Unpacking Qualitative Methodology to Explore Experiences of Mothers with Children with Autism Spectrum Disorder in the UAE: A Thematic Analysis Inquiry

Nishtha Lamba[1] ⓘ, Angelique Van Tonder[2], and Archana Raghavan[3]

Abstract

The current study provides a detailed description of the qualitative research design and methodology, used while exploring challenges and support structures experienced by expat mothers of children with Autism Spectrum Disorder (ASD) in the United Arab Emirates. In-depth, face-to-face, semi-structured interviews were administered with 17 mothers recruited using purposive and snowball sampling. Recurrent and relevant themes were generated using thematic analysis. Given there is a greater need for highlighting methodological rigor in qualitative research, we discuss steps such as a) using field knowledge to create an interview protocol, b) administering collaborative qualitative research, c) having strong eligibility criteria for participants, d) incorporating perspectives of multiple coders in the analytical process, e) being reflective and aware of one's potential biases, f) enhancing interview protocol based on pilot interviews, g) and focusing on the quality of perspectives or information power instead of quantity of perspectives. Interpretation of findings and recommendation of evidence-informed guidelines incorporates strengths and limitations of the qualitative methodology utilized in the study.

Keywords

methods in qualitative inquiry, qualitative evaluation, mixed methods, community based research, interpretive description

Background

ASD is a developmental disability where children experience deficits in their social and communication skills, often combined with repetitive behaviors and other behavioral problems, making parenting extremely distressing (Kuhn & Carter, 2006). Parents of children with ASD face greater parenting stress (Hayes & Watson, 2013) and poorer family functioning than parents of children with other developmental disabilities (Al Khateeb et al., 2019; Cridland et al., 2014). Diagnosis is often delayed (Linnsand et al., 2021) and may lead to feelings of loss and failure as a parent (Ying et al., 2018). In addition, parents may also experience systemic challenges related to admissions to mainstream schools and streamlining therapeutic interventions.

Moreover, it has been noted that parents of children with ASD experience greater stress related to family functioning, parenting along with increased levels of financial stress when compared with typically developing children (Zeffane & Melhem, 2017). Mothers, often primary caregivers, experience greater psychological problems and often have to move away from their careers (Meadan et al., 2010; Riahi & Izadi–mazidi, 2012). Research further suggests that they lack support and may feel alienated from family and community (Solomon & Chung, 2012). Such issues often exasperate in expat or immigrant families, who must learn to navigate new social, cultural, and political structures.

[1]Middlesex University Dubai, Dubai, United Arab Emirates
[2]Ajyal International School, Abu Dhabi, United Arab Emirates
[3]Tata Institute of Social Sciences, Mumbai, India

Corresponding Author:
Nishtha Lamba, Psychology, Middlesex University Dubai, Block 16, Office 305, Dubai, United Arab Emirates.
Email: n.lamba@mdx.ac.ae

Eighty-eight percent of the population in the UAE are expats (Edarabia, 2021). While the government prioritizes support for children with special needs (Federal Law No. 29), the advancements are relatively recent compared to several countries in the West (Borsay, 2012; Kim et al., 2019). Therefore, with its aim to facilitate support for citizens and residents in the UAE, the government encourages research examining the effectiveness of laws and policies regarding families and children with special needs (Sheikh, 2015). However, there is little information about, both personal and systemic, support structures and challenges experienced by caregivers of children with special needs, especially from a qualitative perspective (Hussein & Taha, 2013; Shahrokhi et al., 2021; Sheikh, 2015).

Overall factors such as a) lack of knowledge about experiences of expat parents of children with ASD, b) limited research in the field of inclusive and special education, c) call for identification of areas of advancement and development in the field, and most importantly, and d) lack of information on protective factors for expat mothers who are likely to experience psychological problems and high parenting stress – inspired this research in the UAE.

Theoretical Positioning

A family-systems theory acknowledges the uniqueness of a family as an interactive and reactive unit, consisting of its own norms and values. Hodgetts et al., (2013) mention that family systems theory extends beyond immediate family and includes support structures from environmental factors. In line with the present study's context, previous research has shown that families with children with ASD experience high adjustment difficultiesCridland et al., 2014).

The experience of raising children with ASD depends on various support structures. Mothers with adequate social support have demonstrated to experience less stress and increased levels of optimism, leading to better family outcomes (Ekas et al., 2010; Zaidman-Zait et al., 2017). 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., 2021).

Cridland and colleagues (2014) further report that internal as well as external support provides caregivers with the opportunity to convey experiences, share emotional difficulties and receive support. This support ranges from social support from other parents with children with Autism to problem-solving skills and strategies along with adequate health and medical support.

