

Title: Exploring challenges and support structures of mothers with children with Autism Spectrum Disorder in the United Arab Emirates

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1. Introduction

The prevalence of Autism Spectrum Disorder (ASD), within the United Arab Emirates (UAE), is one in 80 males and one in every 240 females (Kelly et al., 2016). Children with ASD experience deficits in social and communication skills, often combined with behavioral problems making parenting extremely distressing (Kuhn & Carter, 2006). Parents of children with ASD face extreme psychological, social, physical, and financial challenges (Dieleman et al., 2018a; Chan et al.,

2018). Specifically, they experience greater parenting stress (Zaidman-Zait et al., 2017), poorer family functioning, and higher levels of conflict, than parents with typically developing children and children with other developmental disabilities (Al Khateeb et al., 2019; Cridland et al., 2014). In terms of parenting, they often experience a form of loss after the diagnosis of their child which may induce a sense of failure as a parent (O'Brien, 2007).

Mothers often assume a larger sense of caregiving responsibility (Meadan et al., 2010), especially in the Middle East (Crabtree, 2007). Previous research, primarily administered in the West, has shown that raising a child with ASD significantly impacts the day-to-day lives and psychological health of mothers (Zaidman-Zait et al., 2017; Krakovich et al., 2016). For example, they often experience higher levels of depression, anxiety, anger, and grief, and step away from their careers to prioritize care for their child with ASD (Riahi & Izadi-Mazidi, 2012; Meadan et al., 2010), and earn 56% less in comparison to mothers of other neurotypical children (Zeffane et al., 2017). In addition, denial and lack of understanding from spouses further negatively impact mothers' mental health (Alnemary et al., 2017; Samadi & McConkey, 2014). Expat mothers may experience greater challenges while navigating through new social, cultural, and political structures.

Mothers with children with ASD often lack support from their families, experience social isolation, guilt, and shame of having a child with ASD (Solomon & Chung, 2012). In contrast, mothers with social support experience less stress, more optimism (Zaidman-Zait et al., 2017; Ekas et al., 2010) and are better able to address the needs of their children (Karst & van Hecke, 2012). Formal and informal support provided to families with children with ASD show positive adjustment (Meadan et al., 2010), thus facilitating the opportunity to share frustrations, expectations, achievements, and

receive and provide support (Cridland et al., 2014). Additionally, a recent meta-analysis showed that positive sources of support, including parent-to-parent support, decreases symptoms of depression in mothers (Schiller et al., 2020; Rios et al., 2020).

The current research explores experiences of expat mothers based in the UAE. Disability prevalence in the UAE is similar to the global average of 8-10% (Bradshaw et al., 2004). ‘Special classrooms’ were incorporated in some public schools in the 1980s, however in line with United Nations Protocols, the official Federal Law (No. 29) supporting children with special needs was created in 2006 (In Respect of The Rights of People with Special Needs, 2006). While the UAE government has prioritized support for children with special needs, often referred to as ‘people with determination’ in the region, the advancements are relatively recent compared to several countries in the West, such as the U.K. and the U.S.A. where protective laws for special needs children were initiated in 1944 and 1975 respectively (Borsay, 2012; Kim et al., 2019). Moreover, UAE has different Health Regulatory bodies, unlike a national health system in the U.K., which may lead to different policies being practiced across the Emirates.

The UAE offers support to children with special needs in both public and private sectors through schools, therapy centers, and non-profit organizations. All schools are required to provide admissions to children with developmental disorders in mainstream schools with typically developing children (Knowledge and Human Development Authority, 2017; Gaad, 2019). However, resources and infrastructure, are often not standardized which may lead to some schools refusing admissions to children with special needs. Most institutions are rapidly expanding their infrastructure for children with special needs, however there is a lack of research on its

effectiveness. There is also limited information on potential systemic challenges experienced by families, especially expat families, who are 88% of the population in the UAE (Edarabia, 2021; Sheikh, 2015).

For expats in Dubai, the annual tuition fees in private schools vary from 14,500 – 77,600 AED per annum (2,883 – 15,432 GBP) (Rizvi, 2021), and is inclusive of special needs support. Private fees for school and therapy adds to the financial burden of parents as only 16% of the expats' employers provide fees for children's education (Dhall, 2015). It is also important to note that there is less streamlined information regarding children with autism spectrum disorder (Sheikh, 2015). Quality of therapeutic and learning support in schools are crucial for a child with ASD, (Zeina et al., 2014; Alnemaary et al., 2017), but these have not been explored much in the UAE.

