



## The “Western disease”: Autism and Somali parents' embodied health movements



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### ABSTRACT

There is some statistical evidence indicating that Somali refugees and immigrants have high rates of autism spectrum disorder (ASD). Somalis in North America call autism the “Western disease” because there is no word for autism in the Somali language and because many believe it does not exist in Somalia. In Toronto, Somali parents have forged an “epistemic community,” united around a coherent theory of the development of autism, its defining features, and most successful therapies. They work together with researchers to support the theory that gut bacteria is a causal factor for the development of autism. They argue that it is the diet and medical environment in North America (including the use of preservatives, genetically-modified processing, and antibiotics in both health care and food production) that explains the high rates of autism within the Somali diaspora. The paper argues that race and nationality have been underexplored in theories of embodied health movements. I argue that Somali parents' organizing pushes theories of health social movements in new directions, by suggesting that experiences of forced migration and racial exclusion, as well as non-Western cultural ontologies of health, are important for understanding embodied experiences of illness and the forging of “politicized collective illness identities” that challenge mainstream scientific understandings of autism. As such, Somalis' race and nationality play key roles in their pathways to group construction, in their embodied experiences of illness, and in their resources for mobilization.

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According to the Centers for Disease Control (CDC), the prevalence of autism in the United States has increased from 1 in 2500 children in 1989 (Ritvo et al., 1989) to 1 in 68 in 2014 (Baio, 2014). The cause of this increase and the etiology of autism remain unknown. Autism spectrum disorder (ASD) is defined by delays in language development, social skills and behavioral repertoire (often presenting as repetitive play, object fixation and self-stimulation). Biomarkers for the disorder remain elusive, and many argue that autism has become a more heterogeneous category as research into the disorder has broadened (Eyal et al., 2010; Singh, 2016a).

In 2009, the Minnesota Department of Health published a study revealing that children of Somali parents in Minneapolis were 2–7 times more likely to receive ASD special education services than children of non-Somali parents (2009). The CDC and the University of Minnesota then conducted a surveillance study in Minneapolis from 2011 to 2012, which confirmed a high rate of autism in the

Somali population (Hewitt et al., 2016). One in 32 children of Somali descent, aged 7–9 in 2010, were identified with autism, which was roughly equivalent to white children (1 in 36), but higher than any other ethnic group. Unlike their white counterparts, one hundred percent of the Somali children with ASD had an accompanying intellectual disability (ID). These findings contribute to a small but growing international body of literature demonstrating a high prevalence of ASD in the Somali diaspora (Barnevik-Olsson et al., 2008; Keen et al., 2010; Hassan, 2012). Somalis living in North America call autism the “Western disease” because there is no word for autism in the Somali language and many believe it does not exist in Somalia.

Autism “clustering” in white, wealthy populations has been attributed to social networks, the availability of pediatric care, diagnostic expansion, and better detection and reporting (King and Bearman, 2011; Liu et al., 2010; Mazumdar et al., 2013). Exposure to pesticides is another causal explanation for autism “clustering” (Shelton et al., 2014; Pearson et al., 2016). To my knowledge, clusters within Somali communities in the diaspora are the first clusters discovered in racially marginalized and economically

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disadvantaged populations. This partially stems from disparities in the diagnosis and reporting of autism (Liptak et al., 2008; Mandell et al., 2009; Travers et al., 2011; Baio, 2014). These racial disparities have serious consequences for poor populations and people of color because lack of access to health care and late diagnostic recognition are associated with co-occurrences of intellectual disabilities and more severe autism behaviors (Horovitz et al., 2011; Chaidez et al., 2012; Becerra et al., 2014). Speech capacity, cognitive functioning and behavioral issues like aggression are used to measure the severity of autism impairment.

This article draws on three years of qualitative research conducted with Somali refugees as well as health providers, government officials, policy specialists, educators, and social workers who provide services to children with autism in Toronto and Minneapolis; however, this article focuses on my findings from Toronto. Most Somalis began immigrating after the outbreak of civil war in Somalia in 1991. There are 70,000 Somali immigrants living in Canada with 23,000 in Toronto (Kusow, 2006). In Ontario as of 2006, the unemployment rate for adult Somali-Canadians was 16.4%, and in 2005, 57% of Somali-Canadians lived below the Low-Income Cut-Off, making them one of the most disadvantaged groups (OCASI, 2016).

In both Minneapolis and Toronto, Somalis have forged “epistemic communities” united around coherent theories of the etiology of autism, its defining features, and most promising therapies. The term is borrowed from international studies research focusing on policy development during global crises (Haas, 1992), but is expanded here through application to a lay population whose unique ontology of autism is based on shared experiences of exclusion and a normative approach to illness that defies the mainstream. In Toronto, the Somali “epistemic community” has consolidated around gut bacteria as a causal mechanism for the development of autism. Somali parents of children with autism in Toronto argue that the diet and medical environment in North America (including the use of preservatives, genetic-modification, and antibiotics in health care and food production) explains the high rates of autism within the Somali diaspora. I argue that this group has forged an embodied health movement (EHM) based in a “politicized collective illness identity” (Brown et al., 2004) because of their experiences of forced migration and racial exclusion, as well as their cultural ontologies of health. This paper fills a gap in the existing literature on health social movements, which has largely sidelined issues of race (Epstein, 2008) and nationality. I argue that race and nationality not only lead people to join embodied health movements, they also generate critiques of existing science and become sites for knowledge production. I argue that Somalis' race and nationality play key roles in their pathways to group construction (Epstein, 2008, p. 513), in their embodied experiences of illness, and in their resources for mobilization.

