



# Autism in the Context of Humanitarian Emergency: The Lived Experiences of Syrian Refugee Mothers of Children on the Autism Spectrum

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## ABSTRACT

This study explored the resettlement experiences of Syrian refugees accessing supports and services for their autistic children in Alberta, Canada. Using interpretive phenomenological analysis (IPA), in-depth interviews with three participants led to seven shared themes regarding parental experiences with the Syrian crisis, access to supports and services, barriers to resettlement, and sentiments regarding their resettlement. Findings are explained using migrant adaptation models to situate practice within a social justice orientation by understanding the perspectives of vulnerable migrant populations. Practical implications include ways to benefit refugees, imbue culture within practice, inform policy initiatives, and highlight the importance of trauma-informed care.

## KEYWORDS

Syrian crisis; autism; Syrian refugees; resettlement; forced migration

## RÉSUMÉ

Cette étude a exploré les expériences de réinstallation de réfugiés syriens accédant à du soutien et à des services pour leurs enfants autistes en Alberta, au Canada. En recourant à l'analyse phénoménologique interprétative (IPA), les entretiens approfondis avec trois participants ont permis de dégager sept thèmes communs concernant les expériences parentales liées à la crise syrienne, l'accès aux aides et aux services, les obstacles à la réinstallation et les sentiments à l'égard de leur réinstallation. Les résultats sont interprétés à partir de modèles d'adaptation des migrants qui permettent de situer la pratique dans une perspective de justice sociale en comprenant les points de vue des populations migrantes vulnérables. Les implications pratiques comprennent des façons de faire bénéficier les réfugiés, de mettre la culture au cœur de la pratique, de guider les initiatives politiques et de souligner l'importance des soins tenant compte des traumatismes.

As one of the largest-scale humanitarian crises (Karim & Islam, 2016), the Syrian crisis has profoundly impacted the mental health of affected persons (A. Hassan, 2019). The crisis has induced trauma via violence and displacement, negatively impacting the social,

psychological, and life outcomes of Syrians (A. Hassan, 2019; Raslan et al., 2021). Canadian researchers have recently investigated the resettlement experiences of Syrian refugees, reporting tension between gratefulness and barriers to adaptation owing to dif-

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difficulties adjusting to social, socio-economic, linguistic, and cultural demands (Agrawal, 2019; Oudshoorn et al., 2020). Indeed, Syrian refugee children may experience challenges with their development and adjusting to the Canadian socio-cultural environment, while Syrian refugee parents may require support with parenting practices due to lack of familiarity with the new host country (CMAS, 2015). In addition, there are physical and mental health needs that Syrian refugees require but do not obtain as varied perception, language, and/or systemic barriers contribute to reduced support access (Tuck et al., 2019).

While research has been done on the resettlement experiences and barriers among Syrian refugees in Canada (e.g., Oudshoorn et al., 2020), little is known regarding the challenges encountered by Syrian refugee parents of children with developmental conditions, such as those on the autism spectrum. Indeed, parental trauma can influence children's social-emotional, language, and cognitive development (CMAS, 2015; UNHCR, 2015). Such an understanding of the lived experiences of Syrian refugee parents of autistic<sup>1</sup> children is important to inform culturally responsive practice (Brosinsky et al., 2018) and provide insight for optimizing support and acquiring services (Dababnah et al., 2019). Indeed, the traumatic impacts of war can exacerbate aspects of one's diagnostic presentation (Jabri, 2015) and complicate adaptive functioning among autistic children (Dababnah et al., 2019). For example, individuals on the autism spectrum may experience increased externalizing behaviours, social withdrawal, and rigid and repetitive behaviours and interests, as well as difficulty

copied with changes in routine (Dababnah et al., 2019; Jabri, 2015). Therefore, understanding how parents of autistic children interact with supports and services may inform their lived experiences following forced displacement.

Culturally responsive strategies are crucial given reports of increased mental health concerns (UNHCR, 2015) and impact on well-being (G. Hassan et al., 2016) that thwart academic and social functioning in autistic children (Çeri et al., 2018), a population already at risk for poor outcomes in these and other domains. Exploring the lived experiences of resettlement and support/service access among Syrian refugee parents of autistic children is important given that caregiving (e.g., parenting practices) is a significant part of their experience as migrants (Oudshoorn et al., 2020). Given identified barriers to service acquisition in Canada, bolstering culturally responsive practice and the types of supports and services available to refugees is crucial (Bhayana & Bhayana, 2018). Indeed, both culturally sensitive practice and trauma-informed care are important aspects to consider when servicing resettled refugees with multiple layers of vulnerability. Understanding parental experiences is important to autism service providers to provide effective care, to immigration agencies and policy-makers to promote migrant adaptation, and to educators to incorporate strategies to work with Syrian refugee autistic children and adolescents.

## SYRIAN REFUGEES AND AUTISM

Autism is a neurodevelopmental condition with a varying diagnostic presentation as outlined in the **Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision** (American Psychiatric Association [APA], 2022). Autism impacts approximately 1 in 44 children (Maenner et al., 2021),

<sup>1</sup>The terms **autistic**, **on the autism spectrum**, and **autism** will be used interchangeably in alignment with current perspectives on language and labelling and to respect the recommendations and views of self-advocates (Canadian Autism Spectrum Disorder Alliance, 2020; Kenny et al., 2016).

with a complex etiology and varying levels of behavioural presentation across the domains of social communication and restrictive and repetitive behaviours (APA, 2022).

Autistic Syrian refugee children are likely “to be forgotten” and are one of the “most vulnerable groups” (Jabri, 2015, p. 676) affected by the Syrian crisis. Research indicates that children with exceptional needs are at greater risk for further complications during war (Dababnah et al., 2019). Autistic children can experience clinical regression and/or manifest various additional internalizing and externalizing behaviours (Jabri, 2015) following the impact of “prolonged exposure to extreme trauma, stress, and uncertainty” (Raslan et al., 2021, p. 3). Additionally, asylum seeking can thwart adequate parenting/caregiving practices (Jabri, 2015) and adversely impact parental mental health, which influences responsive caregiving (Minhas et al., 2017). Research suggests Syrian refugee families of autistic children face heightened challenges, such as navigation of the health care system, comprehension of the diagnosis, language barriers, cultural disparities, rapport with professionals, and adherence to treatment (Moore et al., 2020).