However, seeking support and relying on support structures could differ due to cultural and socio-economic differences. Moreover, external factors as geographical location and internal factors such as ethnicity or education could also significantly impact a family's willingness to seek support services (Krakovich et al., 2016).

Overall lack of research in the field in the middle east, lack of information about experiences of expat mothers, and need for identifying challenges and support structures of families with children with ASD, inclusive of the pandemic related experiences, were primary research-based motivations of the authors.

The Present Study

Therefore, the primary aim is to explore experiences of support for expat mothers of children with ASD.

The aim of the study is to explore support structures and challenges experienced by expat mothers of children with ASD in the UAE (Lamba et al., 2022). The current article describes the rationale and methodology used to qualitatively analyze lived experiences of these mothers. Mothers shared their experiences of - parenting, help-seeking, diagnoses, schooling, support groups and community, in relation to their children's ASD. The materials used were interview domains designed using previous research studies that explored similar domains. The findings of the study can be used on a psychosocial and policy level.

Explanation and Justification of Method

Design: Qualitative analysis of semi-structured interviews

We utilized a qualitative approach to enable an in-depth understanding of lived experiences of mothers with children with ASD. The qualitative methodology requires participants to reflect on their experiences, embraces subjectivity and meaning-making within a specific socio-cultural context, and establishes 'truth' by using intersubjectivity (Biggerstaff, 2012; Howitt & Cramer, 2010; (Lazard & McAvoy, 2020). A well-researched qualitative study focuses on 'the understanding and explanation' of the dynamics of social relations (Queirós et al., 2017). Based on this principle, the core values of this research are structured around social relationships and the interactions between them. The methodology also supported the larger aim of the study as qualitative research studies are increasingly being used to inform policy guidelines and systems decisions (Lewin & Glenton, 2018).

Qualitative research is often administered in a natural setting, and unlike quantitative research, the researchers actively engage in the generation and analysis of detailed textual data. There are many data sources such as interviews, diary entries, focus groups, and observations. We used in-depth, semi-structured, face-to-face interviews in the current study to collect data.

Sampling/Recruitment

Participants were recruited with a combination of purposive and snowball sampling. We defined the target group and established the inclusion criteria. The interviewer (AT), being a special needs educator in the region, had immense field

knowledge and network, and initially approached two participants via email (purposive sampling). Afterwards, these two participants were requested to identify and approach mothers in their networks who would be willing and appropriate for the study (snowball sampling). Fifteen participants were successfully recruited using snowball sampling. They also approached a few prospective participants via social media. Phase 2 of the study was administered to explore participants' experiences during the pandemic.

Both purposive and snowball samplings are non-probability sampling techniques commonly used in qualitative research (Verma, 2019). In particular, snowball sampling facilitates the collection of data from "hidden", systematically marginalized, or vulnerable populations (Woodley & Lockard, 2016), this supported collection of data from otherwise 'hard to reach' participants in the current study.

Inclusion criteria. Key characteristics such as specific demographics and experienced-based attributes are often used in high-quality research to closely define the sample. In the current study, a strong eligibility criterion for participants facilitated a psychologically homogeneous sample (Robinson, 2014) and increased the internal and external validity of the research (Patino & Ferreira, 2018). Mothers who 1) had at least one child diagnosed with ASD, 2) were expats in the UAE, and 3) spoke basic communicative English were invited for participation. These characteristics were closely in line with the research objective. In particular, since expats or immigrants often have different challenges and support structures and may not have access to similar sources of information compared to individuals from the host cultures, we deemed it necessary to study their experiences separately.

Given the lack of similar previous research in the UAE, exploratory nature of the current study, and 'hard to reach' sample, we made sure that the inclusion criteria were not too restrictive but still facilitated external validity, greater homogeneity in the sample, and quality data collection (Golafshani, 2003).

Overall, 37 mothers were identified and approached for the study; however, 20 participants could not find time to participate, leading to a response rate of 46%. We anticipated a low response rate as mothers with children with ASD have extremely hectic schedules. It is possible that mothers who were extremely distressed could not find time to participate in the research. In addition, participants were not provided any incentives for participation. The final sample consisted of 17 mothers.

Qualitative researchers use a sample size that enables the creation of nuanced and insightful information (Biggerstaff, 2012). For the current study, a rather broad aim of the study, the feasibility of data collection, diversity of experiences shared by the participants, previous studies of similar designs, and choice of data analysis inspired the final sample size (Malterud et al., 2016; Onwuegbuzie & Leech, 2007a). Based on Onwuegbuzie and Leech (2007b) recommendation, we

ensured that a) the sample size was not too large that it became difficult to extract rich and meaningful themes and that b) the sample size was not too small that it became difficult to reach data saturation and achieve information power (Malterud et al., 2016).

