

# Exploring Autism, Culture, and Immigrant Experiences: Lessons from Sri Lankan Tamil Mothers

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## Autisme, culture et expériences d'immigration: les leçons de mères Tamoules du Sri Lanka

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**Key words:** Autism spectrum disorder; Cultural competency; Sri Lankan-Tamil; Occupational therapy; Parents.

**Mots-clés :** Compétence culturelle ; ergothérapie ; parents ; Tamouls du Sri Lanka ; trouble du spectre de l'autisme.

### Abstract

**Background:** Canada is home to a mosaic of cultures with immigrant communities from a wide range of countries, but there are significant variations in how autism spectrum disorder (ASD) may be understood across different immigrant groups, including Sri Lankan Tamils. Such gaps in knowledge may present challenges for immigrant families that are trying to access appropriate care for their child, including occupational therapy services. **Purpose:** This descriptive qualitative study aimed to better understand the experiences of immigrant Sri Lankan Tamil parents of children diagnosed with ASD in Southern Ontario, Canada. **Method:** Interviews were analyzed using an in-depth content analysis. **Findings:** Results demonstrated parents' perceived supports and barriers towards ASD intervention planning, and indicated that parents were generally satisfied by the level of cultural competence in current ASD systems. However, families may still experience significant immigrant-related barriers that are not fully addressed. **Implications:** Recommendations to improve cultural awareness among occupational therapists utilizing ASD interventions are suggested.

### Résumé

**Description:** Le Canada comporte une mosaïque de cultures, avec des communautés immigrantes d'une grande diversité de pays, mais il existe des variations importantes dans la manière dont le trouble du spectre de l'autisme (TSA) est compris entre les groupes d'immigrants, dont les Tamouls du Sri Lanka. De tels écarts dans les connaissances peuvent poser des défis aux familles immigrantes qui tentent d'accéder à des soins appropriés pour leurs enfants, y compris des services d'ergothérapie. **But:** Cette étude qualitative descriptive réalisée dans le sud de l'Ontario, au Canada, vise à mieux comprendre l'expérience des parents immigrants d'origine tamoule du Sri Lanka dont les enfants ont reçu un diagnostic de TSA. **Méthodologie:** Les entrevues ont fait l'objet d'une analyse de contenu approfondie. **Résultats:** Les résultats font état des obstacles et des éléments favorables à la planification de l'intervention en TSA selon la perspective des parents, et indiquent que ceux-ci sont généralement satisfaits du niveau de compétence culturelle dans les systèmes actuels. Cependant, les familles peuvent faire face à des obstacles importants liés à l'immigration qui ne sont pas pleinement pris en compte. **Conséquences:** Des recommandations pour améliorer la sensibilité culturelle des ergothérapeutes qui interviennent en TSA sont suggérées.

**Funding:** The authors received no financial support for the research, authorship, and/or publication of this article.

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## Introduction

In Canada, approximately one in 66 children and youth (aged 5–17 years) is diagnosed with autism spectrum disorder (ASD) (Public Health Agency of Canada, 2018). According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), ASD refers to a group of conditions characterized by specific impairments or difficulties in the social use of verbal and non-verbal communication, social interaction, and/or restrictive and repetitive behaviors (American Psychiatric Association, 2013). Challenges in ASD research are heterogeneous and complex since individuals within this group have a wide range of abilities and needs; however, there continue to be overall gaps in ASD research regarding what is examined beyond the Western scope of practice (Amaral et al., 2019; Welterlin & Larue, 2007).

Although early intervention has been shown to provide benefits for children diagnosed with ASD, such health services and supports require equitable access to services (Centers for Disease Control & Prevention, 2019; Rudra et al., 2014; Sritharan & Koola, 2019). Typical challenges for families with a child diagnosed with ASD include lengthy waiting periods for diagnosis, number of visits required for various health service providers, navigation of services, difficulties in obtaining information on ASD and interventions, and a lack of collaboration among healthcare providers (Hutton & Caron, 2005; Jegatheesan et al., 2010; Schall, 2000; Sritharan & Koola, 2019). These challenges may be considerably more difficult for families from minority backgrounds, especially immigrants, who may face various sociocultural barriers when accessing ASD services, including socioeconomic, language, ethnic, and/or religious barriers (Abdullahi et al., 2018; Sritharan & Koola, 2019).