Although limited, research related to ASD in the Middle East, has been conducted primarily in Saudi Arabia, Egypt, Lebanon, and Oman, and discusses mothers' social, physical, and psychological health concerns with regards to raising children with ASD (Alnemaary et al., 2017; Dardas & Ahmad, 2013; Zeina et al., 2014; Hussein & Taha, 2013). Researchers have highlighted issues related to lack of appropriate support services (Manee et al., 2016), failure of treatment (Zeina et al., 2014; Alnemaary et al., 2017), and lack of social support (Alwhaibi et al., 2020). Moreover, as compared to its Western counterparts, UAE lacks skilled professionals despite high demand and limited capacity (Hussein & Taha, 2013; Almalki et al., 2021).

Overall, lack of research in the field of inclusive and special education, limited information about experiences of expat parents of children with ASD in the country, need for identifying areas of

improvement based on experiences of expats, and most importantly lack of knowledge about protective factors for mothers who experience extreme parenting stress – drives this research in the context of UAE. Moreover, the limited research on ASD in the UAE has mostly focused on causes, characteristics, interventions, and therapy (Alnemary et al., 2017). Little is known about challenges and available support structures for caregivers, especially from a qualitative perspective (Hussein & Taha, 2013; Shahrokhi et al., 2021). Therefore, the primary aim is to explore challenges and experiences of support for expat mothers of children with ASD.

2. Method

2.1 Participants

Participants were recruited using purposive and snowball sampling. Inclusion criteria were mothers who 1) had at least one child diagnosed with ASD, 2) were immigrants in the UAE, and 2) spoke basic communicative English. The interviewer (AT) knew of two mothers with children with ASD through her experience as a special needs teacher in Dubai, UAE. These participants approached other mothers in their personal networks. Additional participants were recruited through social media posts. Through these methods an initial sample of 37 mothers was contacted, however, due to busy schedules, 20 prospective participants could not find time to schedule an interview, leading to a response rate of 46%. The aim of the study, feasibility of data collection, diversity of experiences shared by participants, and choice of analysis inspired the final sample size (Malterud et al., 2016).

The final sample consisted of 17 mothers (Age_{mean}= 40.8 years; Age_{range}= 33-58). As per UAE standard of living, others were from medium to high income groups. Majority of the participants were married and were residing in the UAE since the diagnosis of their child/ren with ASD. Participants were from diverse cultures, representing the expat population of the UAE (29% from Africa, 23% from East Asia, 18% from South Asia, 18% from Great Britain and Ireland, 6% from North America, 6% from Oceania). Age of children ranged between 5 and 22, and all children of school going age (n = 14) were enrolled in international schools or mainstream schools with typically developing children, at the time of interviews. Please see Table I for detailed sample characteristics.

Table I: Participant information

Participant	Nationality	Occupation	Age of participants (years)	Child/ren with ASD	Marital status	Age and gender of child with ASD (years)	Age at Diagnoses (years)
M1	British	Teacher	35	1	Married	8, M	Not specified
M2	Pilipino	Nurse	35	1	Married	6, M	3.5
M3	Pakistani	Homemaker	33	1	Married	9, M	3.5
M4	Egyptian	Pharmacist	36	1	Married	7, M	6
M5	Egyptian	Homemaker	45	1	Married	13, M	6
M6	Pilipino	Administrative Manager	38	1	Married	7, F	3.5
M7	Indian	Learning Support Assistant	50	1	Married	21, M	7

M8	Pakistani	Dyslexia Specialist	39	1	Separated	8, M	3
M9	Indonesian	Homemaker	44	1	Married	7, M	5
M10	Singaporean	Homemaker	58	1	Married	13, M	6
M11	South African	Animal Handler	42	1	Separated	12, M	1.5
M12	New Zealander	Homemaker	36	1	Married	6, M	6
M13	British	Teacher	56	2	Married	19, M 22, M	3
M14	Nigerian	Homemaker	43	2	Married	10, M (twins)	4.5
M15	Egyptian	Homemaker	36	1	Married	5, F	5
M16	Irish	Homemaker	41	1	Married	6, M	6
M17	Canadian	Homemaker	37	2	Married	5, M (twins)	5