It is also important to note that we observed a saturation of ideas after approximately 10 interviews concerning experiences with spouses and support groups; however, participants continued to showcase the diversity of experiences and share unique anecdotes about systemic challenges such as diagnoses of their children and experience with teachers and schools. Therefore, we continued data collection and interviewed all the mothers who accepted our invitation. We believe that the final sample size of 17 participants is sufficient to report frequencies and qualitative insights using thematic analysis.

The end of the initial phase of data collection overlapped with the start of the pandemic. To explore the experiences of participants in the context of the COVID-19 pandemic, we emailed follow-up questions, exploring challenges and support structures during the pandemic, to all the participants. Seven participants sent detailed responses of their experiences, leading to a response rate of 41%. Again, the researchers expected a lower response rate during participants' extremely busy schedules during the pandemic, however participants who responded to the questions offered detailed insights regarding their experiences. Therefore, despite a small sample size, a clear theme related to the pandemic emerged.

Other procedural insights. The interviews were administered in a private conference room of a hotel in Dubai. We wanted to ensure that participants felt comfortable in a secure and non-threatening environment. Open and noisy public spaces are discouraged for interviews of personal nature as they do not provide the participants with a 'relaxed and safe' environment that they may need to share their thoughts and feelings (Ecker, 2017; Elwood & Martin, 2000). The interviewer (AT) engaged them in informal conversations and ensured that the participants felt comfortable before starting the interview. The questions were communicated in simple spoken English as it was not the first language of several respondents. The interviews were conducted between March 2019 and August 2020 and ranged from 37 minutes to 110 minutes. At the end of each interview, participants were asked if they wanted to add anything that they felt might be relevant to the research. It allowed some participants to offer new information, which we may have missed during the interview.

After the first two interviews, NL and AT, re-evaluated the interviewer's (AT) positionality in relation to the research topic and identified potential weaknesses in the interview protocol. This step, often underutilized in qualitative research (Sampson, 2004), allows for methodological adjustments, strengthens the interview protocol, and enhances the quality of the research (Malmqvist et al., 2019). In fact, during the pilot stage, the first two participants also helped improve the

interview schedule by providing their inputs, supporting the integrated knowledge transmission model of research (Nguyen et al., 2020).

Given participants' enthusiasm for increasing awareness related to autism and the interviewer's personal and professional network as a special needs educator in the UAE, the findings will be disseminated in concerned schools and governmental institutions upon publishing.

Measures. We used semi-structured in-depth interviews to collect data as it provides opportunities for detailed probing and follow up questions. The interviewer (AT) included the participant's non-verbal behavior and tone of voice into her field notes which were later incorporated into the coding process.

The interview schedule was created based on our readings of previous literature and discussion on key factors associated with lived experiences of expat mothers with children with ASD in the UAE (see Appendix A). The questions tapped into the challenges experienced and the support structures available to the participants. Each section contained approximately 4–5 questions, related to:

A. Diagnosis (e.g., What were some of the early signs that you picked up?)
B. School system (e.g., Does your child receive additional support services in the school?)
C. Therapeutic services (e.g., Do you feel that some therapy services are more essential than others?)
D. Support from family and other structures (e.g., What was your family's reaction to the diagnosis of your child?),
E. Other life challenges (e.g., How do you prepare your child for new experiences?).
F. Experiences related to the pandemic (e.g., Please describe your experience of challenges of caregiving during the pandemic).

Participants were also asked to rate their satisfaction with diagnosis, schooling system, therapy, spouse, and support groups on a five-point rating scale ranging from 1 (very dissatisfied) to 5 (very satisfied).

Data Handling/Analysis

The audio recordings were transcribed verbatim, and the transcriptions were verified by the AT and NL.

Deciding on an Analytic Approach and Process of Analysis Chosen

The study adopted an inductive, bottom-up, data-driven approach to gain insight into participants' lived experiences (Potter & Wetherell, 1987; Priya & Dalal, 2016). The interviews were transcribed and then analyzed using Thematic Analysis (Braun & Clarke, 2006) to identify repetitive patterns and themes in the textual data collected from mothers with children with ASD in the UAE. Thematic analysis was selected as it is a flexible approach, offers theoretical independence, and searches for themes that concisely describe the phenomenon studied and its relations to the social context (Terry et al., 2017). Braun and Clarke (2006) highlight the importance of a researcher's judgment in identifying themes. We recognized a theme when it was repetitive and captured crucial points in relation to the research question. We included semantic and latent coding to incorporate explicit meanings such as frequent keywords and phrases and implicit meanings such as ideas within the coding process (Braun & Clarke, 2006). The data analysis involved a six-step process to ensure validity and reliability (Howitt & Cramer, 2010). The first step, familiarization with data, included getting familiar with the data by reading, repeated reading, and transcribing the data. The primary coder immersed herself in the data to ensure that they are familiar with the content. The second step included generation of initial codes relevant to the data.

