

Measles, autism and vaccination in the Minnesota Somali community

Public health education campaigns must recognize and respect cultural experiences if they are to be successful

BY FAIZA AZIZ AND STEVEN H. MILES, MD

In March 2011, Minnesota experienced a measles outbreak that arose within, and was largely confined to, the Somali community. Twenty-one cases in Hennepin County were linked to a U.S.-born child of Somali descent who had developed symptoms after travel to Kenya. Sixteen of the 21 individuals had not been fully vaccinated. Of those, nine were old enough to have received MMR vaccination. Six of the seven infected Somali children were too young to have received vaccinations.

Public health officials and news media focused on how the Somali community was receptive to Andrew Wakefield's spurious claim that the measles, mumps and rubella (MMR) vaccine increased the risk of autism, but did not explain why many in the Somali community were susceptible to these claims.

Somalis' unique experience with illness, health care and disease prevention as they left their homeland, sojourned through refugee camps and came to Minnesota shaped the response to the false claim that vaccines cause autism. Many in the Somali community were receptive to false arguments and avoided vaccinations because of:

- Vaccination experiences in Somalia and during immigration.
- Cultural beliefs and expectations affecting Somalis' use of medical care.
- Somalis' perception of autism.
- The media's influence on the community's response to a perceived health crisis.

Measles and vaccinations

Measles is a highly contagious, vaccine-preventable disease. It is a leading cause of death and disability in young children around the world. By 2000, measles had

been largely eliminated in the United States, except for occasional imported cases from developing regions still experiencing outbreaks.

In Somalia, measles is prevalent and leads to high mortality for children younger than 5 years (200 per 1,000 live births). In Somalia and in regional refugee camps, overcrowding, high rates of lung

large refugee camps in Kenya and Ethiopia. Poor sanitation, overcrowding, malnutrition and violence present challenges to United Nations vaccination programs in the camps.

Somalis who are accepted for immigration to the United States go through a medical examination and receive mandatory immunizations. Refugees are medi-

“ How can you help someone you cannot communicate with?

It was hell what I went through with my son. I had to drive him around in my car almost every night when he was little because he would not sleep or calm down...Your life stops when you have an autistic child...You cannot leave them alone, because they might harm themselves. Thank God he is able to care somewhat for himself now, but he still cannot talk after years of therapy.

“I have had measles before, and it was not as bad as autism. You are sick for a couple of days, then you get better. Autism damages for life...it is irreversible.”

– Minnesota Somali father of an autistic child

disease, malnutrition and limited medical care increase the risk of transmission of measles and of ensuing outbreaks. Despite extreme logistical problems, for many years, Somalis had welcomed vaccination in Somalia, where more than half the children are vaccinated. In 1991, the fall of the Somali government and the ensuing collapse of the public health infrastructure damaged national disease surveillance and vaccination programs. Since then, clan rivalries have prevented the formation of national institutions. Many Somalis fled to

cally examined and vaccination status is confirmed on arrival in the United States.

Changing perceptions about vaccinations

Although Somalia is desperately poor and disrupted, rising immunization rates and falling measles rates show broad interest in vaccination to prevent acute disease. In Somalia, clinical care is scarce and is used for treatment of infections, traumas or disabilities, rather than for prevention. Outreach programs through donor orga-

nizations provide supplementary vaccinations. In Somalia, measles is common and vaccinations are valued because clinics for treating illness are scarce and costly.

When they arrive in the United States, Somalis find clinics to be readily available and measles to be rare, and they have high expectations of the efficacy of disease treatment, so they tend to place less value on preventive health care.

As Somalis in the United States do their risk-benefit analysis, the idea that a chronic complication such as autism might arise from the vaccine can lead them to be highly vaccine-averse.

