A Review of Barriers Experienced by Immigrant Parents of Children with Autism when
Accessing Services

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Abstract

Immigrants have poorer health outcomes due in part to limited access to health care. Children with autism spectrum disorder (ASD) who have immigrant parents are diagnosed at a later age and those whose parents have limited English proficiency receive fewer hours of services. What contributes to these health-care and support services disparities? This review examined eight qualitative studies published between 2010 and 2020 that explored barriers experienced by immigrant parents of children with ASD with regards to accessing diagnostic and/or intervention services. Key barriers included long wait times, language barriers, and limited health literacy. Recommendations for practice and future research are discussed.

More than 258 million people in the world live in a country that is different from the one in which they were born (United Nations, 2017). Immigrants have been identified to be at risk of poorer health outcomes due in part to inadequate health care (Derose et al., 2007). For example, when compared to nonimmigrants, immigrants are less likely to be insured, which reduces access to health care (Ku & Matani, 2001). Even when comparing insured immigrants to nonimmigrants, immigrants persistently have less access to health care due to non-financial barriers, the most prominent being language barriers (Ku & Matani, 2001). In fact, immigrants who experience language barriers have higher levels of stress and poorer health outcomes (Ding & Hargraves, 2008).

Stress has been identified as one of the main factors associated with immigrants' health outcomes (Pumariiega et al., 2005). Major stressors experienced by immigrants include discrimination, poverty, acculturation, and trauma (Pumariiega et al., 2005). Refugees are immigrants who are forcibly displaced from their home countries, and pre-migration is often marked by traumatic experiences such as violence, deaths of family members, and persecution (Henley & Robinson, 2011). Unsurprisingly, refugees have been found to be 10 times more likely to have post-traumatic stress disorder (PTSD) than the general population in their host countries (Fazel et al., 2005).

In addition to the stressors related to the process of immigration itself, immigrant parents of children with autism spectrum disorder (ASD) are likely to experience another layer of stress. This extra layer of stress often reflects the concern they have about their children's deficits in social communication and restricted, repetitive patterns of behaviors and/or interests (American Psychiatric Association, 2013). Parents of children with ASD report higher levels of stress than those of children with other disabilities (Baker-Ericzén et al., 2005; Hayes & Watson, 2013), and

parents of children with more severe ASD symptoms are said to experience the highest levels of stress (Benson, 2006; Ingersoll & Hambrick, 2011). In fact, a recent study found that 18.6% of parents of children with ASD met criteria for a diagnosis of PTSD as opposed to none of the parents of typically developing children (Stewart et al., 2020). Cumulatively, the stress from immigration and raising a child with ASD may suggest that immigrant parents of children with ASD are also likely to be at higher risk for poorer health outcomes.

Parents of children with ASD who have milder symptoms experience lower levels of stress (Ingersoll & Hambrick, 2011). Research findings indicate that early identification and early intervention can lead to improved outcomes for individuals with ASD (Koegel et al., 2014; Zwaigenbaum et al., 2015). However, children with ASD born to immigrant parents have been found to be referred for diagnostic evaluations later than those born to nonimmigrant parents (Valicenti-McDermott et al., 2012). Furthermore, children with ASD whose parents have limited English proficiency are likely to receive fewer hours of disability services and are less likely to have social skills and communication goals on their Individual Education Plan (IEP) than those with parents who are proficient in English (St. Amant et al., 2018). This disparity may mean that children with ASD who have immigrant parents with less proficient language skills in their adopted country make fewer treatment gains than those with non-immigrant parents. These reduced treatment gains may contribute to higher stress levels in immigrant parents.

Given the association between stress and immigrants' health (Pumariiega et al., 2005), reducing the disparity in terms of services received by children with ASD who have immigrant parents and those with nonimmigrant parents is an important issue. To reduce such disparities, an understanding of the barriers experienced by immigrant parents when accessing services for their children with ASD is important. To date, there do not appear to have been any reviews of the

literature on barriers to accessing services experienced by immigrant families with children with ASD. Thus, this review aims to synthesize the literature related to the barriers experienced by immigrant families so as to provide research-informed recommendations on how to ameliorate these barriers. A review of this nature could also inform clinical practice and identify areas for future research to improve outcomes for immigrant families with children with ASD.

Method

Protocol Registration and PRISMA Guidelines

This systematic review was registered on Open Science Framework (Lim et al., 2020) and procedures (e.g., specification of eligibility criteria, describing information sources, presenting electronic search strategy, description of data extraction) followed PRISMA guidelines (Moher et al., 2015).