We also calculated frequencies for each code to explain how many mothers experienced each phenomenon. We then categorized the codes into potential sub-themes. Clusters of sub-themes were identified as primary themes. We also generated a mind map (using simple post-its) with all the important codes and prospective primary and subthemes during this process. It helped us in visualizing all the themes as a team.

After that, we reviewed the themes. At this stage, we discarded codes that did not fit into any cluster of themes. It was an important step as we re-evaluated the importance of each theme in relation to the transcripts and the primary aim of the research study. We made sure that the final map truly reflected the data set (see Appendix B). It is important to note that during the process of analysis, we identified a few quotes that best explained participants' experiences. This was an extremely important step for us as we wanted to showcase mothers' feelings and concerns appropriately. The fifth step included naming all the sub-themes and primary themes using simple and self-explanatory terms. After that, we created a final thematic map. The final step included relating findings to literature and writing the report using frequencies and quotes.

Ethics

Information sheets were provided to the participants, highlighting the aims of the research study. Participants were asked for their consent before participating in the interviews. Interviewers were further informed about their rights as participants to withdraw at any point from the study. In summary, voluntary participation through consent was sought to also maintain the authenticity of the data collected.

Participants were also assured of anonymity and confidentiality. Interview transcripts although recorded were

anonymized through pseudonyms and only anonymized excerpts were used for publication. Direct or indirect identifiers were additionally removed when necessary. Moreover, if the data related to a particular category of a participant reveals information about the wider group that is considerably sensitive, those transcripts were condensed to maintain confidentiality.

As noted in literature, discussing struggles and experiences in relation to parenting a child with ASD can cause significant distress to parents due to the sensitivity of the subject. Participants were informed of how they were allowed to take breaks during the interview or refuse to answer a question asked. Furthermore, if participants did exhibit distress the interviewer would give the participants the time and space to feel better, enquire if they would like to proceed. If the participant expressed their concern and did not want to continue, the interviewer would conclude the formal interview, thank the participant for their time and provide debriefing information.

Dissemination

The findings from the study will only be used for academic purposes which include journal articles, conference presentations, and policy recommendations/proposals. The findings will be disseminated via summaries presented through infographics and power-point presentations. The key study findings will be summarized and presented to groups of educators, mental health professionals, parents, and caregivers in the United Arab Emirates.

These plans may be amended based on feedback from research advisories. Most importantly, interviewer's (AT) network as a special needs teacher in the UAE, is being utilized to further create awareness in the public via discourse and policy recommendations. Therefore, the authors (AT and NL) have created a workshop for parents of children with ASD, teacher assistants, and shadow teachers in the UAE, to highlight some of the concerns raised by mothers in the current study.

Rigor

We followed Lincoln and Guba's (1985) criteria of dependability, transferability, credibility and confirmability as essential factors to ensure rigor in a qualitative study. Protocols were developed for collecting data, refining proposed methods and analysis of findings. They explained that credibility of a study is determined when researchers or readers are confronted with the experience and when they recognize it. To ensure there was credibility in the current study, we engaged in multiple activities such as persistently observing the data collected, prolonged engagement with the data to familiarize ourselves with it, and lastly triangulating data with existing literature as well as researcher triangulation where two researchers attempted to analyze results and compare findings.

To maintain trustworthiness, we maintained reflexivity and rigor throughout the research process (Barrett et al., 2020; Barry et al., 1999). Dependability was another factor that researchers engaged in to ensure the research protocol was traceable, clearly documented, and logical. Additionally, reflexivity is central to the audit trail, therefore the primary researcher kept a self-critical account of the research process including their external and internal dialogue, daily logistics, rationales as well as methodological decisions and personal reflections of their values, insights and interests (Sandelowski, 1986)

To ensure transferability of the maintenance, analysis was designed in a manner that ensured generalizability. Thick descriptions were provided for themes that emerged so that future researchers can attempt to replicate the study protocol. Lastly, confirmability refers to the fact that the researcher's interpretation of the findings is clearly derived from data. Tobin & Begley, (2004) suggest that confirmability is usually met when credibility, transferability and dependability are achieved. Therefore, these processes were included for theoretical, analytical and methodological choices throughout the study to ensure others understood why and how decisions were made.

Sandelowski, (1986) mentions that a study and its findings are auditable when another researcher can clearly follow the decision trail made by the primary investigator. Therefore, 30 percent of the interviews ($n = 5$) were selected using a random number generator in excel and were coded by a second coder (NL). The inter-class correlation coefficient (average measure) was 0.7. Coding disagreements were then discussed to reach a mutual agreement. Themes were cross-checked by both coders (AT and NL), a process that systematically enhanced the "truth value", credibility, and overall trustworthiness of findings (Lincoln & Guba, 1985).

