Reluctance to Vaccinate:
Attitudes, Beliefs and Behaviors of Somali Mothers of King County

Consuelo Echeverria
Our specific qualitative research goals were to better understand the dimensions of knowledge, beliefs, attitudes and practices among the Somali community with respect to:

**Aim 1:** Vaccinations in general.

**Aim 2:** The MMR vaccine in particular, and its association with ASD.

**Aim 3:** How these vary between Somali parents who:
- Have **not** had a child diagnosis with ASD.
- Have had a child diagnosed with ASD.
Measles in USA

In 2000 measles was declared eliminated.

(Orenstein et al., 2004; CDC National Center for Immunization and Respiratory Diseases, 2015)
From Jan. 2014 to March 2015

751 confirmed measles cases

2014:
• 592 measles cases
• 18 outbreaks

2015
• 159 measles cases
• 4 outbreaks

Highest number of cases since measles was declared eliminated in 2000.
Policy is insufficient, we have to consider behavioral factors.
What is a Refugee

Refugee is a legal category of personhood where an asylum seeker must prove a well-founded fear that her government will not protect her for one of five reasons:

• Race
• Religion
• Political opinion
• Social Group
• Nationality

Once recognized a refugee has certain legal rights:

• Access to employment
• Access to education
• The right of non-refoulement (protection from forcible repatriation).

(The 1951 Convention relating to the Status of Refugees, 1967 Protocol, UNHCR)
Who are Refugees?
The Refugee Story

• Pre-migration phase: violent conflict, persecution, disappearances, deaths, & deprivation.

• Migration phase:
  
  Forced & usually sudden evacuation
  Dangers from geography, wild animals, & lack of basic resources.
  Further separation from family members.
  Further violent events: rape, forced conscription (child solders).
  Lengthy stays in refugee camps or cities w/o legal status meaning,
  discrimination & inadequate access to
  education, employment, food, clean water, and security.

  These experiences impact trust in outsiders and systems

(Betancourt et al., 2012; Henley & Robinson, 2011; Ellis et al, 2008; Kanu, 2008)
Why Lack of Trust - Context
Somalis in Seattle -
20-40,000 in King County
- Don’t speak English
- National and State Census
etnicity is not specified for
  African Americans.
- PATH 2010 landscape analysis of
  South Seattle found
  significant racial, linguistic, and
  sociocultural diversity.
  high rates of poverty.
  poor health outcomes.

“SeaTac and Tukwila have health indices
nearly identical to Nairobi, Kenya.”

Dr. Dan Dixon
Swedish Health Services

(Chandler Felt, Demographer, King County, Seattle Wa.; Cohen, J., McGray, S., 2010)
Thesis Question

Our specific qualitative research goals were to better understand the dimensions of knowledge, beliefs, attitudes and practices among the Somali community with respect to:

**Aim 1:** Vaccinations in general.

**Aim 2:** The MMR vaccine in particular, and its association with ASD.

**Aim 3:** How these vary between Somali parents who:
Have **not** had a child diagnosis with ASD.
Have had had a child diagnosed with ASD.
Community Based Participatory Research

Effective methodology for research in closed pocket communities
Cultural and contextual relevance of the study is increased.

Sampling Plan: Purposeful sampling
1. Intensity samples: information-rich cases i.e. Somali mothers of children w/ ASD

2. Critical case samples: permit generalization i.e Somali mothers without a child w/ ASD, 2 sample populations give understand if impact of a child w/ ASD effects intent to vaccinate

3. To avoid pocket effect interview in spread out geographically:
   6 in South Seattle; 4 in West Seattle; 2 in North Seattle; 2 in Central Seattle; 3; South King County.
Bias is Positive

Bias implies that the subject is an expert in his or her field and has very strong opinions.

An understanding of these opinions is necessary for a critical analysis of the drivers of vaccine hesitancy in this population.
Selection Criterion

Intensity samples: Somali mothers 18-45, born overseas, live the King County
1. one child who has been diagnosed with ASD between the ages of 2 to 10 years old (Index child)
2. a subsequent child who at the time of ASD child’s diagnosis was either not yet born or over 12 months later.

