The ‘Western Disease’: Autism in the Somali Refugee Population

Introduction

How do Somali parents make sense of the high prevalence of autism in their communities? How does their understanding influence their health-seeking behaviors for their children?

There is some research suggesting Somali refugee populations have a higher rate of autism than many other racial/ethnic groups in the United States and Canada. Somali-Americans and Canadians call autism the ‘Western disease’ because there is no word for autism in the Somali language and because they claim autism does not exist in Somalia. Yet Somali parents have been confronted with the ‘Western disease’ as they immigrate to the U.S. and Canada and have different explanations for the epidemic. The most prevalent explanations are that: 1) autism is caused by childhood vaccinations (refugee communities are often vaccinated several times during the immigration process); 2) rising rates of autism stem from shifts in diagnostic categories; and 3) shifts in lifestyle (diet and healthcare) alter mother and child gut bacteria making children more vulnerable to autism and other chronic medical conditions. Some Somali parents have formed support groups and advocacy organizations to help them make sense of the causes of autism and fight for treatment for their children.

This project uses focus groups, observations, and interviews with parents, community stakeholders and autism professionals to understand what services are available to children with autism, how Somali parents come to understand autism and how their understandings impact their ideas about healing and health-seeking behaviors. The parents in this study are Somali refugees living in Minneapolis, MN and Toronto, ON.

Findings

- Experiences of marginalization are reflected in the narratives of causation provided by Somali parents. The blaming of vaccines and of the Western lifestyle operates as a critique of their alienation as refugees and of their experiences of racism within the health and welfare system.

- Somali immigrants face serious challenges in accessing resources for their children due to their immigrant and low socioeconomic status. Unequal access to health services, as well as institutionalized racism and xenophobia confront them as they navigate existing systems in search of health care for their children.

- Somali parents of children with autism are caught up in broader debates about the politics of autism and health-related social movements that challenge mainstream science, but their critique of mainstream scientific approaches to autism comes from their experience as racialized others.

Recommendations

The influence of racial and xenophobic isolation in leading to health inequalities needs to be taken account of by health practitioners when dealing with vulnerable populations. Health practitioners and consumers should also recognize that the alienation of vulnerable populations can lead to the development of health ideologies that challenge scientific norms. Culturally sensitive policy initiatives focusing on health care are therefore needed to support refugee populations struggling with institutionalized racism and xenophobia in health provision.
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