Lastly, peer scrutiny and debriefing were utilized, by reaching out to peers. The fresh perspective provided, helped the primary researchers to challenge earlier assumptions. Debriefing sessions amongst the researchers also took place to decrease researchers' bias.

Discussion

We explored support structures and challenges of expat mothers with children with ASD in the UAE (Lamba et al., 2022). Mothers' retrospective narrative suggests that they felt dissatisfied with medical professionals and extremely stressed during the process of diagnosis. Several mothers felt that either their child/ren was misdiagnosed, or the diagnosis was delayed. It was often delayed as symptoms of ASD could be confused with symptoms of comorbid impairments such as delayed language development. Mothers also narrated initial struggles of finding an appropriate school or therapeutic interventions for their child/ren with ASD. Given the mothers are expats, it is possible that initially, access to information related to interventions was scattered and unclear. Perhaps

limited inclusive staff across schools and healthcare settings in the region posed a systemic challenge, leading to often switching between healthcare professionals and schools, further increasing their financial and emotional stress. However, most reported feeling satisfied with therapy at the time of the interview.

Approximately half of the sample was not satisfied with the support they received from husbands. While most appreciated financial support, they wished for more emotional and instrumental support. Mothers also felt alienated from the community at large, and a few narrated experiences of negative comments or behaviors from family members such as grandparents and neurotypical siblings. Qualitative insights suggest that such experiences, unfortunately, perpetuate the feeling of feeling and staying 'invisible' in society.

Importantly, mothers felt extremely satisfied with support groups. Mothers shared their common experiences, empathized with each other, and exchanged key information regarding school admissions and therapeutic support. Previous research has shown that such experiences of belongingness facilitate self-efficacy, effective coping, and overall psychological well-being of participants (Ekas et al., 2010; Zhang et al., 2015). In addition, seven mothers shared their experiences with children with ASD during the pandemic. Children with ASD thrive on routine and predictability, however, uncertainty interrupted schooling and therapy, and lack of routine during the pandemic exacerbated the situation and contributed to violent and disruptive behaviors.

While answers related to the pandemic were rich and insightful, only seven mothers responded to follow-up questions related to the pandemic. It is also important to note that qualitative research does not necessarily include a highly representative sample and lacks the power of generalizability. The findings, however, showcase information power within the social context of the research. Steps described enhancing methodological rigor of the current study contributed to greater validity and trustworthiness in the findings.

Appendix A

Interview Protocol

Participant Information:
  Pseudonym:
  Age:
  Nationality:
  Profession:
  Number of children:
  Number of children diagnosed with ASD and their gender:
  Guidelines for Researcher:

- Turn on the recording device.
- Thank the participant for coming and for contribution to the study.
- Provide the participant with some information on the study (Provide Information Sheet).
- Assure the participant that their identity and the data that they will provide will be confidential and will be kept confidential.
- State that the participant has the right to pass a question if they wish not to answer.
- Inquire whether the participant has any further questions.
- Make sure that the participant signed the consent form prior to continuing the interview.

Consent (*Note whether verbal consent has been provided and whether the participant is aware of the aim of the research*)

1. Developmental History and Personal Information

How old was your child when he/she was diagnosed with Autism Spectrum Disorder?

Satisfaction Scale				
1	2	3	4	5

(*Prompt: Would you like to tell me about that day and what made you decide to seek support/diagnoses from a medical professional? Were you satisfied with the support that the medical professional provided you with?*)

What were some of the early signs that you picked up on that something wasn't quite right?

(*Prompt: Did you child/children start crawling later than other infants/toddlers their age? Did your child have limited vocabulary?*)

What does a typical day at home look like?

(*Prompt: Describe your morning routines to get the children up and ready for the day*)

Can you describe your relationship with your child?

(*Prompt: What makes them happy? How would you describe your child to others around you?*)

How do you communicate with you child?

(*Prompt: Do you use PECS? Do you use gestures? Do you use basic syntax and gestures?*)

2. Schooling

At what age did you child attend school/nursery?

(*Prompt: Was it easy to find a school in the community?*)

Do you think your child has a good relationship with his/her teacher?

(*Prompt: Can you describe this relationship? Does your child respond well to his/her teacher?*)

Did the teachers approach you to speak to you about your child's needs?

(*Prompt: Were the teachers and staff approachable and supportive when speaking to you?*)

Have you ever approached the class teacher to discuss any matters?

Satisfaction Scale

I	2	3	4	5

(Prompt: *Can you describe a particular event that comes to mind when thinking of your relationship with the teacher?*)

Does your child receive additional support services in the school?

(*Prompt: Does your child receive support from a shadow teacher or learning support?*)

Satisfaction Scale

I	2	3	4	5

What has your experience been like with these support services?

