protective factors is to help develop intervention and prevention programs. For example, if respite care was identified as a protective factor, it would be possible for community and government agencies to begin programs that include respite care.

Given that social support has been identified as an important factor in parental psychological well-being, we examined whether it would serve as a protective factor for Qatari parents. Parents reported on the social support they received from their partner, their friends, and their extended family. As discussed above, when children had high levels of behavior problems, parents reported elevated levels of parenting stress,

lower levels of life satisfaction, and less sense of parenting competence. However, where parents reported that they had a healthy social support network, their child's behavior problems no longer affected their levels of life satisfaction or perceptions of parenting competence. Thus, social support can be seen to serve as a protective factor for parents in respect of these outcomes.

We also examined whether the use of certain coping strategies could serve as a protective factor. When faced with a stressful situation, individuals can engage in a variety of ways to cope with it. There are two general categories of coping: emotion-focused and problem-focused. Problem-focused coping involves identifying the cause of the stress and attempting to change it. For example, if someone is feeling stressed because they have a deadline at work they might decide to delegate tasks in order to focus on meeting the project deadline. Emotion-focused coping, on the other hand, involves dealing with the negative emotions that arise as a result of the stressful situation. For example, individuals could attempt to distract themselves by watching their favorite movie. Within each of these broad ways of coping there are a number of specific strategies that individuals can engage in. These include distraction (e.g., engaging in work activities to take your mind off the situation), planning (e.g., trying to come up with a strategy to address the situation), reframing (e.g., turning the challenging situation into an opportunity for growth and learning), religion (e.g., turning to Allah for help), and acceptance.

We found that several coping strategies served as protective factors for Qatari parents of children with autism. With respect to levels of life satisfaction, parents who engaged in distraction or turned to religion to cope were less affected by their child's behavior problems. Even when the child had high levels of behavior problems, these parents reported higher levels of life satisfaction. Several coping strategies also served to buffer the negative effects of children's behavior problems on parents' stress levels and sense of parenting competence. The use of distraction, reframing, planning, acceptance, and religious coping were all protective factors for parents.

3.3.1. Summary

Overall, a strong social support network and the use of adaptive coping strategies served to protect parents from the stressors associated with parenting a child with autism. These findings are consistent with a growing body of literature in non-Arab countries (Boyd, 2002). Qatari parents reported needing social support (instrumental and emotional), and these findings show that their needs are justified. The identification of specific coping strategies also provides a direct target for parent-focused interventions. It would be possible to identify the coping strategies that parents currently use, and then teach them how to implement the ones identified in this report.

CHAPTER FOUR: DISCUSSION

4.1. Overview

Raising a child with autism is a challenging experience for many parents. The experience is often associated with decreased psychological well-being and an increased risk of mental health problems and disruption of the family system. Unfortunately, little is known about the experiences of parents in Arab countries, particularly in Qatar. The primary purpose of this report was to identify the challenges that Qatari mothers and fathers face with respect to raising a child with autism. This was accomplished by conducting qualitative interviews with Qatari mothers and fathers and collecting quantitative survey data. Analysis of the qualitative interviews identified six themes related to the challenges Qatari parents reported, which aligned with the needs parents reported in the quantitative survey. A secondary aim of the current report was to identify factors that negatively impact parents' psychological well-being, as well as protective factors that buffer the negative effects of raising a child with autism. Overall, the multimethod research presented here provides an important first step in understanding the lived experiences of families of children with autism. However, further empirical research is needed in order to better identify the ways in which the needs of such families in Qatar can be met.

The challenges and needs identified in this report are in accord with many of the themes outlined in the Qatar National Autism Plan. As the plan is implemented, it is likely that the lives of families of children with autism will improve. However, as noted in our recommendations, we argue that targeted programs and services for family members are needed in order to directly improve their psychological well-being.

4.2. Families and Service Providers in Qatar

The challenge repeated most often by the parents we interviewed was navigating the system of service provision in Qatar. Parents reported frustrations with the diagnostic process, with long wait times to receive therapy services for their child, and with finding their child a place in an education program that matched his or her developmental level. The parents we interviewed reported feeling that professionals did not take their concerns about their child's development seriously. This resulted in a lag between the time of the parents' first concerns and their child's eventual diagnosis. This time is often fraught with stress and anxiety on the part of the parent. They are concerned about their child, unsure whether there might be something "wrong" with their child, and ill-equipped to handle the behaviors their child is exhibiting. The early years of children's development provide the foundation for the rest of their lives. When parents experience stress and mental health problems (e.g., anxiety) they often engage in parenting behaviors that are detrimental to their children's development. Thus, it is critical to address parents' needs during this time to reduce the stress they are experiencing. The Qatar National Autism Plan is committed to improving the diagnostic process by shortening the amount of time it takes to receive a diagnosis, and facilitating a streamlined process that will reduce the confusion and anxiety that

parents report. Nonetheless, during this period it will be necessary to directly address the stress and anxiety that parents are experiencing.