## SIGNIFICANCE AND SOCIAL JUSTICE

**Cultural competence** refers to efficacious practice with diverse populations while being sensitive to their backgrounds (Song et al., 2019). Researchers have advocated for enhancing cultural competency to skillfully and effectively work with diverse groups of people (Papoudi et al., 2020). Indeed, Canadian practitioners have “an ethical and moral responsibility to engage in work that applies social justice and human rights frameworks” (Ritchie & Sinacore, 2020, p. 5). Many Syrian refugees endure adverse experiences (G. Hassan et al., 2016), service gaps (Hedar, 2017), and mental health risk factors (Raslan

et al., 2021); consideration of these can enhance cultural knowledge, awareness, and skills required to work with diverse groups responsively (see Song et al., 2019). Practitioners can, therefore, enhance their sensitivity towards Syrian refugees while attending to unique resettlement experiences. This project is the first to investigate the resettlement experiences of Syrian refugee parents accessing supports and/or services for their autistic children; its aims are to inform practice, and it was guided by the following research question: What is the lived experience of resettling in Alberta and accessing supports and/or services for Syrian refugee families with an autistic child?

## METHODOLOGY

This phenomenological study was conducted using a semi-structured interview with a guide (see Figure 1) that explored the resettlement experiences of refugee parents of autistic children, availability/acquisition of supports/services across their resettlement, and adjustment to Canada regarding the intersectionality between being a refugee and a parent of an autistic child(ren). Data were analyzed using interpretive phenomenological analysis (IPA; J. A. Smith et al., 2009), which explores the lived experiences of participants and how they attach meaning to those experiences.

### Data Collection

The data collection method deemed most appropriate for this study was semi-structured interviewing as it allows for in-depth, comprehensive, and rich accounts of participant experiences (J. A. Smith et al., 2009). Interviews consisted of open-ended questions to allow participants the opportunity to share their perspectives and experiences freely (Creswell & Creswell, 2018). Virtual interviews were conducted between February and

Figure 1

*Abbreviated Interview Topic Guide*

|                                  |   |
|----------------------------------|---|
| Overall Resettlement Experience  | <ul style="list-style-type: none"> <li>• Pre-migration experiences and migration journey</li> <li>• Resettlement experiences having an autistic child</li> <li>• Explore various aspects of resettlement</li> </ul>   |
| Supports and Services            | <ul style="list-style-type: none"> <li>• Experiences with perceptions towards autism</li> <li>• Explore supports/services available to participants before/during their migration and upon resettling</li> <li>• Navigating the systems and working with professionals</li> </ul> |
| Family Dynamics                  | <ul style="list-style-type: none"> <li>• Impacts of resettlement on child(ren) and family</li> <li>• Explore adjustment to Canada</li> <li>• Relationships with child and family upon resettling</li> </ul>   |
| Parent Perspectives on Servicing | <ul style="list-style-type: none"> <li>• Experiences of resettlement supports/services</li> <li>• Suggestions for professionals servicing Syrian refugee families of autistic children</li> <li>• Further optimal supports/services</li> </ul>                                    |

April 2021 via Zoom due to constraints from the COVID-19 pandemic and geographic distribution of the sample. Participants completed a single interview conducted in English and/or Arabic, depending on participant preferences. Interviews were between 90 and 120 minutes and were manually transcribed verbatim in both English and Arabic by the second and third authors.

The primary author shares an ethnicity and some Arabic competency with participants; however, a professional interpreter was hired to support the interview process for comprehensiveness. Based on potential gender-specific cultural preferences, a female interpreter was chosen to enhance participants' comfort (Attum et al., 2021). The use of interpreters aligns with the tenets of IPA, and this project adhered to cross-

language guidelines to maintain feasibility and methodological rigour (Chiumento et al., 2018; Croot et al., 2011). The English transcriptions were used for analysis, since interpreters take an active role in knowledge construction in phenomenology (Croot et al., 2011). The Arabic transcriptionist (author SN) was consulted to ensure the participant's perspectives were completely accounted for; however, confirming transcription veracity is in opposition to the ontological and epistemological underpinnings of IPA, which does not assert that a singular truth can be accessed, measured, and verified as "it is only possible to get as close to describing a phenomenon as language will allow" (Croot et al., 2011, p. 1009).

**Table 1***Demographics and Descriptions of Participants' Background*

| Participant | Area in Syria | Displacement journey | Area of resettlement | Year | Age bracket | Age of autistic child(ren) at arrival | Type of pre-migration supports/ services           | Available resettlement services   |
|-------------|---------------|----------------------|----------------------|------|-------------|---------------------------------------|--|---|
| Jenny       | Aleppo        | Lebanon              | Calgary              | 2019 | 40–49       | 6 & 13                                | Private schooling (eldest son only)                | Immigration services; schooling; in-home therapeutic support; clinical support; MRHC                                |
| Hannah      | Jaramana      | Not disclosed        | Calgary              | 2019 | 40–49       | 17                                    | Private schooling; in-home speech–language therapy | Immigration services; special education programming; in-home therapeutic support; service acquisition liaison; MRHC |
| Sam         | Daraa         | Egypt, Jordan        | Edmonton             | 2017 | 40–49       | 13/14                                 | None indicated                                     | Immigration services; special education programming; clinical support; English-language learning                    |

Note. MRHC = Mosaic Refugee Health Clinic.