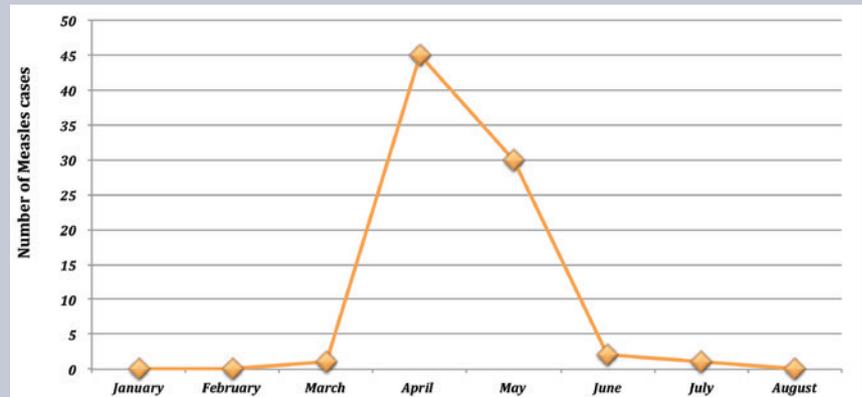
Perceptions of autism

Autism spectrum disorders (ASD) are global neuro-developmental disorders affecting all races and socio-economic groups. ASDs are characterized by a wide range of symptoms, including cognitive and functional disabilities. According to the Centers for Disease Control (CDC), the increasing number of cases of ASD in the United States may be because more are identified through school-based screening and special education programs. It was the results of school-based screening for possible learning disabilities that ignited fears of excess autism in the Somali community. Autism is known in East Africa; there are autism treatment centers in Ethiopia and Kenya. However, many African clinics are not capable of diagnosing ASDs. Some West Africans who care for children attribute ASD symptoms to supernatural causes such as angered ancestral spirits, sinful wrongdoing (most often by the mother) or by action of the devil. In general, the stigma of mental health disorders is a barrier to seeking care. Symptomatic children often are taken to traditional healers before they are seen in medical clinics.

The lack of recognition and identification of ASD in Somalia, contrasted with cases identified through routine school-based screening in the United States, at least partially set the stage for Somalis in the United States believing that ASD was a new health risk for them, incurred during immigration.

FIGURE 1

Minnesota Measles Cases, January-August 2017



Reported Measles cases in Minnesota from January-August 2017 as the outbreak was winding down (Source: Minnesota Department of Health)

Autism, vaccine hesitancy and the 2011 measles outbreak

Three years before the 2011 measles outbreak, a Minnesota Somali parent saw media reports that an unusually high number of Somali school children were being referred to autism-assessment programs. She raised alarms in the Somali community. In 2009, in response to Somali concerns, the Minnesota Department of Health (MDH) collaborated with Minneapolis Public Schools (MPS) to measure the proportion of Somali preschoolers receiving ASD services and found it to be elevated, consistent with the community perception. Vaccine opponents quickly spread information from a 1998 paper by Andrew Wakefield that posited a causal link between ASD and the MMR vaccine. In 2010, *The Lancet*, the journal that had published Wakefield's paper, retracted it and Wakefield's medical license was revoked, but vaccine opponents kept Wakefield's debunked view and celebrity alive. By March 2011, vaccination opponents had organized at least three meetings between Andrew Wakefield and Somali parents in a Minneapolis Somali restaurant. Media coverage engendered by his celebrity and the idea of covering "all sides of the issue" fueled the myth that there was a scientific controversy.

The Somali community is built on extended kinship relationships. Communi-

cation tends to be oral and many Somalis, especially mothers, are not fluent in English. Rumors about the fallacious association between measles vaccination and an increased risk of autism rapidly spread. As Somalis heard that the MMR vaccine increased the risk of autism, immunization rates for Somalis dropped rapidly. And in 2011, there was a first measles outbreak.

Few Minnesota Somalis knew of autism before the 2011 launch of the Minneapolis Somali Autism Spectrum Disorder Prevalence Project (MSASDPP), which was funded by the CDC, the National Institutes of Health (NIH) and Autism Speaks. It was designed to assess whether Somali children in Minneapolis, 7 to 9 years of age, had a higher prevalence of autism than non-Somali children. Its 2013 report noted that Somali and Caucasian children had the same incidence of ASD but that Somali children suffered more severe cognitive defects, possibly because of other experiential or environmental factors.

It is an oversimplification to conclude that Somali parents who rejected measles vaccination for their children are anti-vaxxers, anti-science or homeopaths. A 2014 study examined challenges facing the Somali, Hmong and Latino communities. It found that Somali parents were not anti-Western medicine or passive about seeking care. Indeed, they actively sought out services and alternatives for their

children from schools, ASD centers and expert medical advisers and advocated for insurance coverage to provide family, educational and supportive care service.

The 2017 Measles Outbreak

In 2017, Minnesota’s Somali community experienced another outbreak of measles. Sixty-four of the 79 Somali cases lived in Hennepin County. Statewide, 71 of the 79 children under the age of 10 with measles had not been vaccinated. By the time the outbreak was declared over on Aug. 25, 2017, at least 500 people had been identified as exposed, the most since 1990.