Parents were also concerned about the availability of therapy for their children, finding the appropriate therapies for their children, and finding high-quality service providers. Parents generally want to do everything possible to help their children thrive and live a happy and healthy life. For parents of children with autism this often means finding the therapies that best meet their child's unique needs. Autism is a spectrum disorder, which means that children present with different symptom constellations and the severity of symptoms varies considerably. For example, some children with autism do not speak at all, whereas other children have large vocabularies but struggle with the nonverbal aspects of communication. Thus, it is critical to find the therapy, or combination of therapies, that accurately addresses each child's configuration of symptoms. This can be an overwhelming task for parents, and they report confusion as to the most effective therapy for their child. In order to reduce the stress and anxiety surrounding the search for services, it will be necessary to make the process as easy as possible for parents.

Receiving services early in the child's life is critical for improving the lives of family members. Many children with autism display behavior problems, and many therapies focus on reducing these. Several domains of Qatari parents' psychological well-being were negatively affected by their child's behavior problems. This provides further evidence of the need to provide support to parents in relation to the service provision process.

The education system was also identified as a challenge by Qatari parents of children with autism. Specifically, parents frequently said they wished the education system in Qatar was more inclusive. Some parents felt that their child with autism should be in school full-time in order to have opportunities to engage in traditional learning activities and to interact with typically developing peers. The establishment of an inclusive education system in Qatar is crucial for improving the lives of children with autism and their families. The WISE report on education for students with autism in Qatar (Guldberg, Ashbee, Kossyvaki, Bradley, & Basulayyim, 2017) recommended an expansion of special education services in Qatar. Fortunately, the Qatar National Autism Plan aims to increase educational options for all children with autism with an emphasis on inclusive options.

A systematic study of parents' needs with respect to services was outside the scope of this study. Further studies in Qatar are needed to identify the characteristics of families who perceive the greatest need. It may be possible that certain segments of the population in Qatar experience greater disparities than others in the receipt of services. It would also be interesting to assess whether these needs vary as a function of the child's characteristics. It may be that parents of more severely affected children are in greater need.

4.3. Families and Social Support

The value of a good social support network cannot be overstated. Parents of children with autism need individuals they can turn to for instrumental and emotional

support. Without such a network, parents of children with autism report high levels of loneliness and poorer psychological well-being (Dunn et al., 2001). Social support can come from a variety of sources such as friends, family members (immediate and extended family), and other parents of children with autism. Qatari parents we interviewed described feeling that they couldn't visit friends and family anymore, and that their spouse was not as supportive as they could be. However, some parents reported that their extended family, particularly the child's grandparents, were a comforting source of support. One source of support that may be particularly helpful is the Qatar Autism Families Association. This association was mentioned several times by parents, particularly mothers.

Parents who felt they were not receiving support were the ones more likely to report lower levels of psychological well-being. The area where parents felt they most needed support was help taking care of their child (e.g., receiving respite care), and they reported frustration with their domestic workers not being trained to provide this care. This type of support would provide parents with a psychological breather. It may offer married couples a chance to spend time alone together and reconnect with one another. Although we have focused on parents in this report, it is likely that non-affected siblings (i.e., siblings who do not have autism) would also benefit. Sometimes non-affected siblings take on the role of parent, a phenomenon referred to as "parentification" (Tomeny et al., 2017). If respite care were available to the family, the parents and non-affected siblings could also spend time together enjoying recreational activities that they might not otherwise be able to engage in. Domestic workers already working in the home may be the easiest option for providing this support on a regular basis; however, these workers need training on how to effectively manage the child's comorbid behavior problems.

It was particularly interesting to be able to examine data from a small number of Qatari fathers. These fathers also reported needing someone they could talk to and receive support from, and more so than mothers. Traditional gender roles, which emphasize men playing the role of protector and provider and being the "tough guy," are particularly strong within Arab culture, and within these confined gender roles, men are often belittled for openly sharing emotions. Indeed, male friendships are typically dominated by participation in shared activities, in contrast to female friendships, which emphasize emotional disclosure. Thus, these pronounced gender roles may inhibit men from sharing the struggles they experience as the parent of a child with autism, and from reaching out and seeking help. Help-seeking behaviors may be perceived as a sign of weakness. Thus, greater emphasis needs to be placed on the experience of fathers. Little research exists on fathers of children with autism in Western countries, and we were unable to locate any research conducted in Arab countries on this population.