Search Strategies

Electronic database searches were conducted in PsycInfo, Education Source, ERIC, and MEDLINE in March of 2020. The keywords used in the search were: immigrant or refugee or migrant or foreign born or first generation and autism* or autism spectrum disorder* or Asperger or pervasive developmental disorder*. The search was limited to peer-reviewed articles published in English. Because policies and practices change over time, only articles published between 2010 and 2020 were included to allow for the identification of the contemporary barriers. This initial search returned 268 records. After excluding duplicates, 167 abstracts were screened against the inclusion criteria.

Inclusion Criteria

Because the purpose of this review is to understand barriers experienced by immigrant parents when accessing services for their children with ASD, only qualitative studies were

included. Qualitative studies were defined as involving the thematic analysis of interviews, observations, and/or documents for the purpose of bettering understand participants' experiences. Secondly, participants had to be immigrants (i.e., living in a country outside his/her country of birth) with children with ASD. Finally, the study had to report on the barriers and challenges participants faced with respect to accessing ASD services. A study was deemed to have the theme of barriers/challenges to services if authors identified it as a theme in the manuscript or paraphrased/reported quotes from participants describing the difficulties they encountered when getting their child diagnostic or intervention services.

Figure 1 provides a flowchart of the process used to identify studies for inclusion in this review. In applying the inclusion criteria, 142 abstracts were excluded and the full-text of 25 articles were assessed for eligibility. The first author and a coauthor independently screened all records, excluding duplicates, against the inclusion criteria, resulting in almost 100% agreement (i.e., 166 out of 167). The only article on which there was disagreement was discussed between the two authors until consensus was reached. Based on this process, a total of eight studies were judged to have met the inclusion criteria and are summarized in this review.

INSERT FIGURE 1 ABOUT HERE

Data Extraction and Coding

Data on the following variables were extracted from each included study: (a) host country (i.e., country in which the study was conducted), (b) parent participants' areas of origin, (c) parent characteristics, (d) child characteristics, (e) design, (f) language used for interviewing, and (g) identified barriers to accessing services for children with ASD. The design used in each study

was reported as described by the authors. The first author extracted and summarized data for each included study. The accuracy of summaries was verified for three of the eight studies by a coauthor. The number of agreements on whether the extracted and coded data was correct versus incorrect was divided by the total number of coded variables to determine interrater agreement. Interrater agreement was 97%. Disagreements were discussed until consensus was reached.

INSERT TABLES 1 AND 2 ABOUT HERE

Results

Summaries of included articles in terms of the first set of extracted variables (e.g., host country, participant characteristics, design, and study language) are provided in Table 1. Table 2 provides a summary of the barriers to accessing services that were reported in each study.

Host Countries

Most studies were conducted in the USA ($n = 4$). Two studies were conducted in Canada, one was conducted in the UK, and one was conducted in Ireland.

Areas of Origin

Most parents were originally from Asia ($n = 52$), followed by Africa ($n = 37$), Latin America ($n = 13$), and Europe ($n = 10$).

Parent Characteristics

A total of 112 parents (22 fathers) with children with ASD participated in the eight studies. Parents were between 30 and 50 years of age. Three studies did not report the age of parents (Habib et al., 2017; Rivard et al., 2019; Sakai et al., 2019). The average number of years that parents had spent in their host country was reported in all but one study, which reported the

range (Jegatheesan et al., 2010). Parents in all but one study had spent more than 10 years in their host countries (Rivard et al., 2019).

Child Characteristics

Parents had a total of 111 children (19 females) with ASD. Children ranged from 4 to 31 years of age. One study did not report information on children's ages (Miller-Gairy & Mofya, 2015).

Design and Interview Language

A variety of qualitative research approaches were used (i.e., community-based participatory, ethnographic, constructivist-interpretive). Interviews were the primary source of data in all studies. Parents' native languages (i.e., Mandarin, Cantonese, or Korean) were used in two studies (Sakai et al., 2019; You & Rosenkoetter, 2014). Some studies used both parents' native languages (i.e., Somali, Urdu, Hindi, or Spanish) and the dominant language of the host country, that is English or French (Fox et al., 2017; Habib et al., 2017; Jegatheesan et al., 2010; Rivard et al., 2019). Interviews in one study were conducted entirely in the dominant language of the host country (i.e., English) for all participants (Khanlou et al., 2017). One study did not report the language that was used during interviews (Miller-Gairy & Mofya, 2015).

Barriers to Accessing Services

The most commonly mentioned barriers were long wait times for diagnostic and/or intervention services, language barriers, and limited health literacy. Five out of eight studies mentioned the long wait-times as a barrier. For example, parents in Habib et al. (2017) mentioned experiencing stress due to lengthy waitlists for diagnostic and intervention services and parents in Jegatheesan et al. (2010) described the waiting time as being "long and traumatic".