(*Prompt: Are you satisfied with the services provided by the school?*)

3. Therapeutic Centres

Does your child receive any type of support therapy?

(Prompt: Does your child receive ABA therapy/speech therapy/occupational therapy etc.?)

Let's talk about the support services and your experiences thus far.

(*Prompt: Are you pleased with the type of services available? Do you believe that there are services that are better/worse than others?*)

Do you feel that some therapy services are more essential than others?

(*Prompt: If you could give advice to other mums regarding therapy what would that be? What type of services do you feel are essential to the well-being of your child?*)

Satisfaction Scale

I	2	3	4	5

Do you believe that the services provided by the mentioned centre is beneficial to your child?

(*Prompt: Are you satisfied with the services provided by the centre?*)

Have you seen a significant difference in your child/children's ability/abilities compared to pre and post support services development?

(*Prompt: What are some of the differences you have noticed?*)

4. Relationships

Can you describe your family?

(*Prompt: Can you name the members in your immediate family? Can you name the members in your extended family?*)

If you think about your family, who do you think of?

(*Prompt: What do you think best describes your family?*)

What was your family's reaction to the diagnosis of your child?

(*Prompt: Did you feel that you were supported from the start?*)

What was your spouse's reaction to the diagnosis of your child?

(*Prompt: Did your husband seek a second opinion, did your husband provide you with support?*)

What do you consider your spouse's role in your family to be?

(*Prompt: How does your husband support you?*)

Satisfaction Scale

I	2	3	4	5

Can you describe the level of support that you get from your immediate family?

(*Prompt: How does your spouse support you?*)

And can you describe the level of support that you get from your extended family?

(*Prompt: How do they support you?*)

(If no) What kind of support do you think is needed from extended families?

(*Prompt: Helping with school pick-ups and drop offs or supporting with consistency in behavioural interventions etc.?*)

(If yes) Could you describe the similarities in the types support of the two family structures?

(*Prompt: Can you use some examples of how your immediate family and your extended family supports you?*)

Do you think that support from immediate family or extended family is important in families with special needs children?

(*Prompt: Why is support important in families that have SEN children?*)

5. Environment

What impact do you think home environment has on the well-being of your child?

(*Prompt: Do slight changes in plans upset your child and how do you deal with these changes?*)

How do you prepare your child for new experiences?

(*Prompt: Can you think of a time that you went on holiday or a time when you had to go on an errand?*)

What do you think are the neighbours or community's reaction towards your family?

(*Prompt: What do you think they feel when they see your family?*)

Do you feel that your community or your neighbours are supportive?

(*Prompt: What makes your community reliable? What does not make your community reliable?*)

Are you currently in a support group for mothers who have children with Autism Spectrum Disorder? How has this group supported you? Can you tell me about your experiences in this group?

Satisfaction Scale

I	2	3	4	5

(Prompt: Are you satisfied with the support you are receiving from the mothers in your group?)

6. COVID 19 Pandemic

Please describe (in detail) your experiences of challenges of caregiving during the pandemic.

Please describe (in detail) support structures available to you during the pandemic.

Is there anything else you would like to add?

Thank the participant for taking part in the research.

Additional Notes

Aspects that were mentioned by the participant that requires more probing:

Non-Verbal Communication and Observations by researcher:

Acknowledgments

The authors would like to thank all the mothers for their time and informing research practice in this field.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

ORCID iD

Nishtha Lamba https://orcid.org/0000-0003-2595-5076

Supplemental Material

Supplemental material for this article is available online.

References

Al Khateeb, J. M., Kaczmarek, L., & Al Hadidi, M. S. (2019). Parents' perceptions of raising children with autism spectrum disorders in the United States and Arab countries: A comparative review. *Autism*, *23*(7), 1645–1654. https://doi.org/10.1177/1362361319833929

Barrett, A., Kajamaa, A., & Johnston, J. (2020). How to be reflexive when conducting qualitative research. *The Clinical Teacher*, *17*(1), 9-12. https://doi.org/10.1111/tct.13133.

Barry, C. A., Britten, N., Barber, N., Bradley, C., & Stevenson, F. (1999). Using reflexivity to optimize teamwork in qualitative research. *Qualitative Health Research*, *9*(1), 26–44. https://doi.org/10.1177/104973299129121677

Biggerstaff, D. (2012). Qualitative research methods in psychology. In *Psychology: Selected papers* (pp. 175–206). INTECH.