ASD affects all ethnic and racial groups; however, there can be global and cross-cultural differences in how symptoms for ASD are diagnosed (CDC, 2018). Culture—a pattern of ideas, customs, ideologies, and behaviors shared by a group of people or society—can oftentimes be labeled as a barrier for families with a child diagnosed with ASD (Kang-Yi et al., 2018; Keesing, 1974; Raghavan & Waseem, 2007). Perceptions of disability can vary across cultures either by the method of “treatment” that caretakers choose for their child (i.e., alternative medicine) or in the ways in which caretakers overall perceive the term “disability” (i.e., viewing disability as a gift from God, or viewing disability as karma for a past sin) (Jegatheesan et al., 2010; Kang-Yi et al., 2018; Lai & Surood, 2009). When immigrant families are exposed to differences between their original and other cultures in their “new” country through social systems, relationships, and networks, they may create hybridized perspectives of autism, building new webs of cultural beliefs and practices that can adapt to both cultural and Western systems of thought (Kang-Yi et al., 2018).

According to the 2016 Canadian Census, more than one in five Canadians are foreign-born, with Canada being home to one of the largest Sri Lankan Tamil diaspora in the Western world (Sriskandarajah, 2005; Statistics Canada, 2016). Many of these individuals fled to Canada since the 1980s, as a

result of the civil war and on-going ethnic tensions in Sri Lanka (Sriskandarajah, 2005). There is a lack of literature that explores the different cultural challenges that these individuals have faced since coming to Canada, especially parents who thereafter, also have a child with a diagnosis of ASD (Sritharan & Koola, 2019).

Beyond the gaps in ASD knowledge that can exist among the Tamil diaspora communities, there is also a lack of published literature examining the experiences of Sri Lankan parents navigating an ASD diagnosis for their child in their home country (Mahagamage et al., 2021). Although it is said that one in 93 children in Sri Lanka is diagnosed with ASD, the knowledge of this diagnosis among families is limited (Perera et al., 2009). Based on research that has been conducted in Sri Lanka regarding ASD and the attitudes among healthcare practitioners, there are misconceptions and general unawareness about issues such as appropriate screening measures and common associations of ASD (Rohanachandra et al., 2017; Rohanachandra et al., 2020). When such information varies across healthcare practitioners, these gaps can also provide some indication of the level of ASD knowledge in different communities in Sri Lanka, but also with what knowledge can transcend across generations and what is carried by those who leave the country.

Parents often go through many obstacles to better understand their child’s diagnosis, especially if they lack knowledge about ASD overall (Gentles et al., 2019). After receiving an ASD diagnosis, occupational therapy is one of the most sought-after services by parents (Gibbs, 2017). Occupational therapists play important roles by helping parents better understand the impact of ASD on their child’s development, and assist with age-appropriate occupational issues (Ashburner et al., 2014; Gibbs, 2017). As occupational therapy is grounded in a client-centered philosophy, it is imperative that practitioners prioritize cultural sensitivity and awareness to promote effective practice (Grandpierre et al., 2018; Suarez-Balcazar et al., 2009).

Campinha-Bacote (2002) describes one model of cultural competence, outlining potential tensions that may arise between healthcare providers and culturally diverse families when working towards improving health outcomes. The professional may face barriers when suggesting advice to families of varying cultural beliefs. Immigrant families with different belief systems and customs may struggle to balance their cultural upbringing with their Western environment (Campinha-Bacote, 2002). A lack of cultural competency can create a number of potential barriers in the relationship between the therapist and the parent, such as preventing parents from being able to communicate openly with health service providers and impacting compliance with care recommendations; creating an environment of distrust; and increasing the number of unmet needs of the child and family (Govender et al., 2017; King et al., 2011; Scoles, 2020).