2.2 Measures

In-depth semi-structured interviews were administered and each section of the interview contained approximately 4-5 questions, which addressed experience with diagnosis (e.g. *What were some of the early signs that you picked up on that something wasn't quite right?*), school system (e.g. *Does your child receive additional support services in the school?*), therapeutic services (e.g. *Do you feel that some therapy services are more essential than others?*), support from family and other structures (e.g. *What was your family's reaction to the diagnosis of your child?*), and other life

challenges (e.g. *How do you prepare your child for new experiences?*). An additional question was added to the interview schedule to explore experiences related to the pandemic (*Please describe your experiences of challenges of caregiving and support available during the pandemic*). Participants were also asked to rate their satisfaction with diagnosis, schooling system, therapy, spouse, and support groups (see Table II).

2.3 Procedure

Participants were initially contacted via email with the details of the research and about their role in the study. Written informed consent, ensuring confidentiality, was received from the participants. The interviews administered between March 2019 and August 2020, were digitally recorded, and ranged from 37 minutes to 110 minutes. Interviews were conducted in a private conference room in Dubai, UAE which ensured privacy. As recommended by Bryman (2004), the interviewer made use of probes to ascertain additional elements related to the questions. Interviewer's insider's perspective, as a special needs educator, helped in building a strong rapport with the interviewees. Other steps which improved trustworthiness of the data were inclusion of a second coder, incorporating reflexivity of a collaborative team, and enhancing the interview protocol based on pilot interviews (Lincoln & Guba, 1985). Follow up questions regarding difficulties faced during the pandemic were emailed to all the participants. Seven participants sent detailed responses of their experiences.

2.4 Data analysis

The interviews were transcribed and analyzed using Thematic Analysis (Braun & Clarke, 2006), to effectively identify emerging themes and repetitive experiences of mothers with children with ASD in the UAE. This form of analysis was deemed most appropriate for this study, owing to its theoretical independence and its organic process of theme development (Terry et al., 2017). The study adopted an inductive data-driven approach to gain insight into participants' real-life experiences of available support structures (Potter & Wetherell, 1987). The data analysis involved a 6-step process to ensure validity and reliability (Cramer & Howitt 2004). The process involves (1) familiarization with data, (2) generating initial codes relevant to the data, (3) revisiting codes to generate the initial set of themes, (4) reviewing themes, (5) defining and naming themes, and (6) relating findings to literature and writing the report. Data was primarily analyzed by AT. Thirty percent of the interviews ($n = 5$), selected by random number generator in excel were coded by a second coder (NL). The inter-class correlation coefficient (average measure) was 0.7. Variances were then discussed to reach a mutual agreement. Themes were cross-checked by both coders (AT and NL), a process that enhanced the credibility of findings (Golafshani, 2003). Since thematic analysis is an active process, the interviewer's (AT) own knowledge and experience as a special needs educator may have influenced the data and themes.

During the pilot stage, mothers with children with ASD helped in improving the interview schedule by providing their inputs, supporting integrated knowledge transmission model of research. Given participants' enthusiasm for increasing awareness related to autism and interviewer's personal and professional network as a special needs educator in the UAE, upon publishing, the findings will be disseminated in concerned schools and governmental institutions.

3. Results

Participants' levels of satisfaction with the diagnoses, teachers, schooling system, therapy, spousal, and support groups are available in Table II.

Satisfaction with:	Very Unsatisfied	Unsatisfied	Neutral	Satisfied	Very Satisfied
Diagnoses	2 (11.7%)	4 (23.5%)	6 (35.2%)	5 (29.4%)	-
Teachers	1 (5.8%)	5 (29.4%)	4 (23.5%)	7 (41.1%)	-
Schools	1 (5.8%)	2 (11.7%)	5 (29.4%)	7 (41.1%)	2 (11.7%)
Therapies	-	3 (17.6%)	5 (29.4%)	5 (29.4%)	4 (23.5%)
Spouses	2 (11.7%)	5 (29.4%)	2 (11.7%)	6 (35.2%)	2 (11.7%)
Support Groups	-	-	4 (23.5%)	1 (5.8%)	12 (70.5%)

A number of themes and sub-themes were identified (shown in Table III).