Future studies should continue to examine the role of social support in families of children with autism. It would be particularly interesting to examine the different sources of support. Given the large family size in Qatar, it may be that the immediate family (e.g., siblings) are a greater source of social support for parents. There may also be gender differences regarding the sources of support that parents find helpful. Given that the majority of families in Qatar employ domestic workers, further research is

needed to examine the role of domestic workers in the family and how they provide support to families.

4.4. Families and Awareness about Autism

All of the parents we interviewed mentioned the need for greater awareness of their children's developmental milestones and the early signs of autism. A basic understanding of early milestones in the area of motor, language, and social development is essential for any parent. With this knowledge, parents would be able to bring concerns to their doctor earlier in their child's development. Parents we interviewed spoke of waiting before voicing concerns because they thought it was normal for boys to begin talking later. This lack of knowledge is often pronounced in first-time parents, who do not have an older child against whom to compare milestones. Public awareness campaigns are needed to inform parents about typical developmental milestones. Knowing the red flag symptoms of autism in the early years of life is also important. Many people associate autism with a lack of language, and often late talking (or not talking at all) is the concern that prompts parents to visit the doctor. However, there are other red flags that often emerge during the first 12 months of life, including a lack of eye contact, a lack of social smiling, and a lack of interest in interacting with others (American Psychiatric Association, 2013). New parents should be informed about these early markers of autism so that they can begin the diagnostic process at a younger age. It is possible to reliably diagnose autism under two years of age (Lord et al., 2001), and early intervention is critical for children with autism.

The lack of awareness about autism also extends to the larger community. Several parents discussed feeling that their extended family members didn't understand their child's behavior. Parents also felt they couldn't go out in public with their child because they would get negative looks and comments from people. These experiences likely stem from Qatari residents not knowing what autism is. Or, if they have heard of autism before, they are not aware of the behaviors associated with it. Unlike other developmental disabilities (e.g., Down Syndrome) or physical disabilities, there are no observable characteristics associated with autism. You cannot look at a child with autism and know that they have autism. The Qatar National Autism Plan aims to create media campaigns to raise awareness about autism, which is a step in the right direction. It is crucial, however, that the campaigns highlight the multitude of behaviors that a child with autism might display. The next step is to move toward fostering a sense of acceptance about autism and reducing the stigma surrounding its causes.

Given that there are surveys designed to assess awareness and knowledge of autism, it would be interesting to conduct a population-wide study to ascertain the levels of both in Qatar. In addition, it may be beneficial to examine awareness and knowledge among providers who interact with children with autism. This could include teachers, medical professionals, and domestic helpers. Future studies could also examine the effects of perceived stigma on parental psychological well-being.

4.5. Families and Finances

Raising a child with autism can be an expensive endeavor. Although the Qatari government provides autism-related services to families at no cost, many families reported paying for private services because of long wait lists at the government centers. In addition to the stress of paying for private services, some mothers in Qatar are opting to stop working in order to provide care to their child with autism. Parents are often unable to combine work and taking their child to multiple therapy sessions or doctor visits. Parents reported feeling that they were the only ones who could provide care, because the domestic helpers in their homes were not trained to manage the child's behavior. Because of these challenges, parents identified financial assistance as something they were in need of and greater financial need was associated with poorer psychological well-being. With the Qatar National Autism Plan increasing therapy services for children with autism, it is our hope that the financial stress parents experience will be mitigated in the near future. Nonetheless, further research is needed to systematically examine the financial burden that parents experience, and how that relates to their psychological well-being. For example, parents may report discontent with the cost of services, but the costs may not be substantial enough to actually affect their day-to-day lives.

4.6. Families and their Children's Future

Autism is a lifelong developmental disorder, and children with autism will become adults who may need some level of support. This can range from adults living independently but needing some assistance with finances to those who need full-time care. The transition to adulthood for individuals with autism can be challenging for both the individual and their family. Parents we interviewed reported concerns regarding vocational placements and day programs for their adult child. Parents also reported concerns about who would provide care for their adult child when the parent dies. The Qatar National Autism Plan recognizes these concerns and intends to expand services for adults with autism, including respite care, vocational training, and residential services. For families of adults with autism who require substantial care, it will surely be a relief to know that their child will be cared for when the parent is no longer able to provide such care.