This descriptive qualitative study aimed to describe and better understand the immigrant Sri Lankan-Canadian parent experience when navigating culture, their child’s ASD diagnosis, and Canadian ASD interventions, with specific relevance to occupational therapy. This work focuses specifically on the

experiences of parents that utilize a culturally responsive organization for ASD services based in Scarborough, Ontario.

## Methodology

This report is a descriptive qualitative study that utilized semi-structured interviews and an in-depth content analysis. This study was conducted in Scarborough, Ontario at the SAAAC Autism Centre, where most participating families are of South Asian (primarily Sri Lankan Tamil) descent.

### Interview Procedure & Participant

Based on the topics presented in the current literature on autism and cultures, specific but open-ended interview questions were devised that met project aims. These were categorized into three sections: (a) perceptions of ASD, (b) parents' cultural upbringing and its influence within family and support systems, and (c) potential cultural barriers during intervention planning for ASD.

The SAAAC Autism Centre was responsible for the recruitment process of this study. Purposive sampling was used to recruit participants based on the following criteria: (i) parents of children diagnosed with ASD; (ii) identified as either an immigrant or first-generation Canadian from a South Asian region; and (iii) people who could communicate in English with the interviewer. Initially, the scope of the study was to study South Asian parent

perspectives with a broad lens; however, based on the availability of families during this time, the research team re-directed this work to study the perspectives of mothers of Sri Lankan Tamil descent. During recruitment, interested participants received detailed information about the study through an information letter via email. Informed consent was obtained prior to the interview; however, families were unaware of interview questions. All interviews were recorded with consent for later transcription and analysis. The study protocol and details of informed consent were approved by the Hamilton Integrated Research Ethics Board (Project no: 7689). In-person interviews ranged from 30 to 60 min in length and were conducted in English by the lead author in a private room at the SAAAC Autism Centre.

### Data Analysis of Semi-Structured Interviews

Using Graneheim and Lundman's approach to content analysis, there were five main stages for analyzing interview data: (1) data familiarization; (2) identification of thematic framework (using meaning unit formulation); (3) indexing (coding raw data); (4) organization of data into categories and themes; and (5) interpretation of data (using both the inductive analysis and holistic perspective approaches) (Graneheim & Lundman, 2004).

Transcribed interviews underwent a rigorous content analysis within the data source and details were categorized based on meaning unit formulation of text (Graneheim & Lundman, 2004). Meaning units were determined using an iterative process: each interview was analyzed and relevant ideas to ASD and culture were highlighted, especially if similar ideas were repeated across participants. Meaning units were given general definitions by researchers to help raise further clarification and standardize ideas without losing individual parent experiences. Once all meaning units within interview transcripts were identified, categories and larger themes were established using key ideas. These themes were then examined holistically to further understand potential nuances of parent experiences. Rigorous methods included the use of reflexive practices, including journaling and maintaining audit trails throughout study procedures, and weekly check-in meetings with all members of the research team for coding and analysis.

## Findings

Eight parents recruited from the SAAAC Autism Centre were mothers and immigrants from Sri Lanka. Seven out of the eight children of the parent participants identified as males. They listed Tamil as their first language, varied in religious upbringings, and all lived in Southern Ontario. The age range of the children was 16–23 years, and all lived in homes with two parents. Most participants have resided in Canada for over 15 years. Other characteristics of the participants are summarized in Table 1.

Based on the interview data, several ideas emerging from themes "facilitators" and "barriers" were raised in conversation. The themes, sub-themes, and categories of this study are identified in Tables 2 and 3. (Note that the same major sub-themes are listed

Table 1.  
Characteristics of Parent Participants.

	(n = 8)
Child gender	
Male	7
Female	1
Child diagnosis age	
1–2 years	
2–3 years	3
3–4 years	1
4 years +	2
Family structure and dynamics for child	2
Parents only	
Parents and sibling(s)	1
Parents and grandparent(s)	6
Grandparent(s) location	1
No living grandparents	
GTA, Canada	1
Sri Lanka	3
Mixed (Canada and Sri Lanka)	2
Extended family living nearby?	2
Yes	
No	
Parent working outside home?	
Yes	3
No	5
Family religion mentioned	
None	1
Hindu	3
Christian	2
More than one	2

Table 2.  
Identification of 'Positive' Theme, Sub-Themes, and Categories for Child and Family.