Diagnosis	Schooling and therapy	Key relationships	The wider community

Challenges related to initial diagnoses	Rejection and mistreatment	Spousal support	Rejection & isolation
Denial vs acceptance	Optimizing therapeutic services	Other family members	Difficulties during the pandemic
			Support groups

3.1 Theme 1: Diagnoses

All participants (17, 100%) discussed challenges faced during the initial diagnostic process. Over one-third of participants reported feeling dissatisfied (35%) or neutral (35%) towards diagnoses. The following subthemes describe mothers' experiences of having to consult multiple professionals and denial at the beginning of diagnoses.

3.1.1 Subtheme 1: Challenges related to initial diagnosis

Most mothers (9, 53%) reported that their child/ren was diagnosed after 5 years of age. Two thirds of the mothers (12, 70%) narrated their experience of picking up some early signs regarding their child's atypical development. Mothers who had some prior knowledge about autism felt more confident about their observations. For example, a mother said:

"...I was very well aware of what Autism looked like also {name of son} happened to have two cousins who are quite significantly Autistic [sic], so I think I always knew from the time" {M9}

Several mothers (7, 41%) reported not receiving any appropriate information during the initial diagnoses of their children, which contributed to the difficulty in understanding and accepting diagnoses being presented by multiple professionals. Furthermore, four mothers (23%) expressed that they heard about ASD for the first time upon diagnosis and that, medical professionals did not explain it clearly. A few mothers (3, 18%) narrated experiences of feeling extremely agitated with ambiguous and limited information presented by medical professionals at the time of diagnoses. For example, one mother said:

“...they never said cerebral palsy, no, never gave, uh said autism. They never said like ADHD or they just-what they said is he may have behavioral issues. He may or may not walk. He may or may not feed...may or may not...so they gave horrible diagnoses” {M3}

Few mothers (4, 23%) felt that their children were having some minor developmental delays adding to the difficulty in identifying early signs:

“...So he was very quiet. Here we thought he was just a quiet, shy child with hearing problems...” {M16}

One mother said that such a perception was reaffirmed by a medical professional.

“But the pediatrician said like “Oh, what you're saying it's like signs of ASD. I cannot see it she's perfectly fine don't worry maybe she's just late in development...” {M4}

Additionally, comorbid impairments such as hearing loss, language and speech delays, and attention and behavioral difficulties added to the ambiguity at the time of diagnosis. For example, one mother said *“And they told us that some children have delayed speech and if not then it might be neurological ...”* {M1}

Lack of clarity led mothers to experience a tedious journey of consulting multiple professionals, causing further delay in the diagnosis process. For example, a mother said, *“...I went from pillar to post going to doctors going to pediatricians saying “we need to do something, I mean this child is not sleeping...”* {M9}

3.1.2 Subtheme 2: Denial vs. Acceptance

While mothers had accepted their children’s development disability and embraced the journey of learning about ASD by the time of the interview, few mothers (6, 35%) narrated their experience of undergoing a phase of denial or hiding it from a few family members. For example, one participant expressed that she kept trying to hide the reality from her husband:

“I was not ready because always I knew that some behavior was like you know ...not normal but still I was trying to hide from even...even from my husband...” {M15}

Another mother rationalized her denial as she felt convinced that her daughter’s speech delay problems were due to lack of ability to pick up different languages, in an expat dominated country, and believed that the pre-school might solve the issue.

“...Maybe it (pre-school) will help her because, you know, I- we are from different countries- so speaking different language...” {M4}

Another mother said that observing contradiction in her son of being very aware of the world while lacking comprehension of basic things, created conflict in acceptance of diagnosis.

3.2 Theme 2: Schooling & Therapy

Participants expressed both challenges faced, and support received from teachers, schools, and therapeutic services. While mothers narrated experiences of a lot of initial struggles, a somewhat equal proportion of participants felt dissatisfied (35%) or satisfied (41%) with teachers. In terms of schools and therapies, most felt satisfied (53%), some felt neutral (29%), and only a few rated feeling dissatisfied (18%). Qualitatively, in contrast, most participants narrated experiences in retrospect and described their challenges related to rejection and financial strain.