Four studies mentioned language barriers. Parents' lack of proficiency in the dominant language of their host countries prevented them from communicating effectively with their providers. For example, parents in Miller-Gairy and Mofya (2015) felt that their limited English proficiency prevented them from being able to fully engage in conversations with their providers. This resulted in their providers spending relatively limited amounts of time communicating with them and taking their opinions into consideration. The absence of translated materials, such as application forms for services, was another language barrier. For example, one mother stated, "They told me I had to fill out a form in order to receive a first appointment. The form was all in English, and I did not know what to do" (Sakai et al., 2019).

Parents' limited health literacy appeared to have hindered their abilities to obtain information on how to access services and was reported by parents in four studies. One parent mentioned "When you're new to a country, it's just impossible for you to find all the different services available. The reason that causes further delay to our children or [accessing] services is because you haven't got the capacity, or the ability, or the understanding to access services" (Fox et al., 2017). Another obstacle to parents' understanding of available services is the use of jargon by educators and medical professionals (You & Rosenkoetter, 2014). The lack of understanding of jargon was reportedly a cause of delays to accessing and receiving services for their children with ASD (Jegatheesan et al., 2010; Khanlou et al., 2017).

Other barriers include difficulties navigating unfamiliar health care/education systems (Fox et al., 2017; You & Rosenkoetter, 2014), systemic inefficiencies, such as excessive paperwork (Khanlou et al., 2017; Rivard et al., 2019), the financial costs of services (Khanlou et al., 2017; Rivard et al., 2019), as well as cultural differences between parents and their providers (Jegatheesan et al., 2010; Miller-Gairy & Mofya, 2015). Cultural differences manifested in the

form of disagreements between parents and professionals about what and how to teach the child (Jegatheesan et al., 2010) and inability to communicate with male care providers due to religious and cultural norms (Miller-Gairy & Mofya, 2015).

Discussion

This review identified eight qualitative studies published in the last decade that investigated barriers experienced by immigrant parents when accessing diagnostic and/or intervention services for their children with ASD. The most commonly reported barriers included long wait times for services, language barriers between parents and service providers, and parents' limited health literacy. Of these barriers, language barriers (Ding & Hargraves, 2008) and limited health literacy (Kreps & Sparks, 2008) could be seen as being most closely associated with immigrant stress and health outcomes.

Recent migration trends indicate that the top three countries that immigrants are migrating from are India, Mexico, and China, with the US being the top destination country (United Nations, 2019). The primary languages spoken by people in India, Mexico, and China are different from that of the USA. This means that immigrants from these countries are likely to have limited English proficiencies, which may result in them experiencing language barriers when trying to access services for their children with ASD. The language barriers encountered by immigrant parents may explain why lower levels of English proficiency have been found to be associated with fewer hours of disability services and a lower likelihood of having social skills and communication goals on children with ASD's IEPs (St. Amant et al., 2018). Parents may not be able to advocate for more hours of disability services and goals that are important to them due to their language barriers. This was reflected in Miller-Gairy and Mofya's (2015) finding that providers spent relatively limited amounts of time conversing with parents and

taking their opinions into account due to language barriers. To help level the playing field for immigrant parents, service providers should consider having providers and/or translators who speak the most common languages of these countries (i.e., Hindi, Spanish, and Mandarin) readily available. Websites with information about how to obtain services and application forms to request for services should also be provided in these languages.

Health literacy refers to “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Ratzan et al., 2000, p. 6). To address the barrier posed by limited health literacy, the use of illustrative visuals may be employed (Kreps & Sparks, 2008). For instance, websites explaining the special education system should have illustrative visuals accompanying the text. Even if the text is provided in multiple languages, illustrative visuals should still be included because health literacy is influenced by factors like prior knowledge and resources, which put many immigrants at a disadvantage (Squiers et al., 2012). Additionally, jargon should be avoided in favor of colloquial language (Kreps & Sparks, 2008), even if this requires the use of more words, time, and/or effort.

It is important to highlight that almost all parents in the studies included in this review had been living in their respective host countries for more than 10 years. This means that these parents had a decade to adjust to their host countries. Looking at the age range of children in the included studies, it appears that many of their children, including the adult children, are likely citizens of these countries. Immigrants who have been in their host country for longer periods of time have had more time to practice the dominant language of that country, and therefore are generally more proficient in the dominant language of that country. This is reflected in the finding that almost half of the participants’ interviews were conducted using some English.