Theme	Sub-theme	Definition	Category
Facilitators for support of the child with ASD (and their family)	Family Perceptions of ASD	General comments regarding positive perceptions of ASD experienced by family.	Sibling support Building ASD understanding
	ASD & Family Cultural Beliefs	General comments regarding culture seen as a support for child and family needs.	Use of faith for child support Use of cultural/religious practices for child support
	Extended Family Attitudes Towards ASD	General comments regarding positive attitudes of extended family members for the child diagnosed with ASD and their family.	Grandparent support Extended family member support
	ASD & Health and Social Services	General comments regarding positive supports received by families through health and social services.	Service providers of same ethnicity Culturally-sensitive programs
	ASD & Inclusive Education	General comments regarding positive supports received by families through education systems.	Resources in schools Educator support

Table 3.  
Identification of 'Negative' Theme, Sub-Themes, and Categories for Child and Family.

Theme	Sub-theme	Definition	Category
Barriers that inhibited support for child (and family) with ASD	Family Perceptions of ASD	General comments regarding negative perceptions of ASD experienced by family.	Lack of knowledge about ASD Uncertainty/lack of knowledge towards approaching ASD intervention
	ASD & Family Cultural Beliefs	General comments regarding culture seen as a barrier for child and family needs.	Adapting cultural practices to fit Western norms Dismissing culture altogether
	Extended Family Attitudes Towards ASD	General comments regarding negative attitudes of extended family members for the child diagnosed with ASD and their family.	Stigma of ASD in family Lack of family support Physical/emotional distance of grandparents and/or extended family members
	ASD & Health and Social Services	General comments regarding negative supports received by families through health and social services.	Communication barriers Financial barriers Policy barriers (Funding) Housing barriers
	ASD & Inclusive Education	General comments regarding negative supports received by families through education systems.	School resource allocation Difference in access to special needs education across country Lack of qualified special education teachers in schools Lack of teacher support Technological barriers

in both tables, attesting to the fact that in context, a sub-theme may be experienced as either a facilitator or a barrier.)

### Identifying Broader Themes: Facilitators Versus Barriers

As identified in Tables 2 and 3, mothers reported mixed feelings towards the navigation of suitable ASD intervention plans in Canada, sharing both concerns and positive accounts of their experiences with other family members and the greater community, including health, educational, and social service providers.

### Family Perceptions of ASD

All participants shared that they initially did not know any information about ASD and were confused and unaware of what to do with their child's diagnosis. They also described their thoughts about their child's well-being, including concerns about behaviors, their child's daily life, and general concerns about their child's future. Across interviews, ASD was initially viewed by these mothers with significant concerns.

In contrast, one of the major ways in which some mothers were able to find support for their child within their family was through sibling support. One mother discussed how their

child's sibling worked to raise the funds needed for the child's ASD interventions, providing the hope the family needed to progress with their child's life. Another mother shared that sibling recognition of parent struggles towards navigating ASD interventions helped empower the parent:

My older son said, "Amma, you did a good job with [little brother]." So that makes me really proud. Because nobody ever said like that. But he said (mother of 23-year-old child diagnosed with ASD).

Across interviews, mothers were able to identify various skills of their child, and many had strong feelings towards their child's capabilities. In addition, a few mothers shared that after the initial diagnosis and first few interventions for their child, they were able to become more confident in advocating for their child's needs and be able to build their own personal skills in communication with family members, professionals, and other members in society.

### ASD & Family Cultural Beliefs

These mothers typically regarded "autism" and "culture" as two separate entities. However, there were some instances where the mothers spoke about the significance of their cultural beliefs playing key roles in their child's life. Some mothers shared that regularly praying was important, and not only were these practices playing roles in the child's lifestyle and routine, but some mothers believed that faith and cultural beliefs significantly influenced the child's well-being.

I prayed a lot. I take her to the church and I pray and I'm fasting for her [...] and she started to talk more and more [...]. Yes, so I said it's the God's miracle (mother of 16-year-old child diagnosed with ASD).