3.2.1 Sub-theme 1: Rejection and mistreatment

Most mothers (9, 53%) expressed that they had gone through some type of rejection while searching for schools. Eight of these mothers (88%) were from developing nations. Four mothers (23%) mentioned that they were initially made to feel welcome since schools needed a larger intake of students, but then the individualized needs of their children were never met.

“...then in the last term, they told me “I don’t think this is the right place for your son” So I had to take him out and like keep on looking, looking and looking... I started going and dealing with refusal with one rejection after the other...” {M5}

Another mother expressed serious concerns related to feeling bullied by the school.

“...all of the time, and I felt bullied-I felt bullied by the staff...in the end you just realize that “they are just taking my money...” they are not doing anything for him and its empty promises...” {M9}

Few mothers (3, 17%) also reported frustration and feeling overwhelmed while looking for ‘all-inclusive’ packages in schools. Two mothers (11%) mentioned that schools charged significantly higher fees. For example, one mother said:

“...So we met her but it’s the same thing that the fees were 98 000 dirham and I was like...mmm.... And because I had mentioned to her on the phone that my husband's work were paying...” {M3}

Several mothers (7, 41%) even described how they felt their children were mistreated. For example, one mother said:

“... {son} was made to sit for an entire term was made to sit in a hallway on a desk by himself with one adult, facing a wall I mean underneath the coat stand...” {M9}

Other challenges reported were related to the process of shortlisting schools, establishing the right grade for their children at the time of admission, school’s inaccurate disclosure of support

services in the classroom, and few teachers lacking awareness of ASD suggesting their own ‘cure’ and explanation.

3.2.2 Sub-theme 2: Optimizing therapeutic services

A combination of speech and language therapy, occupational therapy, and ABA therapy generally improves communication and developmental skills in children with ASD. An overwhelming majority of the mothers (14, 82%) mentioned how their child was accessing a combination of these therapies. Most participants (15, 88%) mentioned they were satisfied with these services and noticed significant changes in their child’s behavior and attention, especially after including ABA therapy.

“...I only started noticing real changes when {son} started receiving ABA therapy... {second son} also benefited from other therapies... but ABA was a game changer...” {M6}

One participant explained how a combination of sensory integration and ABA therapy established a good foundation.

“it's like ABA and speech therapist and OT because {name of child} has very high sensory issues. They all work together...” {M4}.

Another mother felt that speech and language therapy was important as she felt that communication is the key to establishing a good foundation to acquire more skills. However, similar to the experiences documented in Sub-theme 1, mothers expressed concerns with regards

to the cost of therapeutic services. Majority of the mothers (9, 53%) explained how multiple testing, long-term therapy, with limited progress caused financial difficulties.

“...I am fed up of this... because we’re paying the fees and there was no improvement...in fact, we are getting all the complaints...” {M15}

“...we can't really sustain it. Like ABA will take a lot like 10,000 to 20,000 AED a month and imagine like we don't we don't earn that like more than that amount...” {M2}

Overall, mothers discussed about experimenting with combination of therapies and providing consistent support for child with ASD. While one mother expressed that *“If you find someone good, just hold on to it...because that's not easy. Now, he's been with his speech therapist for more than two years and I love her”* (M7), another mother expressed frustration about *“too many changes of therapists at {medical centre} because of schedule changes and of-too many changes in approaches”* (M9).

3.3 Theme 3: Key relationships

All mothers (17, 100%) expressed the importance of a strong support system. In terms of spousal support, a somewhat equal proportion of women felt satisfied (47%) and dissatisfied (41%).

3.3.1 Sub-theme 1: Spousal support

All mothers (17, 100%) had assumed responsibilities as primary caregivers. The majority of the married mothers (9, 60%) acknowledged the financial support they received from their husbands, however preferred their husband to lead a more active role. For example, one mother expressed:

“...so he kind of got into the journey a little later he kind of gave me the hand to do whatever I needed to do with him for therapy or this or that...he doesn't want to make decisions ...” {M13}

Upon probing, five mothers (29%) described how their spouses were at a different stage of acceptance of the situation. For instance, one mother expressed:

“...partially he is still in a state of denial...He's not at the same level as- I am concerned for him...I am okay with it. You cannot drag a person to think the same way...” {M1}

However few mothers (3, 17%) found their spouses both instrumentally and emotionally supportive. One of the participants said, *“it's my husband who is looking after her right now...since he has lost his job, he is looking over my daughter...he is the one tutoring” (M8)*, indicating reversal of expected gendered roles.