## 1. Literature review: health social movements

According to theorists of health social movements (HSMs), people are more likely to challenge hegemonic scientific explanations when there is a disjuncture between the “subjective certainty” of their *experience* and doctors' “objective” explanations for an illness (Barker, 2002; Brown et al., 2004). Peoples' ontological positions in the world inform their illness narratives (Barker, 2002). When an illness is “contested” (Brown et al., 2011), patients and their caregivers create “practical epistemologies” to make sense of their “obscure bodies” and to challenge medical science (Kroll-Smith and Hugh Floyd, 1997). Disjunctures between patients' experiences and medical experts' explanations lead to “politicized collective illness identities,” especially when “individuals who are unable to meet their health expectations realize a shared

experience and pursue collective action” (Brown et al., 2004, p. 58). Therefore, navigating structural barriers to health care serves as motivation to join social movements (Brown et al., 2011).

Somalis' pathway to group formation is inextricable from their experiences of race and nationality. Somalis understand autism as an environmental insult associated with their forced migration from Somalia, which challenges hegemonic medical descriptions of the illness as genetically based. In addition, their ontologies of mental health draw on cultural resources situated in Somali conceptualizations of the body. Finally, their experiences of racial exclusion and difficulties navigating an unequal health system lead to the adoption of a “politicized collective illness identity.”

Somalis' establishment of “epistemic communities” around autism most closely resembles an “embodied health movement.” According to Brown and colleagues, there are three types of HSMs: 1) health access movements that seek equitable access to health provision; 2) constituency-based movements, which address health inequality on the basis of identity (race, gender, and sexuality); and 3) embodied health movements (EHMs), which build on illness experience to challenge mainstream science (2004). EHMs differ from the other two categories because they introduce the biological body into social movements, challenge existing medical knowledge and practice, and involve collaborations between activists and scientists. EHMs often form in response to “contested illnesses,” forge lay/expert collaborations, and push normalized scientific practice in new directions. EHMs are not unique for challenging science, but for *how* they do so, via knowledge based on embodied experience (Brown et al., 2004). As this article illustrates, the Somali autism movement in Toronto fulfills all of the characteristics of an EHM. But because it is a movement of parents and not sufferers themselves, the issue of embodiment requires elaboration. In addition, Brown and his colleagues suggest that some movements combine different types of HSMs (2004). Rather than simply understanding the Somali autism movement as a combination of a constituency-based movement and an EHM, I argue that race and nationality need to be incorporated directly into the theory of EHMs. I take each point in turn.

A number of scholars have pointed out the ways that parents of children with disabilities gain intimate bodily knowledge and expertise from their experiences of parenting a child with a disability, thereby embodying disability by proxy (Rouse, 2004; Silverman, 2012; Hart, 2014). Somali parents similarly forge an embodied identity as parents of children with disabilities and use this knowledge to challenge the medical mainstream. This often entails “biographical work” that validates the personhood of their children, framing hopeful futures against dismal prognoses by medical practitioners (Singh, 2016b). Unlike their white counterparts, this article shows that Somali parents' explanations of autism and pursuit of therapies incorporates their experiences and embodiment of “outsider” status as racialized others and immigrants.

Brown and colleagues argue that some movements incorporate aspects of all three HSM ideal-types (2004). They also recognize that experiences of racial and/or class discrimination can lead people to adopt structural explanations for health exclusion and to establish politicized health identities (Brown et al., 2003, 2004, 2011). For example, Brown and colleagues argue that asthma is more prevalent in lower income and minority populations, which allows communities to identify the social determinants of health and the political-economic structures that produce asthma in the first place (2003, pp. 455, 460). For Brown et al. people come to understand their illness as a product of racial and class marginalization, which then becomes an impetus for organizing. But Brown et al. do not explore the process by which this happens or elaborate on the ways that people come to understand their race/class

position in conjunction with illness. The existing literature treats race as a factor and not as a lived experience. My research highlights *how* people make meaning of their race and nationality in becoming embodied health activists. This paper argues that race and nationality influence each stage of politicization: 1) pathways toward group formation and the emergence of “politicized collective illness identities” – Somalis come to understand autism as a result of their forced migration; 2) the adoption of a unique causal theory of autism rooted in an embodied experience of race and illness, which for Somalis is linked to a unique cultural ontology of mental health; and 3) political mobilization and social movement organizing, which is motivated by Somalis' experiences of racial exclusion and xenophobia. Another contribution this article makes is to highlight the epistemological role EHM play in shifting the site of knowledge production from experts to lay populations. The Somali autism movement develops a unique epistemological approach to understanding and treating autism and the parents engage directly with scientific researchers to establish new knowledge that aligns with their racially informed experiences of autism vulnerability and embodiment.