Critical case sample: Somali mothers 18-45, born overseas, live in King County
1. without a child with a developmental disorder (Criterion child)
2. having a child that is a match to an ASD child in this study age plus or minus one year,
   Parity (1-2, 2-4, 4-6, 6+ previous siblings)

Exclusion criteria:
1. Somali Mothers with 1+ ASD child
2. Born in the USA
METHODODOLOGY

Consent:
Mitigate possibility of cohesion:
• read in Somali the same way to each person
• $25 Safeway card
• Signature was accepted as consent given

Recruitment:
• Study Partner Farhiya Mohamed visits participant’s house to explain the study

Data Analysis:
• Grounded Theory using the Integrated Behavioral Model
Social influence:
- Who should vaccinate their children?

Personal agency:
- Barrier of knowledge
- Do vaccines protect you against measles, mumps, ear aches…?

IBM supports more effective interventions because one can assign personal statements to the constructs, measures of self-efficacy, the intention for a behavior or actual behavior.

Results

Description of Study Population

N=23

• 17 mothers ages 19 - 45
• 31-36 mean age group
  Not born in the USA; resided in the King County; children were born USA
• 8 married, 9 divorced
• Mean of 4 children – (3.78, range 3 - 6 children)
• $12-$20,000  Mean income range - all 17 participants at the poverty line
• 11.5 years mean time in USA – (range 2 to 20 years)
  23% living in the USA less than 5 years

• 6 had index child (ASD) < 10 yrs old and a younger child born more than one year later
• 11 had criterion child who matches (+/- 2 yrs) the index child

• **All but one of the mothers had friends or family in Minnesota**
Results

After 15 interviews, themes were established.

Last 2 interview with critical cases to confirm themes;
   Experts as a child care provider and an early education teacher.

Focus group held to confirm results - 6 women all professionals
<table>
<thead>
<tr>
<th>IBM Constructs</th>
<th>Measure</th>
<th>Example of Response</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experiential</td>
<td>Feelings about Behavior</td>
<td>&quot;I worry it can affect her mind, no I worry it can damage her mind&quot;</td>
<td>Worry/fear of specifically MMR vaccine causes ASD</td>
</tr>
<tr>
<td>Attitudes</td>
<td>(Emotional response to behavior)</td>
<td>“I would like to give my child those ones, [vaccines] are important but like [the] MMR, that one, I have to get a good decision.”</td>
<td>No fear of other vaccine side effects</td>
</tr>
<tr>
<td>IBM Constructs Measure</td>
<td>Example of Response</td>
<td>Themes</td>
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<tr>
<td>Instrumental Attitude</td>
<td>“they curse you... they gossip, she is not a good person...they say she is a bad mom...”.</td>
<td>Stigma of having a disabled child</td>
<td></td>
</tr>
<tr>
<td></td>
<td>“My child is more protected from disease, and keeps them (the children) healthy”.</td>
<td>MMR vaccine protects against measles</td>
<td></td>
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<tr>
<td></td>
<td>“this disease does not exist in the USA, only in Africa”</td>
<td>Belief in a low risk of catching measles</td>
<td></td>
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<tr>
<td></td>
<td>“good medicine in the USA, they will fix my kid if she gets sick”</td>
<td>Belief that measles is not a dangerous disease</td>
<td></td>
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<td></td>
<td>“I did not see anything in Africa but I find out here when the kids they get their shot and get sick”</td>
<td>Perception that the Somali community has higher rates of ASD than other communities</td>
<td></td>
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</tbody>
</table>

Table 1 Table of Themes Pile Sorted by the Integrated Behavioral Model
<table>
<thead>
<tr>
<th>IBM Constructs</th>
<th>Measure</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Injunctive norm</td>
<td>Beliefs about other expectations</td>
<td>&quot;yes you(pl.) should do that to protect the kids&quot;</td>
<td>Should vaccinate against measles</td>
</tr>
<tr>
<td>IBM Constructs</td>
<td>Measure</td>
<td>Example of Response</td>
<td>Themes</td>
</tr>
<tr>
<td>----------------</td>
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<td>--------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------</td>
</tr>
<tr>
<td>Descriptive norm</td>
<td>Descriptive belief</td>
<td>“My doctor she is so nice, but we listen too hard when others (Somali mothers) speak too”</td>
<td>Trust in community is higher than trust in doctors</td>
</tr>
<tr>
<td></td>
<td>(What you do)</td>
<td>“I will not vaccinate my others”</td>
<td>MMR Vaccine delaying and refusing behaviors</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I heard the gelatin [in the vaccines] and you know we cannot take the (pork) gelatin.”</td>
<td>Gelatin from Pork in vaccines</td>
</tr>
<tr>
<td>IBM Constructs Measure</td>
<td>Example of Response</td>
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<tr>
<td>------------------------</td>
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<tr>
<td>Personal agency</td>
<td></td>
<td></td>
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<tr>
<td>Barriers</td>
<td></td>
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<tr>
<td>Facilitators</td>
<td></td>
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</tbody>
</table>