3.3.2 Sub-theme 2: Other family members

Mothers also spoke about their parents, in-laws, and other neurotypical children. While in some families, parents, or in-laws, visited for 4-6 months in a year or lived with them, others met extended family members during occasional visits to their home country. Some (6, 35%)

reported that support from grandparents and in-laws was inconsistent primarily due to lack of awareness and understanding on their part. These also included suggestions of unscientific ‘cures’ for ASD. For example, one participant mentioned:

“...my own father will say feed these foods, he'll get cured and I'll be like, okay...” {M3}

Some mothers (5, 29%) described emotional difficulties faced due to actions of in-laws, such as locking their bedroom door as they feared their grandson. In fact, one mother expressed that her in-laws blamed her for the child’s delayed speech. The mother reported *“they brainwashed my husband”* by saying that *“she was not talking to him properly”* *“she was not giving him attention”*. *“She used to make the baby sit in front of TV whole day that’s why his speech is delayed...”* *She is not a good mother at all” (M1)*. Such experiences added to the mother’s emotional distress.

Two mothers (11%) talked about moments of support they received from their own parents. Another difficulty within the family systems was that few mothers (5, 29%) felt guilty for neglecting their other typically developing children who weren’t always able to understand the needs of their siblings with developmental disabilities.

“...[daughter] always thinks that I'm overprotective for my son and I'm not giving her enough of the attention so if we consider her everything or supportive...no, she's not...”
{M5}

The majority of the mothers (9, 52%) reported feeling rejected from extended families. For instance, a mother reported that other teenagers in the family were not accepting of their child/ren with ASD.

“...his aunt and her... kids, although he loves them are not as understanding so they’re always blaming him if he’s being too tough or you know...no I don’t get any help there...” {M13}

Importantly however, a large majority of the mothers (13, 76%) mentioned that they have accepted their families as others cannot be forced to understand or accept children with ASD.

3.4 Theme 4: The wider community

This theme incorporates narratives shared by mothers regarding feeling largely rejected by the community, experiencing hardships during the pandemic, and feelings towards support groups.

3.4.1 Sub-theme 1: Rejection and isolation

Generally, quite a few mothers (6, 35%) discussed about feeling stigmatized in the larger community. They felt that lack of knowledge contributes to people’s judgmental reactions. It appeared that it further made them prefer isolation, as a form of defense mechanism. For example, one participant expressed that when her son climbed over the neighbor’s balcony, the neighbor “*came and hit him very badly*”. She further said, “*my husband raised it with the police...*” (M15) and appreciated the support they received from the police in the UAE.

Few participants (4, 23%) expressed finding it difficult to move around with their child with ASD in public spaces. One mother expressed that it was hard to explain to others as ASD is an “*invisible disorder*”. She narrated an experience with an old woman in a bus, who kept aggressively repeating “*why is he making so much noise tell him to be quiet*” {M3}. Narrating similar experiences, another mother expressed “*deep, deep down-I didn’t want anyone to look at me or my son...*” {M7}. Such thoughts and experiences increase alienation in families with children with special needs.

3.4.2 Sub-theme 2: Difficulties during the pandemic

Nearly half of the participants (8, 47%) mentioned that they prepare their children for the outside world through various methods such as verbal reminders and pictures to improve their cognitive flexibility while exposing them to ‘structured unpredictability’. Up until the pandemic, several parents had not encountered ‘unstructured unpredictability’. While only seven participants responded to the follow up question regarding the pandemic, a clear theme reflecting increased psychological hardships emerged. Regarding the pandemic, all mothers (7, 100%) said that exacerbated uncertainty such as interrupted therapy session, unpredictable school hours, reduced socialization, additional financial and psychological hardships were extremely difficult for the family. Mothers reported that it affected their routine and led to increased repetitive and destructive behaviors in children with ASD. One mother said “*{name of son} thrives on routines, especially the routine of school*”, and during the pandemic, “*we have had destructive behavior like chewing tables and cables, breaking toys even favorite ones, screaming, shouting and lots of crying and even physical attacks especially on his younger brother*” (M11).