4.7. Family Environment

Healthy family dynamics contribute positively to children's development. Families characterized by low levels of conflict (between parents as well as between parents and children), high levels of positive emotions, and open communication are most beneficial for children. Raising a child with autism may disrupt existing family dynamics. Some parents we interviewed reported that their marital relationship has been negatively impacted since their child's diagnosis. Others reported that relationships between siblings are sometimes less positive than parents would like. Given the large family size in Qatar, it will be necessary to address the needs of the entire family system.

In addition to focusing on improving the lives of parents of children with autism, it will be necessary to include **all** family members in any family-centered interventions that are developed and implemented. This type of family-centered program will result in improvements in the psychological well-being of each participant, improved dyadic interactions (e.g., parent-child, mother-father, sibling-sibling), and a more positive general family environment. These improvements may, in turn, result in improvements in the functioning of the child with autism vis-à-vis their interactions with parents and siblings.

Further research is needed from a family systems perspective. For example, the views of non-affected siblings are needed. Given the large family size in Qatar, there are an increasing number of children growing up with a sibling with autism. Having a sibling with autism can be a stressful experience, and may also negatively impact the psychological well-being of the non-affected sibling. It is also important to include the perspectives of grandparents. Parents reported that grandparents would often provide support, and it would be interesting to learn more about how providing that support affects their well-being. There also needs to be research on how the parent-child relationship is impacted when the family is raising a child with autism. Parents in this study reported needing to know more information about how to interact with their child with autism. Thus, studies examining parent-child interaction styles would be particularly informative.

4.8. Targets for Intervention

Within the limited scope of our research, one of our goals was to identify potential avenues for developing interventions aimed at improving the well-being of parents of children with autism. Given the results presented thus far, a common theme has emerged from both the interviews and the surveys. Parents in Qatar need instrumental and emotional support to help cope with the demands of raising a child with autism. Those with greater unmet support needs were more likely to report poorer psychological well-being. We also found that social support served as a protective factor for parents of children with autism. Parents who reported receiving social support were less affected by their children's behavior. Conversely, parents without a good social support network were less able to cope with the stress of raising a child with autism. This suggests that strengthening parents' support networks would be an effective intervention target. Parents should be encouraged to reach out to members of their support network in times of need. Friends and family members are often unsure of how they can help parents, but sometimes the simple act of having a cup of coffee and listening to the parents' concerns is all that is needed. Members of parents' support networks may also need training and guidance in ways to assist the parents.

Individuals vary in the ways in which they handle the ebbs and flows of life. How parents cope with the stress associated with raising a child with autism can influence their psychological well-being. More adaptive coping strategies helped to buffer the negative impact of the child's behavior problems. Adaptive coping strategies include reframing the situation. For example, instead of seeing autism as a negative experience and something that is "wrong" with the child, parents who engage in reframing

might think of their child's autism diagnosis as something that has brought their family closer together and allowed them to appreciate the small things in life. This type of coping may not come naturally to many parents, especially in a society that may attach significant stigma to autism and other disabilities. However, research shows that individuals can be taught to be more optimistic about the future (Littman-Ovadia & Nir, 2014) and engage in hopeful thinking (Berg, Snyder, & Hamilton, 2008). Engaging in gratitude exercises (e.g., writing a gratitude checklist each day) has been shown to increase psychological well-being in parents of children with autism (Timmons & Ekas, 2018).

Engaging in religious coping was also found to be beneficial for Qatari parents of children with autism. When life presents challenges, individuals may turn to their faith to help alleviate their distress. This can include believing that Allah will take care of everything or that Allah has presented this challenge for a reason. Parents may also engage in private prayer or attend formal religious services. In a devoutly religious country such as Qatar, where an individual's faith is an integral part of their identity, it is important for religious communities to be inclusive and foster a culture of acceptance. Spreading this message to the community may be one way to tackle issues surrounding the stigma that some parents reported experiencing.

CHAPTER FIVE: RECOMMENDATIONS

The government of Qatar is committed to improving the lives of individuals with autism and their families. The implementation of the National Autism Plan will likely bring exciting changes to the country over the next five years. Our multimethod study was the first to systematically examine the challenges that families of children with autism face and identify what they need in order to thrive. We also examined how these challenges and unmet needs impact the parents' psychological well-being. By improving the well-being of parents, we believe that parents will be better able to care for their children and provide a positive family environment that will undoubtedly foster healthy child development. In conclusion, we suggest that parents' lives can be improved in two pathways: 1) indirectly, via improved services for their child with autism; and 2) directly, via providing support to parents through support groups and mental health services. Recommendations for each pathway are discussed below.