## Participant Recruitment and Engagement

Participant recruitment was purposeful and occurred through community and participant referrals (snowballing) to ensure participants had experienced the phenomenon under study (Creswell & Poth, 2018). Referrals were made through community agencies and practitioners. Four participants expressed interest and were invited to the study; three met inclusion criteria of being a Syrian refugee parent of an autistic child who relocated to Alberta because of the Syrian crisis. Coincidentally, all three participants were mothers. Specific information for each participant appears in Table 1. According to J. A. Smith et al. (2009), a sample should consist of three to six participants to ensure in-depth exploration and analysis of participant experiences; this study's sample size was therefore adequate. In alignment with criteria set out by J. A. Smith (2011), in-depth interaction with resulting data and each of the participant experiences were accounted for by each theme. As outlined by Morse (2000), the narrow scope of the study as well as the nature of IPA methodology, including longer interviews rendering a large amount of useful data, were factors that influenced considerations for sample size. Participants described unique experiences of being mothers of child(ren) on the autism spectrum and with accessing supports and services before, during, and after their resettlement. They also offered insight regarding the Syrian crisis, resettlement barriers, perceptions of autism, and the implications of support and service availability for their children.

Participants were given English and Arabic copies of the consent document and interview questions before their involvement in the study began. Participants were informed of their ability to withdraw consent at any time prior to completion of data analysis and

were provided a small monetary compensation that was not contingent upon their participation.

## Data Analysis

IPA entails a systematic process of data collection and analysis following an inductive six-step process to conceptualize the data, identify key themes, and develop an interpretive account of the data through identifying patterns across participant experiences (J. A. Smith et al., 2009). Coding was done iteratively by the first author, with thematic samples discussed with the last author until agreement on the thematic structure was reached.

Participant data were anonymized with the use of self-selected pseudonyms prior to data analysis and were analyzed with NVivo12, a qualitative data analysis software. Research-informed qualitative methodological considerations were rigorously applied (e.g., Creswell & Poth, 2018; Fossey et al., 2002). Interpretations drawn from the data underwent member checking, prolonged engagement (broadening knowledge of a topic via multiple contexts), persistent observation (deepening investigation of relevant topics), and thick contextual description (meticulously detail observations and interpretations) during analysis to establish scientific rigour through trustworthiness and authenticity (see Amin et al., 2020). Extensive engagement with data and researcher reflexivity were practised to authentically embed results in the participants' worlds (Fossey et al., 2002). In line with Creswell and Creswell (2018), relevant personal experiences of the first author were documented (e.g., socio-cultural upbringing, religious background, and personal parenting experiences) to consider how these may influence interpretation of data. Engaging with the data over time ensured reflexivity

of the researcher's role as a social agent in knowledge co-construction to authentically embed the results.

Bridling (managing bias to facilitate researcher openness and understanding) was used to acknowledge preconceived notions and control their influence on the data and ensure the researcher did not "make definite what is indefinite" (Dahlberg, 2006, p. 16). One such strategy was through reflexive journaling to document biases, assumptions, and beliefs that emerged throughout data collection and analysis to minimize its effect on interpretation (Tufford & Newman, 2010). Linguistic Arabic interpretations were achieved via peer consultation. Further, Yardley's (2000) four elements of meritorious qualitative research (sensitivity to context, commitment and rigour, transparency and coherence, impact and importance) were adopted. More specifically, sensitivity to socio-cultural context through reflexivity, as well as a deep, thorough, and sophisticated exploration of the topic, were practised. This process bolstered authenticity of the results by accounting for multiple perspectives and realities. Trustworthiness was established from the clear data collection measures and how the research question corresponded to the selected measure. Further, the ontological (critical realism) and epistemological (contextualism) position of the primary author aligned with IPA as a method. Data were analyzed via "an iterative and inductive cycle" (J. A. Smith et al., 2009, p. 80) in congruence with literature guidelines.

After data analysis was completed, participants were invited to engage in virtual member checking; two responded to this invitation. In IPA, there is a concern around member checking because participants may view the results in a different context from their initial interviews, potentially influencing their agreement or disagreement (McGaha

& D'Urso, 2019). Consequently, member-checking feedback was integrated into the discussion rather than the results. This adaptation allowed the researcher to maintain congruency with IPA while ensuring that the interpretations accurately represented participants' intended meanings, which was crucial given the cross-language nature of this study. This study was granted ethical approval at the authors' affiliated university.

## RESULTS

Participants' experiences were analyzed to develop seven superordinate themes illustrating shared meaning and similarities (J. A. Smith et al., 2009). Given that pre- and post-migration experiences were explored with participants, the ordering of themes is temporal in nature. Although parents discussed their pre- and post-migration experiences within each theme, the general thematic structure begins with pre-migration experiences and then outlines crisis, general resettlement experiences, and specific experiences and sentiments associated with resettling in Canada as Syrian refugee parents of an autistic child(ren). The significance of this order translates to the theoretical frameworks that map pre- and post-migration experiences. A description and illustrative quotes are provided following the explanation of each theme.<sup>2</sup>

### Pre-Migration Impactful Perceptions

Participants experienced stigma, discrimination, and negative societal perceptions directed at their children both in Syria and throughout their displacement. These experiences contributed to negative treatment towards the children and discontentment

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<sup>2</sup>As noted, the interviews with the participants included use of a professional interpreter. Therefore, at times, the quote is the interpreter indicating (in English) what the participant said (in Arabic).

among parents regarding such treatment. Considering these pre-migration experiences and how parents navigated societal perceptions of autism upon their resettling is important. Parents experienced their children's societal rejection pre-migration: "They[re] dealt with in a very negative way. They're not accepted in the society" (Jenny).

There were instances of relational bullying, thwarting opportunities for social enrichment:

Even with family they would face people [who] would say stay away from them, take their kids away from the autistic kids. So, nobody plays with them. (Jenny)

A weird look. I feel like they are looking at him in a not normal way. Kids that don't understand him run away from him. They laugh at him. (Hannah)

Stigma towards the participants' children was clearly persistent and pervasive, which impacted access to support:

"I didn't want to go out at all. I wouldn't take them to anywhere because they [autistic children] were not welcomed in the society" (Jenny).