## 2. Methods

This article is part of a larger research project, but I limit my discussion of methods to the data utilized in this article. The overall research project was approved by an Institutional Review Board. This paper draws on in-depth interviews with Somali parents of children with autism in Toronto ( $n = 25$ ); three focus group discussions with Somali parents ( $n = 15$ , with significant overlap in people who attended focus groups and were interviewed); 4 in-depth interviews with the 2 leaders of the support group (Adar Hassan and Idman Roble); 2 interviews with an early childhood specialist who helped form the support group (Fatima Kediye); and multiple in-depth interviews with two researchers who study gut bacteria and autism (Drs. MacFabe and Vercoe). To be eligible for an interview, people had to be of Somali origin, over the age of 18, and parent of a child diagnosed with autism. I employed two recruitment strategies. First, I used purposive sampling to recruit participants in a support group for Somali parents of children with autism ( $n = 16$ ). Second, I recruited parents ( $n = 11$ ) through an organization that provides autism services in Toronto. The organization sent fliers to Somali parents whose children were receiving applied behavioral analysis (ABA). Parents then contacted me if they were interested in an interview.

All interviews with Somali parents were conducted in either the participant's home or in a coffee shop. The interviews lasted 1–3 hours, and a Somali interpreter was used upon request. Somali parent interviewees were compensated \$40 Canadian dollars. With the exception of the two support group leaders, the parent interviews were semi-structured. Questions included: how they first discovered their child had autism and what the diagnostic process entailed; what services they accessed and what barriers they faced; their beliefs about etiology and how they came to these explanations; what therapies they tried and which were most effective; what sources were most useful in making sense of autism and seeking treatments; what stigmas they and their children faced; what hopes they had for their children's future. For support group members: how they became involved and why they attend. Questions for the scientists included: how they became involved in research on autism and gut bacteria, the status of the field, their current projects, and the history of their involvement with Somali parents in the support group.

All interviewees were asked to sign a consent form if they wanted me to use their name. All other interviewees gave verbal consent and remain anonymous. Due to language barriers, the

interviews were transcribed non-verbatim. Memoing was used to make sense of themes emerging from the interviews, based on multiple readings of the transcripts. Memos were clustered around emerging themes, which then translated into more concrete codes. But codes were also deductively applied from relevant, existing theories and scholarship on autism. Memoing and coding were repeated over the course of the three years of data collection (2013–2016), and eventually codes were refined, solidified and compared across categories and interviews.

## 3. Findings

### 3.1. Pathways to groupness

Epstein asks: “what is the pathway by which ‘groupness’ comes into being?” (2008, p. 511). This section explains the pathway taken by Somali parents of children with autism in Toronto as they forged a coherent epistemic community. According to Brown et al. (2004), pathways to groupness have multiple components. First, there is a disconnect between the illness experience and expert explanation (p. 55). Next, the illness experience must be conceptualized as a broader collective issue, often linked to “institutional and political-economy structures that can cause disease as well as treat it” (Brown et al., 2011, p. 16). Confronting structural health obstacles and a hegemonic medical definition that negates embodied experience causes people to develop collective illness identities and pursue collective action (Brown et al., 2004, pp. 58; 61–2). I argue that race and nationality play prominent roles in the epistemological and ontological disconnect confronting Somali parents of autistic children, as well as in their experiences of structural exclusion. Together, these processes facilitate their consolidation as an EHM.

In order to understand the disconnect between parents' subjective experiences and practitioners' “objective” explanations, the orthodox definition of autism requires elaboration. Doctors usually explain that autism is a lifelong condition for which there is no cure, that it is likely a genetic condition, and that early access to Applied Behavioral Analysis (ABA) may improve children's behavior and language acquisition. Yet, it is common for parents of children with autism to seek out “alternative” therapies and theories of autism causation – in part because parents confront a medical establishment that challenges their experiences as parents and fails to give them hope (Singh, 2016b). Estimates of alternative therapy use by parents of children with autism range from 38 to 74% (Hanson et al., 2007; Hart, 2014; Levy and Hyman, 2015). Somalis turn toward alternative therapies and explanations of autism for many of the same reasons as anyone else. Somalis share the following motivations with parents from diverse backgrounds. First, many parents believe their children *acquired* autism as opposed to being born with it and contend that their children suffer from regressive autism, in which children reach developmental milestones (like language acquisition) before starting to regress at 18–24 months (Barger et al., 2013). There is contention in the medical literature about the existence of regressive autism, some of which stems from parents using claims of regression to support theories of vaccine injury. But some parents are certain their children displayed no symptoms until 18 months and thus reject their doctors' assertions that autism was present from birth. Second, many parents believe vaccines caused their children's autism. Because the medical establishment refutes this theory, beliefs of vaccine injury often motivate parents to pursue alternative therapies. Third, it is common for children with autism to suffer from “comorbidities”: eczema, allergies, sleep difficulties, gastrointestinal (GI) problems, and dietary restrictions (Mannion et al., 2013). According to conventional wisdom, these comorbidities are simply

co-occurring. Rather than a simple correlation, however, many parents understand these physiological symptoms as potential *causal* explanations for autism. For these parents, autism is not a neurological condition of the brain or a set of behavioral idiosyncrasies. Rather, autism manifests as a set of behavioral conditions that *signify* deep underlying biological disorders affecting the body's immune system, microbiome, metabolic system, and cellular function. Finally, many parents believe their children can fully “recover” from autism with the proper therapies, which causes them to seek out alternative therapies like chelation, vitamin supplements, and special diets.