The Somali vaccination rates during the 2017 epidemic showed progress. As the outbreak peaked in the months of April and May, there also was a surge in MMR vaccination administered, particularly in the hardest hit region of the state, Hennepin County (Figures 1 and 2). The number of people vaccinated in 2016 greatly exceeded the number during the 2011 outbreak.

In April and May 2017, two community forums to listen to the public health message were held. Public health officials, Somali leaders and Somali health practitio-

ners who attended were well prepared with facts. But the public forum was conducted in English without bilateral simultaneous translation (speaker to audience and audience questioner to speaker), as is standard practice for cross-cultural health presentations in refugee camps. The lack of simultaneous translation deterred attendance and participation by less enculturated members of the Somali community and by mothers, who are less likely to speak English. The core message of the panelists was: “Vaccinate; the measles vaccination does not cause autism.” The panelists noted that vaccine hesitancy is deeply rooted, but they did not address why or how these roots were formed.

The public health officials did not outline any plans for future autism studies in the Somali community. Given the skepticism of the Somali community about the applicability of studies of the autism-vaccine relationship in European communities, this seemed a missed opportunity to reassure the community that the biomedical susceptibility to autism is the same in Europeans, North Americans and Somalis.

Going forward

Health risks in children engender high emotions. Anxious parents will interpret information in light of science, experience, anecdotes, love and fear. Some criticized parents who did not vaccinate their children because of unwarranted fears. They even argued that such parents were negligent, unconcerned about their child’s interests or the public health. Such criticism is off the mark; non-vaccinating parents are trying to protect, not endanger, their children. A civil and culturally informed dialogue is needed to prevent the next measles outbreak.

Minnesota’s public health officials have much to do if they are to prevent another measles outbreak. Certainly, they must encourage vaccination and rebut the Wakefield fraud as they have done. In addition:

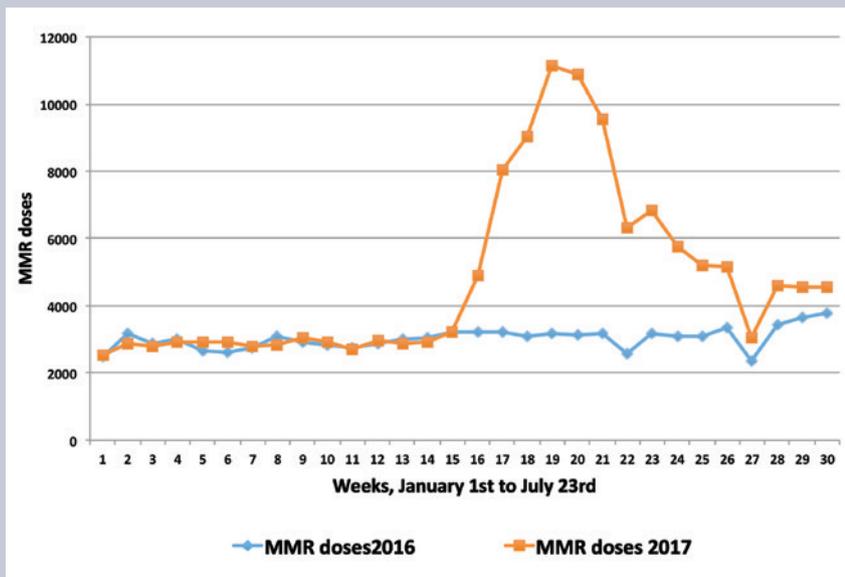
- They must work with media so that news coverage does not legitimize a spurious vaccine controversy with two-sided coverage of Wakefield’s position.
- Their communication with the Somali community must be more substantive than handing out multilingual pamphlets and engaging Somali leaders.
- Public meetings must have full real-time bilateral translation of all presentations and audience questions if they are to draw Somalis who are not fluent in English and who are otherwise influenced by lay peers.
- They should seek to understand and engage how the Somalis’ experience in their homeland, in refugee camps and through immigration has shaped their understanding of the benefits and risks of vaccination.

Health departments must cultivate better ongoing community engagement, rather than simply prioritize relations with the Somali community during disease outbreaks. **MM**

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FIGURE 2

MMR Vaccine Doses Administered by week, 2016 vs 2017



A comparison of 2016 vs 2017 weekly number of Measles, Mumps, and Rubella (MMR) vaccine administered from January 1 through July 23.

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