5.1. Indirect Ways to Improve Parental Well-Being

This pathway is labeled "indirect pathway" because the parents here are not the direct targets. In this pathway, the child with autism receives services, or changes are implemented at a community-wide level. Thus, children benefit directly from these changes and the parents benefit indirectly, through the improvement in their children's lives. For example, parents may experience stress because their child engages in aggressive behavior. Once the child begins receiving services that target behavior problems it is likely that the parents' stress levels will decrease. Thus, to indirectly improve parental psychological well-being, we recommend the following:

- Children should not have to wait so long to receive a diagnosis of autism. This can be accomplished by having a streamlined process whereby parents can turn to a single agency for assistance. Reducing the length of time it takes to receive a diagnosis will increase the likelihood that children receive services earlier. This may translate into improvements in children's behavior and, thus, reduced stress for parents. Similarly, the process of seeking services for children with autism should be simplified and greater access provided to families. All children should be able to receive services, ideally at a young age.
- To reduce the financial burden on families, and the stress associated with needing financial assistance, the Qatari government should ensure that all families have access to government-provided services. These services should be of the highest quality, delivered by well-trained therapists. This will ensure that parents do not feel as if they need to seek private services. In addition, the process of seeking paid leave for mothers who choose to stay home to provide full-time care for their child should be simplified. Parents do not need the additional stress of trying to navigate another government service while providing critical care for their child.
- Community awareness about autism should be increased. Public awareness campaigns need to move beyond presenting statistics about the prevalence of

autism. Instead, campaigns should aim to teach community members about the causes of autism, the symptoms of autism, and the behaviors that children with autism might exhibit. This will help to reduce the stigma surrounding autism and improve interactions between community members and parents. Given the strong religious identity of many Qatar residents, it would be beneficial to involve faith-based communities in the transmission of such messages.

5.2. Direct Ways to Improve Parental Well-Being

In this pathway, parents are the direct recipients of services that are created to alleviate the stress they experience in their role as the parent of a child with autism. To directly improve parents' psychological well-being, we make the following recommendations:

- To reduce the stress associated with the lengthy diagnostic process, we recommend that there should be more and better communication with parents. Medical professionals should provide parents with feedback throughout the diagnostic process and explain why certain tests are being administered or why they are being referred to a different professional. This will reduce the anxiety surrounding this stressful process.
- Parents should have access to multifaceted social support services that include both instrumental and emotional forms of support. Instrumental support services in the form of respite care for families would be particularly beneficial. These services could be implemented via therapy providers or community centers, or through the public education system. Research shows that respite care given as little as once per month is enough to provide direct benefits to parents (Harper et al., 2013). Domestic workers already employed in the home could also be utilized, provided that they receive appropriate training. Emotional support could be provided through the implementation of parent support groups facilitated by the service centers or schools that the children attend. Given the unique needs of fathers, we recommend the establishment of separate fathers-only groups. Men may feel more comfortable talking with other men who are sharing the same experiences.
- In addition to social support, parents should have access to mental health services that directly address the stress they are experiencing. Although there may still be stigma surrounding mental health problems in the larger society, information about such services should be provided to parents by medical professionals. Parents need to be assured that their confidentiality will be maintained and that their family members (e.g., spouses) will not be informed about their visits.
- Parents should be taught coping skills to deal with the stress associated with raising a child with autism. These skills can be shared by qualified mental health professionals in a one-on-one setting (see the mental health recommendation above) or in group settings (see the social support recommendation above).

5.3. The Future

The future looks bright for families of children with autism in Qatar. The government of Qatar is taking important steps in acknowledging the increased prevalence of autism. The voice of families is being heard, and some of their needs are being addressed with the implementation of the National Autism Plan. In addition to the recommendations above, we would encourage continued research into families of children with autism. Although our investigation has provided a glimpse into families' lives, the diversity of family life in Qatar cannot be captured in a single study. Further research is needed to identify additional protective factors that can be incorporated into family-focused interventions. We also encourage policy makers to consider the needs of all family members in future planning. All too often the emphasis is solely on addressing diagnostic and treatment services for the child with autism. Of course, this should be a primary aim of government and community agencies. However, family members are also affected by the child's diagnosis, and improving their psychological well-being will ultimately benefit the individual, the child with autism, and the larger community.

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