Individuals with greater English proficiency are likely to have more access to health care services (Neufeld et al., 2001). In light of the above, one might argue that the barriers experienced by more recent immigrant parents of children with ASD are probably even more serious than those identified in this review. To reduce the barriers experienced by recent immigrants when accessing services for their children with ASD, involving this population in research is important. However, conventional recruitment strategies such as using advertisements and health care agencies may not be effective (Neufeld et al., 2001). Future research may want to explore direct community recruitment strategies to reach this population.

Notably, only one study included participants who were refugees (Miller-Gairy & Mofya, 2015). Due to pre-migration circumstances, refugees may experience PTSD and/or depression (Silove et al., 2017). Compounded with the stress from raising a child with ASD, refugee parents of children with ASD may require additional health care support. With immigrant parents describing the waiting period between requesting and receiving services as “traumatic” (Jegatheesan et al., 2010), mental health support may be especially important during this time.

Immigrant parents of children with ASD experience stress related to the process of immigration and raising a child with a disability. Parents of children with ASD whose children have more severe symptoms experience more stress (Benson, 2006; Ingersoll & Hambrick, 2011). Children with ASD who have immigrant parents with limited English proficiencies are diagnosed at a later age (Valicenti-McDermott et al., 2012) and receive fewer hours of services (St. Amant et al., 2018), which may contribute to more severe symptoms of ASD in these children. Not only does this disparity in age of diagnosis and hours of services affect outcomes for children with ASD, but it may also have consequences for the health of their parents. To reduce the barriers faced by immigrant parents of children with ASD when accessing diagnostic

and intervention services, issues of language barriers and limited health literacy have to be addressed. Suggestions for service providers include having translators available and using illustrative visuals.

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Figure Captions

Figure 1. Flowchart of included studies

Figure 1 top

Table 1

Summary of included studies

Study	Host country	Country of origin (N of parents)	N of parents (<i>n</i> fathers); Age (years); Years in host country	N of children with ASD (<i>n</i> female); Age (years)	Language used in interviews
Fox et al. (2017)	UK	Somalia (15)	<i>N</i> = 15 (3) <i>M</i> = 36 <i>M</i> = 11.7	<i>N</i> = 17 (5) Range = 4-13	Somali (<i>n</i> = 8) English (<i>n</i> = 5) Both (<i>n</i> = 2)
Habib et al. (2017)	Ireland	Pakistan (7)	<i>N</i> = 7 (0) <i>M</i> = NR <i>M</i> = 13.3	<i>N</i> = 8 (1) Range = 4-18	English (<i>n</i> = 6) Mostly English with some Urdu (<i>n</i> = 1)
Jegatheesan et al. (2010)	US	Bangladesh (3), Pakistan (3)	<i>N</i> = 6 (3) Range = 30s to 40s Range = 10-15	<i>N</i> = 3 Range = 5-6	Hindi and English (<i>n</i> = 3) Urdu and English (<i>n</i> = 3)
Khanlou et al. (2017)	Canada	Asia (14), Europe (5), Latin America (2)	<i>N</i> = 21 (0) <i>M</i> = 41.3 <i>M</i> = 10.7	<i>N</i> = 27 (11) Range = 2-31	English
Miller-Gairy et al., (2015)	US	Somalia (8)	<i>N</i> = 8 (0) <i>M</i> = 38.7 <i>M</i> = 15.4	<i>N</i> = 11 (1) NR	NR
Rivard et al. (2019)	Canada	Africa (14), Asia (4), Europe (5), Latin America (11)	<i>N</i> = 34 (13) <i>M</i> = NR <i>M</i> = 8.6	<i>N</i> = 24 (NR) <i>M</i> = 4.1	English, French, or Spanish
Sakai et al. (2019)	US	China (16)	<i>N</i> = 16 (2) <i>M</i> = NR <i>M</i> = 13.9	<i>N</i> = 16 <i>M</i> = 5.9	Mandarin or Cantonese
You & Rosenkoetter (2014)	US	Korea (4)	<i>N</i> = 4 Range = mid-30s to mid-40s <i>M</i> = 12	<i>N</i> = 4 (NR) Range = 7-18	Korean

Table 2

Summary of barriers experienced by immigrant parents

Study	Types of barriers						
	Unfamiliar system	Language barrier	Cultural differences	Limited health literacy	Long wait-time	System inefficiency	Cost of services
Fox et al. (2017)	X	X		X			
Habib et al. (2017)					X		
Jegatheesan et al. (2010)			X	X	X		
Khanlou et al. (2017)				X	X	X	X
Miller-Gairy et al., (2015)		X	X				
Rivard et al. (2019)					X	X	X
Sakai et al. (2019)		X			X		
You & Rosenkoetter (2014)	X	X		X			