Borsay, A. (2012). Disabled children and special education, 1944-1981. A presentation delivered at the Department for Education, 26 November 2012.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Cridland, E. K., Jones, S. C., Magee, C. A., & Caputi, P. (2014). Family-focused autism spectrum disorder research: A review of the utility of family systems approaches. *Autism*, *18*(3), 213–222. https://doi.org/10.1177/1362361312472261

Ecker, J. (2017). A reflexive inquiry on the effect of place on research interviews conducted with homeless and vulnerably housed individuals. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, *18*(1), 5. DEU. https://doi.org/10.17169/fqs-18.1.2706

Edarabia. (2021). Population of the UAE. Retrieved from https://www.edarabia.com/population-uae/. (Accessed on 20th May, 2021).

Ekas, N. V., Lickenbrock, D. M., & Whitman, T. L. (2010). Optimism, social support, and well-being in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *40*(10), 1274–1284. https://doi.org/10.1007/s10803-010-0986-y

Elwood, S. A., & Martin, D. G. (2000). Placing interviews: Location and scales of power in qualitative research. *The Professional Geographer*, *52*(4), 649–657. https://doi.org/10.1111/0033-0124.00253

Golafshani, N. (2003). Understanding reliability and validity in qualitative research. *The Qualitative Report*, *8*(4), 597–607. https://doi.org/10.46743/2160-3715/2003.1870

Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *43*(3), 629–642. https://doi.org/10.1007/s10803-012-1604-y

Hodgetts, S., Nicholas, D., Zwaigenbaum, L., & McConnell, D. (2013). Parents' and professionals' perceptions of family-centered care for children with autism spectrum disorder across service sectors. *Social Science & Medicine*, *96*, 138-146.

Howitt, D., & Cramer, D. (2010). *Introduction to qualitative methods in psychology*. Pearson Educacin.

Hussein, H., & Taha, G. R. (2013). Autism spectrum disorders: A review of the literature from Arab countries. *Middle East Current Psychiatry*, *20*(3), 106–116. https://doi.org/10.1097/01.xme.0000430433.49160.a4

Kim, E., Zhang, J., & Sun, X. (2019). Comparison of special education in the United States, Korea, and China. *International Journal of Special Education*, *33*(4), 796-814. https://files.eric.ed.gov/fulltext/EJ1219486.pdf.

Krakovich, T. M., McGrew, J. H., Yu, Y., & Ruble, L. A. (2016). Stress in parents of children with autism spectrum disorder: An exploration of demands and resources. *Journal of autism and developmental disorders*, *46*(6), 2042-2053.

Kuhn, J. C., & Carter, A. S. (2006). Maternal self-efficacy and associated parenting cognitions among mothers of children with autism. *American Journal of Orthopsychiatry*, *76*(4), 564–575. https://doi.org/10.1037/0002-9432.76.4.564

Lamba, N., Van Tonder, A., Shrivastava, A., & Raghavan, A. (2022). Exploring challenges and support structures of mothers with children with Autism Spectrum Disorder in the United Arab Emirates. *Research in Developmental Disabilities*, *120*, 104138. https://doi.org/10.1016/j.ridd.2021.104138

Lazard, L., & McAvoy, J. (2020). Doing reflexivity in psychological research: What's the point? What's the practice? *Qualitative Research in Psychology*, *17*(2), 159–177. https://doi.org/10.1080/14780887.2017.1400144

Lewin, S., & Glenton, C. (2018). Are we entering a new era for qualitative research? Using qualitative evidence to support guidance and guideline development by the world health organization. *International Journal for Equity in Health*, *17*(1), 1–5. https://doi.org/10.1186/s12939-018-0841-x

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Sage.

Linnsand, P., Gillberg, C., Nilses, Å., Hagberg, B., & Nygren, G. (2021). A high prevalence of autism spectrum disorder in preschool children in an immigrant, multiethnic population in Sweden: Challenges for health care. *Journal of Autism and Developmental Disorders*, *51*(2), 538–549. https://doi.org/10.1007/s10803-020-04563-8

Malmqvist, J., Hellberg, K., Möllås, G., Rose, R., & Shevlin, M. (2019). Conducting the pilot study: A neglected part of the research process? Methodological findings supporting the importance of piloting in qualitative research studies. *International Journal of Qualitative Methods*, *18*, 1609406919878341. https://doi.org/10.1177/1609406919878341

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research*, *26*(13), 1753–1760. https://doi.org/10.1177/1049732315617444

Meadan, H., Halle, J. W., & Ebata, A. T. (2010). Families with children who have autism spectrum disorders: Stress and support. *Exceptional Children*, *77*(1), 7–36. https://doi.org/10.1177/001440291007700101

Nguyen, T., Graham, I. D., Mrklas, K. J., Bowen, S., Cargo, M., Estabrooks, C. A., Kothari, A., Lavis, J., Macaulay, A. C., MacLeod, M., Phipps, D., Ramsden, V. R., Renfrew, M. J., Salsberg, J., & Wallerstein, N. (2020). How does integrated knowledge translation (IKT) compare to other collaborative research approaches to generating and translating knowledge? Learning from experts in the field. *Health Research Policy and Systems*, *18*(1), 1–20. https://doi.org/10.1186/s12961-020-0539-6

Onwuegbuzie, A. J., & Leech, N. L. (2007a). A call for qualitative power analyses. *Quality & Quantity*, *41*(1), 105–121. https://doi.org/10.1007/s11135-005-1098-1

Onwuegbuzie, A. J., & Leech, N. L. (2007b). Sampling designs in qualitative research: Making the sampling process more public. *Qualitative Report*, *12*(2), 238–254.