The prospects of Canada being less stigmatizing towards autism was a motivating aspect of resettlement and to secure access to supports/services:

She [Jenny] said, "Maybe God listen to us and to our need" because she and her husband kept thinking, "What's gonna happen to them [autistic children] when they grow older? [When] Mom and Dad pass. Those kids are gonna be left in the streets. Nobody's gonna take care of them."

Overall, participants expressed that societal perceptions and stigma were distressing experiences, resulting in either feelings of upset or future uncertainty.

### Crises Affecting Autism

Participants described the unprecedented impact of the Syrian crisis as disruptive for their child, which impacted parents' perceptions of their child's diagnostic complexity

and behavioural presentation. This theme represents how parental experiences of crisis affected their resettlement, access to support and services, and differing family needs for addressing lasting impacts of war. Participants' children were adversely impacted by the Syrian crisis, which was described to be "very dangerous" (Jenny), "horrible" (Sam), and filled with "atrocities" (Hannah). The crisis complicated existing services and supports for participants: "When the war started it [supports/services] went downhill" (Jenny).

The crisis contributed to experiences of trauma for the autistic children, and the impacts of the war were exacerbated due to their diagnostic presentation:

"He feels everything that surround him except he cannot express. So, he shows and demonstrates that anxiety in acting up and being nervous. And you can feel them, that they're not themselves" (Sam).

Parents felt that, in addition to autism, experiencing the Syrian crisis was part of the children's identity:

The Syrian kids, and especially the autistic. They really experienced real fear and scare from the war. ... They are not only autistic. Add to it the atrocities and what they went through in the war. (Hannah)

Participants described COVID-19 as an added barrier to acquisition of supports/services:

Everything was going smoothly till COVID happened and things stopped. (Jenny)

But this school, they don't have any activities because coronavirus. So, he [son] doesn't like this school. (Hannah)

In sum, the experiences of the Syrian Crisis and health and safety protocols related to COVID-19 have an impact on autistic Syrian children and, therefore, should be considered in the provision of supports and services.

## Day-to-Day Resettlement Difficulties

Participants experienced difficulties in their daily lives that posed challenges to their overall adjustment. This theme considers how constant difficulties, in many ways, impacted their ability to access supports and services pertaining to autism. These challenges included navigating systems (e.g., completing paperwork, commuting, finding accommodation, familiarizing with the health system), adapting to a novel society, finding employment, and facing language barriers.

The lack of language resources to navigate society and access supports and services for their autistic children impeded adjustment to life in Canada:

When we can't speak English, we can't speak and ask the doctor, go to the doctor, talk to him. Ask him about my son. Ask him to write reports about his case. Like this. So, everything you get in Canada is given for the language. (Sam)

Participants felt that resettling in Canada was novel, which initially hindered their adjustment:

"It took a year. It was very difficult in the first year. The whole system. It was using credit cards, the affairs, the language, the renting a place. Everything was new" (Hannah).

These day-to-day difficulties posed additional challenges for parents attempting to navigate services for their autistic children. In fact, one parent noted how support from English-speaking family members streamlined this process:

"The sisters had the command of the English language, so they were able to follow up with the appointments and everything and all the affairs" (Hannah).

Over time, however, participants felt they could adapt to living in Canada while having a child on the autism spectrum:

The first time we came, it's very difficult for us to know everything. So, we need someone to help us. ... Usually, the first thing for everything is very difficult. So, it's very difficult to move up from country to another country, another culture. ... For us, and for my children, [it] was very difficult. In the beginning [it] was very difficult. (Sam)

Obstacles in securing employment are, perhaps, exacerbated by other factors like limited language skills and the unfamiliarity of the Canadian job market, which pose additional barriers:

He [husband] tried to find the store to open, like, butcher halal meat, but he can't because like the rental is very expensive. The bills also is very expensive, so he can't open a new job or a new store for him. (Sam)

These barriers to everyday living impacted participants' adjustment, lifestyle, and daily living. They are important to consider in the context of raising autistic children, given that they impact family functioning and the resources available to implement supports and services for their children. Indeed, these are difficulties that refugees require ongoing support for.

## Positive Attributions

This theme addresses how positive parental attributions are associated with participant experiences involving both support services and the broader aspects of resettlement. Participants felt positive about resettlement in Canada and the available supports and services, including being happy in Canada, thankful, and satisfied with support and service provision; they also viewed resettlement as beneficial for their children's development. Increased access to autism-related services and fewer experiences with stigma in Canada contributed to a sense of happiness. Parents felt grateful for the opportunities afforded them, both related to their autistic children and otherwise, as well as their resettlement experiences in Canada:

They [Canadian society] are welcoming you. Doesn't matter that you have to pay money for that [supports/services] or the way you look or [where] you came from. The way they are dealing with us [is] in a very humane manner. This is making us, from inside, very happy. (Jenny)

It's very nice for me and for my family. We are very happy in Canada. ... We are very excited. We are very happy. This is, to come to Canada, it was my dream and thank God, that God would give me this a dream. (Sam)

Parents felt their autistic children benefited greatly from resettlement:

He [son] loved everything that is in Canada now. He loves everything. ... Those services contributed to this betterment of life. (Hannah)

They [children] enjoy all those services they are getting so, they look happier. (Jenny)

Parents were also grateful for the quality of supports and services provided to them in Canada:

What I found here is a beautiful country and a country that accommodated me and my son. He learned and picked up a lot of skills. ... The school was good, the teachers were good, the doctors were good, the professionals [were good]. (Sam)

The educational system in general is different here than it is in Syria. Even for [non-autistic] kids, not just for kids who have autism. So, he will for sure find a difference. As a child, he quickly acclimates, especially when he sees that here is 100% better than over there. (Hannah)

Their perspectives were due in part to the experience of their children receiving a drastic increase in care upon resettling:

If I had lived forever in Jordan and Syria, he wouldn't have got this kind of education. (Sam)

Here, she [Jenny] knows the kids are safe. They will be taken care of, so this is a big difference. They can see doctors, they can be examined, they can be checked. So, she's very happy that this is the situation. All of this did not exist in Lebanon.