[My child] really wants to go to church. He doesn't want to stay at home on Sundays. It's like his routine (mother of 23-year-old child diagnosed with ASD).

Mothers who regularly practiced religious activities felt that the incorporation of their family's culture and faith into their child's life gave them some form of hope, either through believing in the improvement of their child's behavior outcomes, receiving intervention/program funding, or overall child well-being.

In contrast, some mothers shared that they adapted their cultural lifestyles to fit more Western systems. These caregivers shared that due to their child's diagnosis, it was difficult for them to continue to engage in cultural or religious practices, with one mother specifically reporting that she had to dismiss her cultural beliefs altogether. Lack of time, child behavior(s), and general beliefs were a few of the reasons for the lack of cultural inclusion to some families' daily life and practices.

Most interviewed mothers identified with a religion and type of cultural upbringing; however, many families stated that their culture did not play a direct role in the way they perceived their child's diagnosis or influence any type of the intervention plan. One mother believed that prayers and attending cultural festivals would directly help her son. Others said that

they had tried alternative, non-Western approaches to ASD intervention, but these suggestions were mainly from extended family and friends and not specifically associated with cultural practice.

In addition, most mothers stated that if they were to engage in cultural practices or alternative intervention methods, these would not typically be shared with their health service provider. These mothers believed the service provider would not understand the family's rationale, or that it was not relevant to the health service, nor did it need to be shared. They also shared that they typically did not find major cultural differences with service provider beliefs towards intervention methods; differences in beliefs were typically around non-cultural issues, such as the use of certain medications (often medications with adverse side effects) for their child. In these situations, the mothers found health service providers to be responsive to family beliefs.

### Extended Family Attitudes Toward ASD

The mothers typically expressed mixed feelings about a grandparent and extended family support. Although there were different levels of grandparent participation in the child's ASD intervention across participants, parents found there to be no significant barriers caused by differences between parental and grandparental thinking. Grandparent involvement typically included childcare, meal prepping, and moral support (often through prayers). Many caregivers chose to withhold information from grandparents either to prevent excess worry or because they believed their parents would not be able to understand their child's diagnosis.

In addition, the mothers typically knew which extended family members were supportive of their child, and would adapt their life to fit such needs:

Some homes we [don't] go. Some we like. My son, he knows ... who likes me (mother of 16-year-old child diagnosed with ASD).

Distance may have also played a factor, as some extended family members may not have been able to physically support these parents as needed. However, due to the varying sizes and attitudes of families across participants, many of the mothers noted that they were still able to find support within their extended families despite the one or two members that may not show as strong support.

Some mothers found family support to be extremely beneficial to their child's health and well-being. One mother noted that their child's cousins always included the child for family events, which helped play a large role in the development of their child's social skills. Another mother discussed how their niece was able to inform the parent about a school bullying incident that had involved the parent's child as the victim. These are ways in which family members played significant roles in creating safe spaces for children diagnosed with ASD to receive adequate support, and aided parents with reducing some of

the burdensome feelings often experienced by parents who believe they are solely responsible for their child's well-being.

### ASD & Health and Social Services

The mothers were generally satisfied with the quality of services they received in Ontario, Canada, especially when comparing the facilities and knowledge of ASD in Sri Lanka of that time. Most children of parent participants only saw a family physician or developmental pediatrician for routine check-ups, and went to the SAAAC Autism Centre for certain programming, including after-school programs, applied behavior analysis (ABA) therapy, music therapy, art therapy, and community living programs.

When discussing health and social services, all mothers referenced various organizations in the Greater Toronto Area and intervention plans (including occupational therapy services) that were used after the diagnosis of their child. Some mothers noted that programs initially recommended by their developmental pediatrician provided good services for their child, but were not necessarily helpful for parent support or with the child's specific needs. Although some mothers were able to learn from parent support groups and information sessions held by organizations, others found difficulty with these programs, such as uncertainty in whether support groups were able to understand the diverse needs of their family or the presence of language barriers inhibiting open communication:

We're not used to those things and all the groups, you know? The parent groups and all those things, we went there. They didn't understand our feelings (mother of 22-year-old child diagnosed with ASD).