Given these overlapping reasons that Somali and non-Somali parents turn to “alternative” therapies, it is not surprising that many members of the Somali support group in Toronto have ties with the “biomedical” autism movement, including organizations like Defeat Autism Now! (DAN!, now known as the Medical Academy of Pediatric Special Needs, MAPS), the Age of Autism, Generation Rescue, and Autism One. The members of these organizations refer to their approach as “biomedical” because they do not treat autism as simply a behavioral or psychiatric disorder, but understand it as a “whole body” disorder that must be treated with a variety of therapies including detoxification, immune boosting, mitochondrial reinforcement, microbiome balancing, and behavior therapies (see Decoteau and Underman, 2015; Silverman, 2012; Eyal et al., 2010). Members of these movements position themselves as antagonistic to mainstream approaches to autism etiology and therapy, in part because they view autism as an acquired illness from which children can recover.

Early leaders of the Toronto support group forged affiliations with the alternative autism movement. Adar Hassan and Idman Roble first met in 2002, when their children with autism were attending the same summer camp. They soon met Fatima Kediye, an early childhood specialist, and the three of them began a support group for Somali parents of autistic children in 2004; thirty mothers regularly attend (FGD, 6/5/14). Starting in 2005, Idman and Adar began to annually attend Autism One, where scientists affiliated with these “alternative” organizations share their latest research and therapies. Support group members also regularly visit doctors in Canada and the US who are affiliated with DAN! or MAPS. In addition, many support group members use social media to keep in regular contact with parents they have met through Autism One.

Somalis are thus attracted to the “biomedical” autism movement for many of the same reasons as wealthy and middle-class white parents. But the involvement of Somali parents is distinct from their white counterparts because their understandings of autism and their approaches to treatment are informed by experiences of racial and national exclusion.

Somalis contend that autism never existed in Somalia and that Somalis living in Western countries are particularly vulnerable to severe forms of autism – manifesting in nonverbal communication, intellectual disabilities, and aggressive behavior. “Autism is something related to North America ... it is caused by the environment here. When you compare the Somali community in North America and those in Somalia, you see autism only in North America” (Interview, Abdiwahid Jama, 7/24/15). Adar explains: “They say a Western disease now. They call it Western disease, because the kids who [are] born in Somalia, who grow up in Somalia, they don't have those kind of behaviours. They are not exhibiting at all those traits” (Interview, 6/12/14). For this reason, many parents return to Somalia to try to help their children recover from the illness. In Toronto, 12 parents I interviewed had returned to East Africa with their autistic children and seen improvements in their behaviour. They cited several reasons, including cleaner air and environment, fresher food (without genetic modification, pesticides or

herbicides), sunshine and Vitamin D (Interviews, 5/19/15; 6/11/15; 6/12/14; 6/10/15; 6/15/15; 6/19/15; 6/21/15; 7/15/15; 7/24/15; 7/26/15; 7/27/15). Safia Gassem explains: “The behavior was gone when I took [my son] to Somalia because there's no artificial ... There is no junk food. Everything's natural ... That woke me up. My son, when I took him there, the behavior is gone. After a few months, he had natural detoxification ... After six years, I came back [to Toronto]. The first week, the behavior is there that I left” (Interview, 6/3/15). Safia explains that her son's negative behaviors returned as soon as they returned to Toronto.

Based on their understanding that autism did not exist in Somalia, these parents also question the logic of genetic explanations for autism. Adar does not believe that autism is genetic because no one in her family has ever seen such behaviors. Moreover, unlike Americans, Somalis know their ancestors “like a hundred fathers back” (Interview, 6/12/14). In addition, Adar explained to me, the rates of autism prevalence have climbed steadily since the early 1990s. Adar explains, “that can't be explained genetically. Genetics don't explode ... They *know* even if they don't say it. There's something environmental” (Interview, 6/12/14).

Instead of understanding autism as a genetic disorder, many of the Somali parents I interviewed believe autism is the result of a series of environmental factors, including lack of Vitamin D (due to low sunlight exposure), shifts in gut heterogeneity due to changing diets, environmental toxins, stress, the overuse of antibiotics in health and food production, the overuse of caesarian sections in birthing practices, and vaccine exposure, especially to the Measles, Mumps and Rubella (MMR) vaccine (see also Miller-Gairy and Mofya, 2015). The following conversation took place during a focus group discussion with parents in Toronto (6/5/14):

Woman 1: The question is why we are seeing it in [the] Western context. Why are kids getting high rates of autism in Sweden, England, everywhere we know?