Another mother shared her experience:

“...He used to cry and scream. He was extremely uncomfortable with the online therapy sessions sitting in front of the laptop. So, we discontinued his online classes and designed our own curriculum. I had to control my own frustration levels also because only then I could take good care of him” {M6}.

3.4.3 Sub-theme 3: Support group

All mothers had been part of a support group at least once, however two were no longer visiting support groups at the time of the interview. Unlike other sources of support, the majority of the mothers (12, 71%) reported feeling very satisfied with parent-to-parent support groups. Given that they often felt alienated from extended family members and the community at large, these groups made participants feel that they were not alone and provided a platform to share ideas and experienced-based knowledge.

“...These people really helped and supported us emotionally at least, an emotional support knowing that somebody else is there you're not alone...I would go and try and ask for advice and try to do the same thing. So, it is really helpful...” {M5}.

There were varied preferences in terms of support groups. For example, some mothers felt supported via online groups on Facebook or by building close bonds in exclusive groups.

4. Discussion

Expatriate mothers in the UAE with children with ASD shared their experiences about initial diagnoses, family members, school and therapy, and the wider community. While the average age of diagnosis in the present study matches the global average of 5 years (van't Hof et al., 2020), it is delayed diagnosis in comparison to several developed countries (Linnsand et al., 2021). Several mothers felt that diagnosis and treatment were often delayed as symptoms of ASD were confused with other comorbid impairments such as delayed language development. These findings are in line with previous research suggesting that diagnoses and intervention are often delayed, especially in the Middle East and South Asia, and is an extremely distressing process for parents (Hussein & Taha, 2013; Dieleman et al., 2018b). A timely diagnosis is important as it helps parents cope better with emotional distress, decreases burden of care, and supports strategies for early intervention (Elder et al., 2017; Rabba et al., 2019). In fact, similar to previous research (Farooq & Ahmed, 2020), few mothers also reported experiencing denial related to the diagnosis. In addition to delaying intervention, denial may further contribute to conflict between immediate family members (Zwaigenbaum, 2017). Importantly, mothers who were aware of ASD before the diagnosis were better able to observe and report early signs to medical professionals, facilitating early intervention.

Several mothers experienced difficulties with multiple professionals and narrated initial struggles of finding an appropriate school and therapist for their child with ASD. These were related to difficulties in finding the right educational institutions, lack of transparency from the school, and additional financial strain. It appears that mothers from developing nations experienced greater systemic challenges. Future research could investigate this further. While recent research in the Middle East has highlighted lack of effective collaboration between parents and schools (Almalki

et al., 2021), studies administered in the West found that most parents felt satisfied, especially with therapeutic services provided by schools (Peters et al., 2021).

While the UAE government has made attempts to prioritize infrastructure for children with special needs (Knowledge and Human Development Authority, 2017), in line with previous research (Shahrokhi et al., 2021), mothers reported finding it difficult to find appropriate interventions due to scarcity of resources and training. It appears that initially access to information related to interventions was scattered and unclear. Despite an increase in children being diagnosed with ASD in the region (Chiarotti & Venerosi, 2020), limited inclusive staff across schools and healthcare settings may pose a systemic challenge, leading the caregivers to switch between healthcare professionals and schools; further increasing their financial and emotional stress. Findings from the current study highlight the need for more structured support services as it facilitates informed decision making (Alsem et al. 2017).

In terms of therapy, mothers discussed the importance of experimenting with speech, occupational, and ABA therapy as per the child's needs. Most of the expat mothers shared stories of initial struggles in accessing information about appropriate schools and therapies, however it appears that they were somewhat satisfied once they found a stable intervention. Few mothers expressed that consistency in support facilitated growth in the child. As suggested in previous research (Karst & van Hecke, 2012; Shattnawi et al., 2020), it was also evident that schools and therapeutic services posed an extreme financial burden on families with children with ASD.