Overall, despite areas of further need, participants were largely thankful for their re-

settlement experience in Canada and appreciated the supports and services available to their children.

## Support and Service Gaps

In contrast to the previous theme outlining how parents feel supported, this theme explores challenges parents experienced with pre- and post-migration support services. It also examines how the availability or lack of these supports and services is linked to their resettlement. Parents described a lack supports and services available during pre-migration and that their children's needs were not met. Participants expressed a sense of satisfaction with supports and services in Canada; however, several areas of further need were identified.

Participants lacked access to autism-related supports and services, both in Syria and during their displacement. In fact, access to supports and services were complicated by the "very dangerous life of war" (Jenny). The limited extent to which families accessed early intervention support is important for service providers to remain cognizant of during treatment planning:

They [society] didn't give the services because the society does not acknowledge those kids with needs—those children in need. (Sam)

Similarly, stigma towards autism may hinder parents' support- and service-seeking due to their feelings of being socially isolated in society. In Canada, participants identified additional areas of need, reflecting perceived gaps in supports and services. Parents expressed desire to address and fill these gaps. Jenny indicated her priority was centred around services for the whole family:

"So, no service as far as the whole family, but for the kids, they started with the paperwork and then they started receiving the benefits."

Difficulty accessing supports and services was, in part, due to barriers with scheduling appointments:

“They’re [professionals] good and everything, everybody in his work. However, it takes a long time to take an appointment” (Hannah).

Two participants yearned for vocational training opportunities for their children so they could make tangible contributions to society. Specifically, Sam indicated she would “love to see some specialized programs, where he [child] can pick up more skills, more skills that would enable [son’s name] to have a profession, to work. To be an active member of the society”.

Last, pre-migration experiences regarding the Syrian crisis are unique factors that impact autistic Syrian children. For example, Hannah indicated that, for her son, it may have been beneficial for professionals to “understand and work on his inner fears and inner worries.” Indeed, the impacts of crisis should be attended to when providing supports and services:

The service provided for the children here [should] take into consideration those children coming from war. So, this [war] gave them high anxiety and [the] language barrier here [in Canada] adds to that anxiety. They go to school, they deal with professionals whom they cannot communicate with. ... For those kids, [if they] would have an average teacher or professional who can communicate between the professionals and the kids, it might, at least at the beginning, ease up a little bit of that anxious barrier between the kids and the professionals and the new society. (Sam)

Although families were generally satisfied, gaps in supports and services needed to fully address their children’s needs remained. This partly owed to parents having little familiarity with the appropriate channels to acquire certain supports and services.

## Vital Relational Networks

This theme acknowledges the profound impact that the presence or absence of relational networks has on parental resettlement experiences. Parents mentioned the importance of social or family support systems to their resettlement. Resettling within existing familial or social networks or establishing such networks upon arrival helped alleviate certain challenges linked to resettlement. These relational networks were considered vital to participants as they contributed to positive resettlement experiences, skill development, and an overall sense of well-being:

I have many classmates from different countries. They helped me to accept other friends from different culture. I talked to them. They be my friends. I call them every time. It’s helped me. ... I need to speak with them. I need to speak English with them. I can’t speak Arabic with them. So, it helped me to improve my speaking. (Sam)

Parents noted that having relational supports is crucial to accessing supports and services for their autistic children:

He can understand if I go with him. ... He asked me what the teacher said, “What does the teacher say?” But when he was alone, he can’t understand the teacher. He can’t speak with his teacher. (Sam)

It was difficult a little bit when he came missing out on his friends; however, he really adjusted quickly ... because of the relationship he has with the sisters—and he loved everything that is in Canada now. He loves everything. (Hannah)

Alternatively, barriers to establishing a social network thwarted adjustment to Canada:

They [Hannah and her partner] did not have the enough time to make friendship with people, to get to know people so they can have friends. ... Because of COVID, they were deprived from the opportunity of making friends and knowing and meeting new people and this is leading for mom and dad to be bored at home.

In fact, the presence of a relational network offered comfort and familiarity regard-

less of whether direct support was provided for the autistic child:

Everybody's so much into his own business and his own affairs, so we did not receive any help from any of them. For us, it was nice to know that we have a family and there are families and so forth. (Jenny)

The presence of nuclear family members also provided a support system, which aided participants' adjustment to living in Canada. These were pivotal supports for their autistic children, contributing to positive interpersonal relationships:

Now they're closer to each other because they have no [extended] family, they only have each other. ... It is like the family is getting closer. The kids, mom, and dad are closer to each other, which is a positive change. (Sam)

Surprisingly, he [son] adapted quickly. ... The reason for that is his relationship with the sisters. He loves his sisters so much. He trusts them so much. (Hannah)

The absence of extended family members was a barrier to adjustment:

We left family behind; we left our life behind. So, actually we are struggling between those—we are happy when we see the kids—they have, you know, a life and they go to school. However, we miss home and family. (Jenny)

Indeed, parents' relational networks and their associated experiences illustrate the importance of family and social connections for resettled Syrian refugees. Importantly, the presence or absence of a relational network also influences both the family dynamic and access to supports and services for parents of autistic children.

### Cultural Importance and Relevance

Parents described their perceptions regarding the extent to which culture is significant and/or meaningful to them. These findings suggest that culture is nuanced in terms of permeating resettlement and perspectives

of supports and services for their children. For Jenny, shared human experience was more important than culture during service delivery:

"I have humanity to share with, not a culture. ... I'm like my kids, I have no preference, no difference between any culture."