Woman 2: Australia.

Woman 1: Yeah. So the only thing I can come up is the environment is the big thing. Where we come from, we have sunshine the whole ... year ... [Here] we don't have a lot of Vitamin D. The food, the food we eat back home was 100% organic food. Here, the conventional food we eat, [has] pesticide and herbicide.

Woman 3: Plus GMO. Genetically modified. Most of the food here.

Woman 1: ... our kids have a lot, a lot of toxicity in their body.

Woman 3: And not to mention vaccination. So all those, when you add them together, they fill the pot and that's why our kids, they don't stand a chance. And we don't even get high functioning autistic. We get, you know, the severe forms.

Because of their understanding that autism is caused by living in a North American environment, Somalis began to question the institutional and political-economic structures that cause and treat illness (Brown et al., 2011), blaming the health and food industries for their children's vulnerability to autism. These parents then began to forge politicized illness identities tied to their experiences as forced migrants.

As Table 1 indicates, there are only slight differences in the beliefs of support group members and Somali parents recruited outside of the support group. It should be noted that parents were not asked specifically to comment on these different beliefs about autism, but were asked general questions about etiology; therefore, the “no comment” category captures parents for whom that

**Table 1**  
Comparison of Toronto informants' beliefs about autism.

Toronto	All <sup>a</sup> 25 Households; 27 Children	Support Group <sup>b</sup> 16 Households, 17 Children
Child Age @ Interview: Mean (Range)	12.5 yrs (4 –20 yrs)	13.5 yrs (5–18 yrs)
Child Age @ First Notice: Mean (Range)	1.66 yrs (1m-3 yrs)	1.7 yrs (1m-3 yrs.)
Child Age @ Diagnosis: Mean (Range)	3 yrs (2.5–4 yrs)	3 yrs (2.5–4 yrs)
Gender of Child	82% Male; 18% Female	82% Male, 18% Female
Parent Reported Severity	63% Severe; 30% Mild; 7% No Comment	76.5% Severe; 17.5% Mild; 6% No Comment
	<b>Yes</b> <b>No</b> <b>NC</b>	<b>Yes</b> <b>No</b> <b>NC</b>
Vaccines a Causal Factor?	84% 8% 8%	88% 12% –
Alternative Therapy Use?	88% 12% –	100% – –
Parent Reported Regression	37% 63% –	35% 65% –
Environmental Cause	80% – 20%	87.5% – 12.5%
Genetic Cause	12% 12% 76%	– 18.75% 81.25%
Is Recovery Possible?	48% 4% 56%	56.25% – 43.75%
Said “no autism in Somalia”	40% 4% 56%	50% – 50%
Have Visited East Africa?	44% – –	43.75% – –
Post-Return Improvement?	73% 18% 9%	71% 29% –

<sup>a</sup> Although 27 parents were interviewed, this represented only 25 households. Two of the interviewees had 2 children with autism.

<sup>b</sup> One of the interviewees had 2 children with autism.

particular explanation did not arise during the interview. One of the main differences between support group members and other informants is the involvement of the support group in research dedicated to pursuing the link between gut bacteria and autism development. According to scientists in this field, migration from Somalia to Canada could shift a population's disease profile (ABC Four Corners, 2009). One theory is that antibiotics, especially repeated doses at a young age (before the gut microbiome has stabilized), can cause permanent damage by wiping out the diversity of bacteria living in the gut. This can render children vulnerable to attack by hostile or pathogenic bacteria, which might in turn affect synaptic development in the brain (Interview, Dr. Vercoe, 6/10/14).

It is this theory of the relationship between gut heterogeneity and brain development that attracted the Somali community to researchers of the gut microbiome because so many members of the group had children who suffered from severe gut dysfunction. Fatima began to notice in 2003 that the rates of autism in the Somali community were “out of this planet” (Interview, 6/10/15) because her own caseload, as an early childhood development specialist, was expanding. She observed that the Somali children she worked with were really picky eaters and were not getting the nutrients they needed in their diets. She began to experiment with diets and saw dramatic improvements in behaviour after eliminating sugar, diversifying the diet and limiting carbohydrates (Interview, 6/10/15).

At about the same time, Adar began seeing connections between the brain and the gut. “The gut is really the crux of the problem ... it manifests through the whole body” (Interview, 6/30/15). Adar believes high dosages of antibiotics are partially responsible for the development of her son's autism:

Pneumonia came in 1999 January. We took him to the ... hospital. They treated him with an IV [intravenous] antibiotic ... [When] we get out of the hospital ... he starts tippy-toeing. Diarrhea even got worse because of the antibiotic. I think now, what I know now, the bad bacteria took over his body and wiped

out the good flora. He became completely autistic at that point when he was two years old” (Interview, 6/12/14).

This belief that the gut is the key to autism led many Somali parents to see autism as a “western disease,” linked to environmental, diet and health conditions associated with living in North America.