Language, or communication barriers, were a common concern shared among parents. The mothers found that in certain environments, such as hospitals or even school settings, it was difficult to communicate with professionals; at times, some struggled with understanding the professional and/or being able to communicate personal beliefs and feelings:

I'm not in fluent in English, right? So sometimes I go to the hospital [and] they're explaining in English, so half understanding, half not understanding. Language is the big barrier for me (mother of 23-year-old child diagnosed with ASD).

Communication barriers were concerning to the mothers for fear they would be missing beneficial information or because they felt it created a disconnect between the health service provider and the family. Some mothers were also unsure whether their GP was providing proper services for their child (i.e., in-depth check-ups), further building distrust in the parent-service provider relationship. One mother noted that having a GP of her cultural identity was especially beneficial, as she could communicate her needs in her language (Tamil).

Financial barriers played large roles for almost all participants. Most families could not afford the diverse services needed for their children, especially during the initial search for interventions and programs. Others found that obtaining

government funding for programs and interventions also posed challenges because it was difficult to receive, and often had long waiting lists. Those who did not receive funding struggled with balancing the needs of their family and their child's specific needs and interests. Financial barriers also played a role beyond intervention costs, with one mother discussing the difficulty in finding affordable housing that fit the child and family needs:

We were living in the basement and you know, [having a child with ASD] is not that easy there [...] we cannot even have proper housing because not everyone is going to accept a child (mother of 22-year old child with ASD).

All participants were satisfied with services at the SAAAC Autism Centre and believed the organization fostered a community that gave both quality services for their child as well as family support. Some mothers noted that due to the cultural similarities between families, it was easier to communicate and share similar concerns. Culturally-sensitive programs like the SAAAC Autism Centre were found to be large facilitators in both child and parent well-being.

### ASD & Inclusive Education

Some concerns were raised by these mothers about their child's education, noting that systems were not well suited for their child's needs. These concerns included incorrect learning development assessments; children not placed in classrooms with neurotypical peers; a lack of teacher support and awareness of a child's learning; and difficulties communicating effective individual education planning (IEPs). One mother noted that although she had communicated about her child's skills and interests to a special education teacher, she felt her requests were not prioritized or considered.

I asked to teach her some things [on] the computer, but there's no teacher. They have [a] teacher [...] but for these kids, they don't have. They have for the regular kids. So how can she improve that, the computer knowledge? Because I am not good on the computer, so I can't help her, right? (mother with 16-year-old child diagnosed with ASD).

This mother went on to add that due to a lack of personal technological understanding, she struggled with personally teaching her child these skills and was dependent on the child's teachers for this task. Some mothers reported similar concerns, sharing that they would have to communicate several times with the child's teachers for their concerns to be addressed.

## Discussion

The primary objective of this study was to explore potential cultural dissonances associated with first-generation Sri Lankan Tamils navigating the Canadian healthcare system. Evidence indicates a lack of non-Western insight in ASD research and gaps in research focusing on autism. However, in the last several years, a growing number of publications have provided perspectives of ASD from families of various

ethnic upbringings. With the rise of support for client/family-centered care and prioritizing cultural competence within occupational therapy, there is a further acceptance of diverse healthcare beliefs. With this in mind, more cultural perspectives continue to be needed to further advance the current scope of ASD research. The findings of this study are applicable for occupational therapists and other health service providers that work closely with diverse families of children with ASD, who wish to provide more culturally sensitive care, and can empower immigrant families to continue to use their stories experiences to better shape the cultural understanding of ASD care systems.

In general, the mothers had mixed feelings towards their overall navigation into ASD services for their child, typically indicating both “facilitators” and “barriers” throughout their journey. Five key areas of consideration were identified in this study: *Family Perceptions of ASD, ASD & Family Cultural Beliefs, Extended Family Attitudes Towards ASD, ASD & Health and Social Services, and ASD & Inclusive Education*, and were further broken down to analyze parent experiences. Despite this study having a particular scope, a wide range of conversations took place that identified the nuanced nature of the immigrant parent experience caring for a child diagnosed with ASD.