Other participants indicated culture as important; however, they suggested that culture was imperceptible to their children and, so, not as relevant. This sentiment may reflect impairments with social communication as a key behavioural presentation of autism:

[Son] does not realize very much what a culture is and what is the difference of cultures. ... He doesn't have the capacity and the awareness of a [non-autistic] person about what is happening around him. So, he did not face this challenge, but for a [non-autistic] person—I don't know. ... So, maybe, he doesn't perceive or realize the big difference and when he came here, he just picked up the way he was taught and the education methods right away. ... A [non-autistic] kid would find a different cultural, educational system. (Hannah)

Based on participant experiences, the relevance and priority of culturally sensitive practice is contingent upon parents' perspectives of their child's diagnosis:

The cultural background of the child has to be taken care of—[taken] into consideration when dealing with him. Because we are people who are, you know, our traditions and our customs are very much part of our identity. (Sam)

There appear to be differences in the extent to which culture is relevant and important to Syrian families of children on the autism spectrum, based on each family's personal experiences and their perspectives of their child's awareness of culture. Just as culture is a complex construct, participants' experiences and perceptions of culture are nuanced.

## DISCUSSION

This study is an initial exploration into the lived experiences of resettlement and access to support and services among Syrian refugee parents of autistic children. It generated rich findings pertaining to various pre- and post-migration factors. These findings provide important context to the experiences of Syrian refugee parents regarding their overall resettlement as well as availability, acquisition, and provision of supports and services for their autistic children. They suggest important implications for consideration by autism service providers, immigration and resettlement agencies, educators, and policy-makers to reduce the plight of refugee families migrating with autistic children.

Consideration of the complexities, nuances, and experiences of minority and vulnerable populations was pivotal to this study. It is important to investigate refugee populations upon resettlement as research suggests greater mental health concerns arise from post-migration rather than pre-migration stressors (Slobodin et al., 2018). Investigating phenomena through participant voices allows for support and service co-construction and mobilization of knowledge that can contribute to practice, policy, and program shifts based on what participants say (J. A. Smith et al., 2009). This project situated parents as experts of their own experience to understand their current needs and bolster resettlement outcomes, especially pertaining to raising children on the autism spectrum, to inform practical implications. This project aimed to enhance knowledge regarding Syrian refugee resettlement in Canada while addressing the nature of supports and services for parents of autistic children.

This study identified several autism-specific (e.g., difficulties with application processes, lack of knowledge of existing programs) and general (e.g., transportation, language,

weather) barriers that impacted resettlement. Following an explanation of theories of refugee resettlement, the subsequent sections will connect this study's results to the broader literature to outline its scholarly contribution.

### Conceptual Frameworks in Refugee Resettlement

To investigate Syrian refugee resettlement experiences and refugees' psycho-social adjustment, Yohani et al. (2019) applied the RAISED Between Cultures model (Georgis et al., 2017) to consider the culture, pre- and post-migration factors, socialization, and influence of multiple environments on immigrant and refugee populations (Brosinsky et al., 2018). This model offers a thorough and applicable framework for understanding the challenges faced by Syrian refugee parents of autistic children and how policy-makers, service providers, and practitioners can attend to them. The six factors of this model will be applied to the findings of this study throughout the discussion.

In addition, the resource-based model of migrant adaptation, drawing on previous works (e.g., Berry, 1997), will also be used to discuss the present study's findings (Ryan et al., 2008). This model emphasizes migrant psychological well-being by describing **migrant adaptation** as a "process through which individuals seek to satisfy their needs, pursue their goals and manage demands encountered after relocating to a new society" (p. 7). Further, this model involves the dynamics of resource losses and gains, with **resources** referring to "the means by which individuals satisfy needs, pursue goals and manage demands" (p. 7). Individuals may experience resource fluctuation across migration stages, creating diverse demands that call for specific resource utilization, all aligned with individual objectives. For a com-

prehensive description of the resource-based model of migrant adaptation, see [Ryan et al. \(2008\)](#). Where appropriate, the RAISED Between Cultures model and resource-based model of migrant adaptation will be used to broadly elucidate and draw implications from the findings ([Georgis et al., 2017](#); [Ryan et al., 2008](#)).

### Attending to Pre- and Post-Migration Difficulties

Pre-migration experiences impact the behaviours, expectations, and understanding of what various social, education, and specialized services consist of ([Georgis et al. \(2017\)](#)). Participants noted a lack of available pre-migration supports and services for their children, which influenced their satisfaction and appreciation upon resettling in Canada. Participants indicated their children's diagnostic behavioural presentation was adversely impacted by the war, echoing previous findings suggesting that autistic individuals are at a higher risk for co-occurring conditions and exacerbated behavioural presentations after experiencing traumatic and/or negative life events ([Dababnah et al., 2019](#); [Jabri, 2015](#)). Research findings have also suggested adverse impacts of stigma on parents and their autistic children ([Broady et al., 2017](#)), which extends to participant experiences in the present study. That is, parents experienced stigma and a lack of resources pre-migration, which contributed to their appreciation of supports and services available in Canada. The amount, duration, and type of care parents received pre-migration are important factors to consider when gauging methods of best practice. According to [Ryan et al. \(2008\)](#), considering the demands, loss in resources, and specific needs among refugees is important to enhance adaptation outcomes.

Post-migration barriers can negatively impact well-being among parents and children and reduce collaboration between home, school, and services ([Georgis et al., 2017](#)). This study identified several resettlement barriers resembling previous findings, such as language, transportation, and social isolation (e.g., [Agrawal, 2019](#); [Oudshoorn et al., 2020](#)), as well as unique barriers to support and service acquisition for autistic children and their families (lack of knowledge of specialized programming, lack of vocational opportunities, unfamiliarity with service application processes, lack of autism-specific trauma-informed care). Although participants spoke about their general resettlement experiences, parenting autistic children is an added stressor that can further complicate day-to-day resettlement barriers. In line with [Ryan et al.'s study \(2008\)](#), our findings indicate that resettling with an autistic child may lead to a loss of personal resources (e.g., psychological, physiological) and increased demands (e.g., higher levels of caregiving resources required, certain pre-migration adversities) that occur alongside resource gains associated with the availability of supports and services. Further, these stressors can complicate support and service acquisition for parents who do not have established information or relational networks. Indeed, general resettlement experiences also impact the experiences of parents resettling as it pertains to their autistic children. These factors interact with their family system and subsequently affect the children, as suggested by the (bio)ecological systems theory ([Bronfenbrenner & Ceci, 1994](#)). For example, language barriers can influence one's ability to access, understand, and implement supports and services; transportation barriers can impact one's ability to attend service appointments and other supports crucial to a child's development; and social

isolation can contribute to having less of the understanding required to navigate systems pertaining to autism-related supports and services, to optimize parental well-being to best support children, and to secure enriching social opportunities for children. As such, attending to pre- and post-migration experiences, support needs, service gaps, co-occurring mental health concerns, and cultural perspectives in an individualized way is important when collaborating with families.