Patino, C. M., & Ferreira, J. C. (2018). Inclusion and exclusion criteria in research studies: Definitions and why they matter. *Jornal Brasileiro de Pneumologia*, *44*(2), 84–84. https://doi.org/10.1590/s1806-37562018000000088

Potter, J., & Wetherell, M. (1987). *Discourse and social psychology: Beyond attitudes and behaviour*. Sage.

Priya, K. R., & Dalal, A. K. (Eds.). (2016). *Qualitative research on illness, wellbeing and self-growth: Contemporary Indian perspectives*. Routledge.

Queirós, A., Faria, D., & Almeida, F. (2017). Strengths and limitations of qualitative and quantitative research methods. *European Journal of Education Studies*, *3*(9), 369-387. https://doi.org/10.5281/zenodo.887089.

Riahi, F., & Izadi–mazidi, S. (2012). Comparison between the mental health of mothers of children with autism and control group. *Iranian Journal of Psychiatry and Behavioral Sciences*, *6*(2), 91–95.

Robinson, O. C. (2014). Sampling in interview-based qualitative research: A theoretical and practical guide. *Qualitative Research in Psychology*, *11*(1), 25–41. https://doi.org/10.1080/14780887.2013.801543

Sampson, H. (2004). Navigating the waves: The usefulness of a pilot in qualitative research. *Qualitative Research*, *4*(3), 383–402. https://doi.org/10.1177/1468794104047236

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in nursing science*.

Schiller, V. F., Dorstyn, D. S., & Taylor, A. M. (2021). The protective role of social support sources and types against depression in caregivers: a meta-analysis. *Journal of Autism and Developmental Disorders*, *51*(4), 1304-1315.

Shahrokhi, H., Ghiasi, A., Gholipour, K., Fanid, L. M., Shamekhi, H. R., & Iezadi, S. (2021). Considerations about the implementation of an autism screening program in Iran from the viewpoints of

professionals and parents: A qualitative study. *BMC Psychiatry*, *21*(1), 1–16. https://doi.org/10.1186/s12888-021-03061-0

Sheikh, S. (2015). *Special educational needs provision in mainstream schools in Dubai – is it working? A review of the evidence and recommendations for further research*. Government of Dubai.

Solomon, A. H., & Chung, B. (2012). Understanding autism: How family therapists can support parents of children with autism spectrum disorders. *Family Process*, *51*(2), 250–264. https://doi.org/10.1111/j.1545-5300.2012.01399.x

Terry, G., Hayfield, N., Clarke, V., & Braun, V. (2017). Thematic analysis. *The SAGE Handbook of Qualitative Research in Psychology*, *2*, 17–37.

Tobin, G. A., & Begley, C. M. (2004). Methodological rigour within a qualitative framework. *Journal of advanced nursing*, *48*(4), 388-396.

Verma, J. P. (2019). *Statistics and research methods in psychology with excel*. Singapore: Springer.

Woodley, X. M., & Lockard, M. (2016). Womanism and snowball sampling: Engaging marginalized populations in holistic research. *The Qualitative Report*, *21*(2), 321–329. https://doi.org/10.46743/2160-3715/2016.2198

Ying, SC., Carter, M., & Stephenson, J. (2018). A systematic review of the comparative pragmatic differences in conversational skills of individuals with autism. *Autism & Developmental Language Impairments*, *3*, 2396941518803806.

Zaidman-Zait, A., Mirenda, P., Duku, E., Vaillancourt, T., Smith, I. M., Szatmari, P., & Thompson, A. (2017). Impact of personal and social resources on parenting stress in mothers of children with autism spectrum disorder. *Autism*, *21*(2), 155-166.

Zeffane, R., & Melhem, S. J. B. (2017). Trust, job satisfaction, perceived organizational performance and turnover intention: A public-private sector comparison in the United Arab Emirates. *Employee Relations*.

Zhang, W., Yan, T. T., Barriball, K. L., While, A. E., & Liu, X. H. (2015). Post-traumatic growth in mothers of children with autism: A phenomenological study. *Autism*, *19*(1), 29–37. https://doi.org/10.1177/1362361313509732