Looking specifically at health services and cultural competence, parent participants were generally satisfied by the care they received from their primary healthcare providers, despite whether these families worked with occupational therapists. However, language and communication barriers still posed great challenges for these families. Although disagreements between parents and service providers were typically not related to culture if parents held different cultural beliefs these were typically not shared. Reasons for withholding such information include their relevance to the discussion, how valued it was to the parent to be shared, and whether parents believed the service provider simply “would not understand.” These can be some areas for improvement for occupational therapists to ensure that open communication opportunities and accommodations are made as appropriate. Some recommendations given by parents include more thorough and active check-ups for children diagnosed with ASD to help build parent trust; more check-ins with families about a child’s behavior and well-being; and building more open communication between parents and health service providers overall. Although no specific instances of OT practice were brought up in these interviews, parents shared their concerns and recommendations with how health professionals could better the quality of their services across health disciplines. Occupational therapy is built on a Westernized philosophical foundation, and there are differences among practitioners with how culture is defined; these both can pose challenges for families when such ideals are imposed on non-Western communities (Castro, Dahlin-Ivanoff, & Mårtensson, 2014; Malkawi et al., 2020).

The recommendations made by mothers are important reminders for occupational therapists, indicating that we may

need to redefine spaces for child and family needs to be better addressed, such as including the exploration of a family’s context (including extended families) in how that may support or shape perceptions around the child with ASD. With family needs put at the forefront of care, we can help ensure that service providers can also provide more culturally-sensitive practice. We also recommend future work to continue to explore and study the cultural phenomenon among parents of children with ASD, to gather potential explanations for why parents’ may hold distinct values about ASD and culture, and to also explore how cultural identity may influence the ways in which parents think about ASD in Sri Lankan Tamil (and South Asian) groups.

Although these ideas were obtained from the interview process, cultural competence was not the main issue of concern for these mothers, but rather part of a larger issue. Throughout interviews, the mothers identified various barriers and support with many concerns that were associated with common immigrant experiences, since most had their children only a few years after they had immigrated to Canada. At the time of their child’s diagnosis, these mothers typically were already balancing other life realities, potentially including financial, housing, and communication barriers. These barriers, mixed with the lack of knowledge of Western systems and ASD, present particular challenges for these families. The findings of this study also demonstrate intersectionality in the different forms of inequities that may exist among families of this particular group that must balance having limited resources, different cultural values, being a mother, and raising a child with ASD; the ways in which these layers of challenges intersect is important to recognize when working with families accessing ASD services (Shmulsky & Gobbo, 2019).

Finally, it is important to acknowledge that the researchers in this study had some expectation that the adaptation of culture to meet Western ideals, mixed with strong family cultural beliefs, would create one of the largest barriers or potential tensions for these immigrant families from Sri Lanka. However, this was apparently not entirely the case in the study’s findings. If health researchers hold an assumption that culture plays a significant role for members of a specific region who have been displaced, do we overlook other areas of concern that might be related to a family’s status as new Canadians?

In the literature, there is a discussion of culture playing significant roles in immigrant Sri Lankan Tamil mothers’ lives, but the element of the immigrant identity was typically not as heavily discussed. This finding then challenges cultural competence and the ways in which health service providers may approach and work with members of different ethnicities. As explained by Kleinman and Benson (2006), although cultural factors may play significant roles in how an individual is diagnosed and treated (and provide nuance to health system beliefs), there may need to be improvements with how health service providers are practicing cultural competence to ensure that other family concerns are not overlooked based on a simple (and perhaps inaccurate, even prejudiced) assumption. Cultural competence is not a technical skill to be learned by

health service providers simply to define how a client and their family should be treated, because that may lead to “dangerous stereotyping,” when such assumptions about members of a particular community are made (Kleinman & Benson, 2006).