### **Migrant Satisfaction and Provision of Care**

This study's findings resembled literature in which participants expressed positive experiences with resettlement, viewed Canada as fated or a blessing, and decided to move to Canada for increased opportunities for their children (e.g., Agrawal, 2019). Participants reported positive resettlement experiences, highlighting improved quality of life, established routines, and family satisfaction with children's skill development. A focal point of parent satisfaction was the availability of beneficial supports and services for autistic children, which were lacking in Syria and during their displacement. Parents felt the increase in autism-related supports and services contributed to their children's enhanced functioning, skill development, and learning opportunities. These benefits positively impacted parents' resettlement experiences as their children had more opportunities for enrichment, formalized schooling, and targeted skill development. To further support Syrian refugee families, both common goals and collaborative support structures need to be established, as these are pivotal to child adjustment (Georgis et al., 2017).

Participants also described how the presence or absence of relational networks im-

acted their resettlement. The importance of such supports has been outlined in research (e.g., Alon, 2019). This study's findings resemble those of previous research, suggesting that family, social, and community supports are pivotal to positive resettlement experiences. For refugees of autistic children, relational networks may be of utmost importance given the added demands of parenting a child on the spectrum.

### **Considerations for Culture Upon Resettlement**

It is important that service providers and educators consider Syrian refugee families' actions, beliefs, and values. Providing culturally sensitive care increases newcomer families' satisfaction; however, given the nuance of how participants viewed culture and whether it should be imbued in supports and services, it is important to explore specific sentiments on an individual basis. Differences in how culture was perceived was based on participants' previous experiences with stigma as well as their perceptions of whether their children had cultural awareness as part of their diagnostic presentation. Nonetheless, bridging the gap between minority children's cultural environments serves as a protective factor for these children by establishing a strong bicultural identity and ensuring that their culture is valued and they do not feel othered (Georgis et al., 2017). Encouraging families to maintain their cultural identity, practices, and beliefs is crucial (Yohani et al., 2019). Participants in this study had diverse perspectives on the interrelations between their culture and Canadian culture. As suggested by this study's findings, participants found it difficult to conceptualize their child's cultural self if they were not attuned to behaviours indicative of cultural experience in their children. However, refugees' existing cultural resources (e.g., linguistic

and occupational skills, cultural knowledge) can serve to constrain or provide “adaptive value” to their post-migration context (Ryan et al., 2008, p. 13). In addition, the results of the study suggest that parents’ views regarding the value of culturally sensitive services are relative to and contingent upon their children’s specific developmental differences and autism-related behaviours. It is important for practitioners to explore refugees’ understanding of culture and their expectations of support and services based on cultural views, as well as their perspectives regarding the intersectionality between autism and culture in their children.

### Promoting Migrant Adaptation and Child Developmental Outcomes

As this study’s findings suggest, families of autistic children have unique resettlement experiences, including stressors and barriers. Therefore, as suggested by Ryan et al. (2008), professionals (e.g., service providers, educators, and policy-makers) may attend to specific resources that families gain or lose upon resettlement. For example, capitalizing on the resource strengths of refugee families is important as those strengths have certain levels of adaptive value (Ryan et al., 2008). Georgis et al. (2017) indicated several strengths that migrant families contribute to their children’s outcomes, including resilience, multilingualism, culture, and family relationships. In line with the present results, relational networks are crucial to adjustment outcomes as they are a strength that migrant families resettle with Yohani et al. (2019). Language also serves as a strength by acting as a vessel for cultural knowledge and facilitating connections between a child and their family and community (Georgis et al., 2017). Therefore, educators, service providers, policy-makers, and practitioners may provide opportunities for refugee families to establish connections

with others through support groups and community events and to facilitate relationships with others in their first language. Establishing relational networks pertaining to the needs of the family in the context of their autistic child may be pivotal to ensuring appropriate care. Indeed, a lack of English-language competency can be a resource loss that can thwart adaptation outcomes in a Canadian socio-cultural environment (Ryan et al., 2008). In addition, limited English proficiency can complicate access to autism-specific supports and services, contributing to barriers to navigating associated systems. As a result, migration agencies must crucially prioritize enhancing English-language learning for the entire family while advocating for retention of the family’s first language to optimize the child’s developmental outcomes.

### Practical Implications

Creating opportunities for gaining a social network through support groups can establish relational and informal information-sharing among Syrian refugee parents of autistic children. Such groups have a host of benefits, such as increased knowledge of autism, psychoeducation, and problem-solving skills (Banach & Couse, 2012). Volunteering opportunities and pre-migration orientations are also crucial to refugee resettlement outcomes (Abid, 2020) and may increase parents’ informal understanding of support and service provision. Such volunteering opportunities may be specific to autism (e.g., not-for-profit organizations, autism awareness events) or community based (e.g., festivals, events, support groups, immigration organizations). Moreover, many refugees noted difficulties navigating the system to access support and services for their children. Therefore, policy initiatives (e.g., migration orientations) that support

refugees with application processes and securing supports at a systemic level may reduce some of the post-migration barriers that refugees face.