In addition, several mothers were dissatisfied with the support received from their husbands and hoped for more instrumental and emotional support. The study highlights the need for spousal support as it contributes to lower psychological problems in mothers with children with developmental disabilities (Samadi & McConkey, 2014). In line with previous research some mothers felt rejected and isolated from the community at large, and experienced negative emotions from strangers (Lopez et al., 2018), parents and in-laws (Shattnawi et al., 2020), neurotypical siblings (Critchley et al., 2021), and other extended networks (Zeina et al., 2014; Samadi & McConkey, 2014). In some extreme scenarios, grandparents were fearful of the child with ASD, suggested unscientific cures, or blamed the mother for the child's developmental delays. Previous research, administered in the Middle East, has shown that such experiences not only act as barriers to seeking support but also encourage families to stay invisible in mainstream society (Manor-Binyamini & Schreiber-Divon, 2021). Similar to previous research that promotes knowledge of ASD as fundamental for inclusion (Jones et al., 2021), mothers expressed that lack of knowledge and visibility of children with special needs in public spaces perpetuates exclusion.

Mothers felt extremely satisfied with support groups. In line with previous research, mothers generally shared common experiences and exchanged key information about schools, therapy, and interventions (Rios et al., 2020) and found experience-based knowledge exchange to be beneficial (Alsem et al., 2017). This is an important finding as social support facilitates psychological well-being in mothers with children with developmental disabilities (Ekas et al., 2010; Slattery et al., 2017) and support groups help mothers to address the needs of their children (Karst & van Hecke, 2012).

Importantly, the study further shows that uncertainty, lack of routine, interrupted online schooling and therapy at the time of the pandemic exacerbated disruptive behaviors in children with ASD. This is one of the first few studies (Critchley et al., 2021; Alhuzimi, 2021), which provides insights into challenges experienced by families with children with developmental disabilities during the pandemic. In line with recent research administered in Saudi Arabia (Alhuzimi, 2021), the current study suggests that mothers in the UAE also faced additional parental stress and financial and emotional burden. It is important for governments to provide support services, in the form of subsidies, helplines, and other childcare services, to parents of children with developmental disabilities, during such health emergencies.

In terms of limitations, the findings cannot be generalized to mothers from lower socio-economic status in the region. Mothers from lower socio-economic strata may not join support groups and may experience extreme psychological hardships and financial burden which may further affect their children's developmental outcomes. However, it is also important to note that expats from lower socio-economic background usually do not move to the UAE with families. While the responses were rich in data and they reflected 'information power' (Malterud et al., 2016), and in-depth analysis was administered, it is important to note that only seven mothers managed to respond to follow up questions regarding pandemic related challenges. However, the novel context, sample size, and in-depth insights into systemic challenges and support structures of mothers with children with developmental disabilities are important strengths of the study. Given 88% of the population in the UAE are expats (Edarabia, 2021), these findings have implications for both policy and practice. Future studies could also explore the experiences of Emirati mothers with children with ASD, to understand experiences of the local population as well in the UAE. It

would also be beneficial to administer quantitative research to examine psychological health, pre-existing health conditions, and perceived social support for mothers in the UAE.

5. Conclusion

To our knowledge, this is the first study to explore support structures and challenges of expat mothers with children with ASD in the UAE. Information on primary caregivers' experiences help service providers and policymakers to identify key areas for change. The current study highlights the importance of support groups for parents of children with ASD. It appears that sharing common experiences may facilitate self-efficacy, personal strength, and effective coping mechanisms (Zhang et al., 2015). Whilst most mothers struggled a lot initially while shortlisting and approaching schools and therapeutic services, they appeared to be somewhat satisfied once they found a stable intervention. The research further emphasizes on the need for a centralized system where expat parents could access important information such as the availability of childcare and therapeutic services, and the process of admissions of children with ASD to mainstream schools. Awareness campaigns to increase autism knowledge in the public may promote greater inclusion and lower explicit biases and stigma against families with children with special needs (Jones et al., 2021). Such initiatives are also in line with the UAE's 2021 vision and national agenda of creating a more inclusive society (Cohesive Society and Preserved Identity, 2021).

Conflicts of interest: The Authors declare that there is no conflict of interest.

Contributions: NL and AT conceptualized and designed the study. AT played a major role in data acquisition. NL and AT analyzed the data and AR supported with summarizing key themes. NL wrote the discussion, edited, and finalized the manuscript. AK critically reviewed the final manuscript.

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