Fatima had read the work of Dr. Derrick MacFabe, a clinical psychiatrist at the University of Western Ontario, on pathways from gut bacteria to brain inflammation (Interview, 6/10/15). His theories about the role that pathogenic bacteria like clostridia may be playing in autistic children's guts (MacFabe, 2015) confirmed many parents' experiences that changing their children's diets improved their behaviours. When he spoke at Autism One in 2009, Fatima, Adar and Idman approached him after his presentation. He then introduced the Somali parents to Dr. Emma Allen Vercoe. These two scientists have become close with support group members – they regularly attend support group sessions, share their work and listen to the stories of the parents. Drs. MacFabe and Vercoe were intrigued by the Somali story because it supported the research they were pursuing. Dr. Vercoe explains the “disconnect” that occurs when a microbiome is suddenly uprooted due to forced migration:

The Somalis in Africa ... their ecosystem in their gut fits in Africa. You bring it here, and it doesn't fit. It's struggling. It's already struggling even if it's diverse. It's struggling because it's not getting the right substrates. It's not getting the right signals. It's getting a whole bunch of things, which it might not have had before. I'm not surprised that a shift that quick causes severe problems for some (Interview, 6/26/15).

Thirty mothers from the support group collected fecal samples from their children who had autism and gut problems. Drs. Vercoe and MacFabe are comparing the samples from the autistic children with samples from non-autistic family members living in the same household. The results of this study are not yet available.

Research about the link between the microbiome and autism is still preliminary, but is gaining national attention. It is funded at the federal level in the US and Canada, as evidenced by the tremendous investment by the US National Institutes of Health in the Human Microbiome Project (<https://commonfund.nih.gov/hmp/overview>). Autism Speaks, the largest American autism advocacy organization, has funded post-doctoral fellows examining these links (2015), and *Scientific American* has recently published an article on the topic (Moyer, 2014).

In summary, although Somali parents share some reasons for turning to “alternative” autism theories with many other parents, their experiences as immigrants also shape their beliefs about autism. These parents have forged a politicized identity as outsiders in North America. This outsider status influences their understanding of autism as a condition that they confront because their immune systems are ill-prepared for the Western climate, food, health system, and environment. In the next section, I explain how their experiences of racial exclusion also influence their beliefs about autism.

### 3.2. Embodied etiology

According to Kroll-Smith and Hugh Floyd (1997), when people challenge dominant systems of medical knowledge, they establish “practical epistemologies” which allow them to navigate their biographical experiences. But these epistemologies also challenge normative theories of the body. Somali support group members in

Toronto have a complicated understanding of autism, which draws from their personal biographies of migration and outsider status and from Somali cultural approaches to illness and embodiment. Their explanations of autism not only challenge hegemonic theories, but also establish unique corporeal ontologies that borrow from alternative scientific theories.

As Brown et al. (2003) note, “connecting a disease with a cause is a powerful effort that shapes illness experience” (p. 454). For many Somali parents, identifying the causes of autism helps them make sense of their children’s vulnerability and mobilize for access to therapeutic resources. The parents in the support group refer to autism etiology as the “perfect storm,” meaning that they see a conjuncture of causal factors that add up, at the perfect moment, to the development of autism. “An avalanche isn’t made up of just one pebble, right? Same thing ... Autism is not one thing. It’s multiple things that happen, unfortunately, for some children at the same time ...” (Fatima Kediye, Interview, 6/10/15). This conjuncture is unique for each child, so not all therapies will work on all children. But each causal conjunction incorporates theories about Somali migration from East Africa to North America, their experiences of racial exclusion in North America, and a Somali cultural approach to the body and health.

One of the main components of the conjuncture of causes commonly cited by the support group is gut bacteria. As explained in the previous section, Somali parents believe that the change of diet, health care, and environment that accompanied their forced migration from Somalia to Toronto altered their gut microbiota, which then affected their children during pregnancy and birth. Many Somali interviewees mentioned that they were given caesarean sections because Western doctors were unfamiliar with labor in women who have been circumcised (the preferred term among interviewees). Children born by caesarean delivery do not acquire the mother’s vaginal and intestinal microbes, which can lead to difficulties in the development of their immune systems (Neu and Rushing, 2011).

Many Somalis also believe that vaccines make up part of the “perfect storm.” But Somalis’ stories of vaccine harm differ from those of mainstream vaccine skeptics because they incorporate risks that are unique to refugees. “Double vaccinations” are a common part of forced migration, due to the difficulties of maintaining documentation of previous vaccines and the distrust among Western officials of vaccine cards provided in Somalia or refugee camps (Lifson et al., 2001). A public health specialist who works closely with the Somali community told me that Somali parents’ critiques of vaccines are very sophisticated because Somalis believe that too many vaccines given in a short period leads to an “overload” and that people are often vaccinated multiple times during migration (Fieldnotes, 10/23/15). One interviewee explained to me that the reason Somalis are vulnerable to vaccine injury in North America is because the vaccine dosages are stronger, given more frequently, and combine multiple vaccines into one shot, which he argues is not how they are administered in African countries:

The way they prepare the vaccination, maybe it’s not accurate ... MMR is three different vaccines ... I think there is no reason that we give our child who is 9 months—we give them 15 vaccinations within 2, 3 months ... In Kenya, Somalia, Africa, they give one by one, not in [combinations of] three or four different vaccines in one (Father, Interview, 7/24/15).