Additionally, some participants perceived their autistic children to be disproportionately affected by the impacts of the Syrian crisis due to their existing autism diagnosis. Given that they outlined the importance of more trauma-informed care, adapting established strategies such as trauma-informed interventions designed for autistic Syrian refugee children is crucial (see [Dababnah et al., 2019](#)). Policy-makers and practitioners may consider designing psychoeducational groups to teach behavioural strategies and facilitate social support for refugees ([Dababnah et al., 2019](#)).

Moreover, culture greatly influences both the presentation of autism ([Dababnah et al., 2019](#)) and how mental health concerns manifest ([Kirmayer & Jarvis, 2019](#)). Embedding cultural modifications into practice as well as capitalizing on identified strengths and coping mechanisms of refugees can be beneficial ([Gruner et al., 2020](#)). It is crucial that practitioners and educators attend to “culturally shaped expectations and behaviours” and collaborate with parents to optimize support/service provision to autistic children ([Yohani et al., 2019](#), p. 20).

Last, the results of this study may inform contributions to policy for refugee families and children on the autism spectrum. The following recommendations are, in part, gleaned from the [Autism Alliance of Canada \(2021\)](#) Policy Compendium and adapted to fit the results of this study. Indeed, to better understand the intersectionality between refugees and autism as well as promote social inclusion, professional development opportunities for immigration and resettlement agencies on autism and autism-related supports and services may better equip staff

to help families navigate complicated systems. Similarly, opportunities for autism service providers to learn about the pre- and post-migration experiences of refugees may enhance quality of care by informing their approach to practice. Next, service providers, community agencies, and educators may support autistic refugee children and their families with accessing mental health information by “using existing infrastructure to provide mental health information and resources for Autistic Canadians” ([Autism Alliance of Canada, 2021](#), p. 20). Such resources include the [Autism Mental Health Literacy Project Group’s](#) mental health literacy guide (2021). Community agencies or private practices may spearhead capacity-building initiatives that partner diverse stakeholders, including refugees, community leaders, and service providers to develop outreach programs that aim to create culturally sensitive services and reduce barriers (e.g., language, understanding autism, and navigating systems) to accessing government-funded supports. Overall, consideration of Syrian refugees’ pre- and post-migration experiences is significant in the development of psychoeducational resources and could inform policy-makers, support and service providers, and settlement agencies about ways to support refugees’ process of adapting to Canada.

## Limitations and Future Directions

Utilizing interpreters in cross-language research is compatible with phenomenology ([Chimento et al., 2018](#); [Croot et al., 2011](#)). This approach offers several advantages, including the opportunity for linguistic minorities to address practices that impact them ([Squires et al., 2020](#)); however, the use of interpreters remains contentious (e.g., [Squires, 2009](#)). Although the authors adhered to guidelines to establish rigour in

this cross-language study, certain limitations remain.

The researchers' lack of linguistic competency to conduct academic projects in a minority language may contribute to a power imbalance, especially when a language liaison is present (Cormier, 2018). In this study, the interpreter was not a member of the research team, which limited additional opportunities for consultation due to considerable financial implications. Future research may consider additional consultative sessions in the budget.

Researcher bias is important to attend to in qualitative research. In line with literature guidelines, the primary author adopted reflexivity (J. A. Smith et al., 2009) and bridling (Dahlberg, 2006) to ensure interpretations were authentically represented. While essential measures were implemented to reduce bias, eliminating it in qualitative research is unattainable and should be "acknowledged as a limitation in all types of research" (Roberts & Priest, 2006, p. 45). Despite following guidelines by J. A. Smith et al. (2009), sampling biases are acknowledged: the sample consisted of a small subset of refugees, there were temporal constraints on participants migrating between 2017 and 2019, and limited opportunities were available for recruitment given this niche population. Indeed, the time frame of refugee resettlement may alter their lived experiences in accessing supports and services. However, the study's small sample size and detailed interviews are strengths that provide rich insights (B. Smith, 2018). Generalizability isn't a focus, as not all qualitative studies aim for it (B. Smith, 2018). Instead, the study offers context, observations, and participant quotes for readers to connect with.

As this study unfolded, it revealed existing gaps in the literature, which may benefit from future exploration. First, although the

present study investigated experiences of mothers of autistic children, future research should consider investigating fathers' experiences as well as those of the autistic Syrian refugee population to discern how they make sense of accessing supports and services. Researchers should also investigate the resettlement experiences of autistic Syrian refugee adults given that adults tend to receive less supports and services than youth and are relatively under-represented in research (Howlin & Moss, 2012). Future research may also consider investigating the understanding of autism among refugees as it pertains to how they access, use, and provide supports to their children.

## CONCLUSION

This project examined the lived experiences of Syrian refugee parents of autistic children regarding their resettlement in Alberta. Participants described supports and barriers to resettlement, their perspectives on incorporating culture in services for their children, pre-migration impacts, and the influence of migration on their autistic children as well as the services available to them. Accounting for these experiences is crucial for developing strategies that best serve autistic Syrian refugees and their families. Canada offers annual asylum to refugees; increasing international conflict will contribute to ongoing influxes in refugee resettlement in Canada (Ghahari et al., 2020). Therefore, policy-makers may consider the unique experiences of refugees who migrate with children who have developmental conditions such as autism.

Our results have the potential to benefit Syrian refugees as well as other migrant populations by providing an understanding of minority perspectives, an investigation of pre- and post-migration experiences, amplification of the voices of Syrian refugee parents of autistic children, and key impli-

cations for professionals to incorporate into practice. Syrian refugees are an important part of Canada's diverse mosaic, and this project aspired to enhance their resettlement outcomes as well as encourage future research to support refugees migrating with children with developmental conditions. Further research can support the integration of multiply vulnerable refugee populations into Canadian society via access to supports and services that enhance adjustment and developmental outcomes.

## AUTHOR NOTE

This paper is based on the unpublished master's thesis of Abdullah Bernier through the University of Calgary. Therefore, any overlap in content is owed to the same participants, results, and overall study design.

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