These findings are also in line with the growing paradigm shift from “cultural competency” to “cultural humility” among health service providers, including occupational therapists. By incorporating “cultural humility,” in health practices with diverse families, there is a higher level of importance placed on valuable concepts like practitioner flexibility when working with families; awareness of bias; incorporating a learning-oriented approach towards diversity; and recognizing the role of power structures within the health system (Agner, 2020). These practices are also in line with the recommendations and guidelines made by the Canadian Association of Occupational Therapists, who suggest that collaboration with diverse stakeholders is necessary to conduct the goals of health, well-being, and justice for clients of occupational therapy (CAOT, 2011). When we continue to work towards developing more culturally-sensitive environments and safe spaces for families to share their needs, we will then be able to deliver more effective client and family-centered practice, and ultimately help improve overall health outcomes for children with ASD.

### Limitations

There are some limitations to this study that may have affected overall study findings. The cited literature regarding Sri Lankan knowledge toward ASD was not focused on the Tamil population in Sri Lanka, as there is not enough existing published literature to focus on the specific cultural issues in this group. However, we believe that the lessons learned from the mothers included in this study can provide valuable information to this space, and continue the important dialogue of the needs of immigrant Sri Lankan Tamil Canadian families of children diagnosed with ASD, and how these types of needs may transcend beyond this cultural group. We also did not account for the role of gender in caretaking children with ASD, and the potential influences of culture towards this relationship; all interviewed participants were mothers, which was not anticipated during recruitment. We suggest future work should continue to explore the roles of maternal caretaking in this regard.

Secondly, all children of parent participants were adolescents or older, ranging from 16 to 23 years. As health and social services are continuing to become more culturally sensitive, parents of younger children may today have different experiences of cultural competence compared to this participant group. In addition, parents who have recently immigrated to Canada and are now navigating the healthcare system with a child that has been recently diagnosed may have a completely different experience not captured in this study. This information is important to note because the concerns raised during interviews regarding initial intervention challenges may have applied to an older model of health services; the issues these families now experience might be different from what they

likely encountered when their children were quite young. The parents in this study had lived with the issues for many years, and had probably made many accommodations that parents earlier in their journey might not yet have made. All participants were parents of families that already had access to culturally sensitive programming for South Asian families through the SAAAC Autism Centre, and were generally satisfied with that level of support. Due to this project’s scope, no voices of families outside of this organization, particularly those without culturally sensitive programming in place, were included in this interview data; this creates another potential explanation for our results.

Finally, some mothers experienced significant language barriers with the interview process. This interview was conducted in English and despite all measures to ensure plain-language interview questions, some parents still found the questions asked to be challenging. Therefore, full perceptions and thoughts may not have been captured or well understood during this process. We recognize that more conversations need to take place regarding these research topics, and be conducted with a larger team to include language translators to help gain a more accurate understanding of parent experiences.

### Conclusion

The intersection of autism and culture is a relevant topic in today’s world, as Canada continues to see its population grow and diversify. This study aimed to develop a better understanding of the potential tensions that Tamil immigrants from Sri Lanka may face when balancing culture through the navigation of ASD interventions in Southern Ontario. Using interviews with eight participants to develop a unique understanding of maternal perspectives, it was found that there were less significant challenges associated with culture as such, but rather a series of issues that particularly relate more broadly to the immigrant experience.

The mothers’ recommendations for health service providers, including occupational therapists, suggest more open communication, regular check-ins with families to learn more about their needs, and the building of parent trust; these are ways to ensure that key components of client-centered care are experienced. Beyond these ideas, it is important for service providers to truly understand the needs of the family. The experiences shared by these mothers create areas for further study not only in the other issues that may be largely affecting this particular group, but also with how cultural competence is understood among health researchers and service providers and the ways in which improvements need to be made.

### Key messages

- First-generation Sri Lankan Canadian mothers/caregivers of children diagnosed with autism spectrum disorder have particular needs.
- These families may experience a multitude of barriers and supports within health and social systems that need to be



considered by service providers, including occupational therapists.

- By creating opportunities for more open communication and trust-building between parents and clinicians, a higher level of cultural competence can be achieved within these systems.

## Acknowledgments

First and foremost, we would like to thank the SAAAC Autism Centre and SAAAC families for choosing to engage in this study. This research project would not have been conducted without the enthusiasm and support from this organization. We would also like to thank Drs. Mohammed Zubairi and Kinga Pozniak for their insight and guidance for helping build and advance this study.

## Declaration of Conflicting Interests

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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