Racial exclusion also contributes to Somalis’ understandings of autism. Most Somali refugees in Toronto are settled in high-rise complexes in urban ghettos and most live in comparative poverty, reliant on the welfare system and poorly remunerated low-skill jobs. Because of these living conditions, Somalis believe

they are at risk for environmental toxicity and pollution, as well as being isolated from sources of organic and healthy food. Adar refers to this as “toxic overload” (Interview, 11/8/14). Several mothers in the Toronto support group discussed how isolated they felt when they found out their children were diagnosed with autism. They said that white mothers contribute to their isolation by refusing to engage with them at service agencies. One mother mentioned that the stigmatization she experiences when she takes her child out in public is exacerbated by feeling racially marginalized — she said it made her feel more “like an outsider” (FGD, 6/5/14). And many parents discussed the fact that they face barriers to service provision because of racial disparities, which put their children at a life-long disadvantage. For example, many Somalis believe they are being systematically excluded from early intervention programs. As Adar explains, “The Canadian government is funding millions and millions ... of dollars into [an early intensive behavioral therapy intervention] ... and we Somalians, we cannot get access to it ... you wait and wait and wait and wait” (Interview, 5/15/15). Children without access to early intervention therapies are more likely to develop more severe forms of autism. Many parents mentioned in interviews that they believed “recovery” from autism was possible, but that you had to be wealthy to achieve it, making recovery itself a privilege (Interview, 10/7/15). All racial minorities experience exclusion from autism services (which is an underexplored area of research). For Somalis, racial exclusion, xenophobia and Islamophobia combine to influence their experiences.

Many of the explanations that Somalis’ provide for autism are informed by Somali cultural approaches to healing. Somalis often explain that mental illness stems from multiple sources and cannot be healed by a single treatment, epitomized by the Somali proverb: “a sick man is advised by a hundred” (Molsa et al., 2010). It is also common for Somalis to express psychological distress through somatic complaints (Kuittinen et al., 2014). Finally, many Somalis situate their personal symptoms in broader social, political and transnational structures and forces (Zarowsky, 2000; Tiilikainen and Koehn, 2011). Somalis rarely cite biological causes when asked about the etiology of mental illnesses. Rather, they point to social and psychological strain stemming from structural issues or alienation from family and community (Zarowsky, 2000). Although most of my informants did understand autism as a biomedical issue, affecting core metabolic, immune, gut and cell function, they pointed to environmental and structural causes. For these parents, autism is caused by a whole host of environmental injuries emerging from the structural conditions of the Western world, which settle into the body. The gut bacteria theory is particularly resonant with a Somali conception of health. Fatima Kediye explained a Somali proverb, which roughly translates to “illness is the stomach.” To her, this means that illness begins in the stomach and radiates out (Interview, 6/10/15).

The conjunctural logic Somalis utilize to explain their children’s vulnerability to autism is informed by cultural beliefs: they cite multiple causes of mental illness that are structural and situational as opposed to biological, and understand illness as treatable with a variety of spiritual, biomedical, and psychological therapies. Most of the parents in this study were hybrid in their approach to healing. It was quite common for Somali parents to utilize alternative therapies, mainstream medicine, applied behavioral therapy, as well as spiritual and religious healing. Somalis’ explanations for autism also capture their experiences of alienation and marginalization: their forced migration and the health inequalities they face as poor, Black, Muslim refugees in a major Western urban metropolis. Their experiences and structural positioning are reflected in the “perfect storm” theory of autism causation, which also serves as a critique of Western welfare, housing, refugee, and health care policies and practices.

### 3.3. Somali social movements

As soon as the news came out in Minnesota, when they found out that a lot of Somalis have autistic kids ... Everybody ... came to the rescue. They paid attention and it resulted in better access to education, speech [therapy] and ABA ... Where is ours? Where is ours? We did a documentary with David Suzuki. Before that, we published an article in the *Globe and Mail*. Of all of that, not one Canadian stood up to try to help these poor, poor people who don't know ... what's happening to their kids. Who don't know how to help them (Adar Hassan, Interview, 6/12/14).

Members of the support group in Toronto have tried to gain public attention by shedding light on Somali children's vulnerability to autism. As Adar explains, they made a film with David Suzuki called the "Autism Enigma" (ABC Four Corners), which has aired on major media outlets throughout Canada since 2009. Adar was featured in a *Globe and Mail* newspaper article around the same time (Jiménez, 2009). Support group members have also met with government officials from the Ministries of Health, Child and Youth, and Education, to raise the issues of vulnerability to autism and struggles accessing services for their children. These efforts have not produced significant results.

Somalis in Minneapolis, on the other hand, have been very successful in mobilizing resources and media attention. As a result, the CDC conducted a surveillance study focused on Somalis and the Minnesota state formed a task force on autism. Somalis were key contributors to the development of an Autism Benefit. And a Somali mother in Minneapolis joined the NIH Interagency Autism Coordinating Committee, a federal committee that sets research and policy agendas (Fieldnotes, 6/13/13). Concerns about racial discrimination and racial disparities were key to the success of the Minneapolis-based social movement (Fieldnotes, 6/20/14). According to Toronto support group members, accusations of racial disparities are less successful in Canada due to the colorblind discourse of multiculturalism. Idman Roble told me that when people are accused of being racist in Canada, they back away instead of stepping up. People try so hard, she said, to avoid conversations about race that they make racism worse. Idman explained that when support group members discuss the high rates of autism in the Somali community with government officials, they are told, "we cannot look into this without any proof of what you are saying." Idman responds by asking, "how are we to get proof if no one is willing to help us?" (Fieldnotes, 6/13/15).

Despite their difficulties gaining the attention of the public and government, Somali parents in Toronto have had some success in social movement organizing. They made a film, formed a support group, and joined in research with scientists exploring the connections between autism and the microbiome. They also built connections with other social movements, thus benefitting from social movement spillover (Brown et al., 2004). They have worked with a refugee resettlement agency organizing for Somalis' rights to housing, jobs, education and citizenship. This allows support group members to understand their struggles, at least in part, through a racial lens that is broader than health disparities. It also helps them focus attention on structural matters like access to housing and education. And, as I have already explained, many Somalis have also joined forces with alternative autism movements like DAN!

Somali parents and Drs MacFabe and Vercoe are drawn to their collaboration for the same reasons: gut bacteria allows them to explore possible environmental factors related to the development of autism. Although microbiome research is beginning to garner attention, environmental causes have received far less investment than genetic research. The microbiome provides a new gateway for

explorations of environmental causality and may help explain why a migrant community is experiencing high rates of autism. While Brown et al. (2004) point to the importance of conceptualizing EHMs as lay-expert hybrids, they do not highlight the epistemological significance of these collaborations. Because their migration lends credence to the gut bacteria theory of autism, Somali parents' experiences are important sites for the production of new knowledge that challenges the epistemic hegemony of mainstream autism science. They do so by centering their experiences of racial and national exclusion.

### 4. Discussion and conclusion

Epstein argues that a focus on illness identity in social movement organizing can be problematic because it presumes internal homogeneity and assumes that experiences of illness exceed other experiences of exclusion (2008, p. 509). He quotes Cartwright, who cautions "experiences and cultures of illnesses ... are always lived through identity positions ... that exceed the frameworks and cultures of disease" (2000, pp. 21–22, quoted in Epstein, 2008, p. 509). Taking this into account, I argue that race and nationality matter for how illnesses are embodied, explained and mobilized around. To ignore this aspect of embodiment in theories of EHMs is to disregard not only a critical variable that leads to health organizing, but also an important feature of illness experience itself. Brown and colleagues (2003 and 2004) recognize that experiences of racial, structural exclusion can become primary factors in the emergence of "politicized illness identities." Yet the existing literature has not fully examined *how* race and nationality matter to people involved in EHMs. In this article, I have illustrated the ways that Somalis' illness narratives are inextricable from their experiences of racial and national exclusion by focusing on the impact of Somalis' immigrant status on their understandings of autism's etiology and their questioning of the medical mainstream, the impact of Somali cultural approaches on their understanding of health and embodiment, and the impact of racial exclusion on their mobilization toward a "politicized illness identity."

I have shown that race and nationality play key roles in the pathways Somalis take toward group construction, in their explanations of the etiology and ontology of autism, and in their efforts to mobilize on behalf of their children – to receive recognition of their plight and access to better services, but also to participate in innovative research that might offer hope for new therapies. First, with regard to group construction, the Somalis I interviewed suggested that forced migration to North America was a primary causal factor for their children's development of autism. Nationality thus played a key role in their coming together as a social movement. Second, race and nationality were integral to their conceptualization of autism as resulting from a conjuncture of environmental insults and structural exclusions. Finally, race and nationality were also important for their mobilization around autism. The Toronto support group has been less successful than groups in Minneapolis raising concerns about racial exclusion. But their attention to gut bacteria and environmental insult have allowed them to join forces with other social movements and to collaborate with scientists exploring links between autism and the microbiome. This scientific collaboration is important because it unveils the epistemological role that laypeople involved in EHMs can play in shifting the site of knowledge production to challenge mainstream science.

In addition, centering Somali immigrant experiences brings into focus a unique explanation for why people pursue contested theories of illness causation. Existing explanations for the popularity of heterodox approaches to autism are enhanced and given new meaning when migration, racial exclusion and non-western cultural ontologies of the body are considered. Throughout its

contested history, autism has inspired the use of alternative therapies; however, this case contextualizes how cultural and structural dynamics associated with racial inequality and difference operate as causal mechanisms for heterodox health beliefs and practices. This case also suggests that the unique health conditions and experiences of immigrant populations are an important site for future research.

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