**Table 1**

Table of Themes Pile Sorted by the Integrated Behavioral Model

<table>
<thead>
<tr>
<th>Disease</th>
<th>IBM Constructs Measure</th>
<th>Measure</th>
<th>Example of Response</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tetanus</td>
<td></td>
<td></td>
<td>16</td>
<td>1</td>
</tr>
<tr>
<td>Pneumonia</td>
<td></td>
<td></td>
<td>16</td>
<td>1</td>
</tr>
<tr>
<td>Mumps</td>
<td></td>
<td></td>
<td>17</td>
<td></td>
</tr>
<tr>
<td>Meningitis</td>
<td></td>
<td></td>
<td>16</td>
<td>1</td>
</tr>
<tr>
<td>Measles</td>
<td></td>
<td></td>
<td>16</td>
<td>1</td>
</tr>
<tr>
<td>Hepatitis</td>
<td></td>
<td></td>
<td>15</td>
<td>2</td>
</tr>
<tr>
<td>Ear Aches</td>
<td></td>
<td></td>
<td>15</td>
<td>2</td>
</tr>
<tr>
<td>Polio</td>
<td></td>
<td></td>
<td>16</td>
<td>1</td>
</tr>
<tr>
<td>Chickenpox</td>
<td></td>
<td></td>
<td>16</td>
<td>1</td>
</tr>
<tr>
<td>Blood infections</td>
<td></td>
<td></td>
<td>14</td>
<td>2</td>
</tr>
</tbody>
</table>

**Question:** Do vaccines protect you against the following diseases?

**Options:** Y, N, Unsure

- **Tetanus:** 16 (Y)
- **Pneumonia:** 16 (Y)
- **Mumps:** 17
- **Meningitis:** 16 (Y)
- **Measles:** 16
- **Hepatitis:** 15 (2)
- **Ear Aches:** 15 (2)
- **Polio:** 16 (Y)
- **Chickenpox:** 16
- **Blood infections:** 14 (2)

**Themes:**

- Lack of health knowledge
- Willingness to learn
Discussion

CBPR:
The Task Force was essential for access to Somali Mothers and to translate IBM categories into a culturally competent tool:

• Language, using the plural ‘you’ found in Somali which implies social norms.
• Changed three-point and five-point scale questions to “yes/no” or circle responses.

The cultural sensitivity of the questionnaire would have been impossible without the input from our community partner.
Attitudes: Feelings about Behavior

- 2 contradictory emotions:
  Mothers feel good when they protect their child with vaccines.
  Mothers are scared that the MMR vaccine will cause ASD.
- Delay and refuse behaviors is not driven by distrust of big Pharma and government.
  Underlying the fear of having a child with ASD lies stigma and shame.
- Fears and beliefs target only MMR vaccines not other vaccines

The public health significance:
- No studies have accessed the health impact of the stigma of having a disabled child on the Somali community’s health practices and how those practices impact the health of the general population.
Belief in higher rates of ASD in Somali Community

2009 Minnesota Department of Health’s analysis of Minneapolis Early Childhood Special Education enrollment data.

6% of school age children in Minnesota,
25% of those attending ASD special needs programs are Somali

Re-enforced a belief in the Somali population of a higher rates of ASD than the host community.

But

2013 Minneapolis Somali ASD Prevalence Project Community Report found:

1 in 32 Somali children were identified as having ASD
1 in 36 in the white population

Public Health Significance:

• Failure to educate the Somali community on the results points to a need for a culturally acceptable format to educate this population.
Social Influences

- Not vaccinating is the social norm driven by the belief that the MMR vaccine causes ASD. Wakefield came to MN and talked with leaders in the Somali community 3 times reinforcing this belief. Many Somalis in Seattle have family and friends in MN means there is a low motivation to comply with vaccinating children with MMR as the perception of behavior is not to vaccinate.

The public health significance:
- Impact in the Minnesota Somali community drop in MMR vaccine rates from 91% in 2004 to 48% in 2010

No studies as yet to evaluate MMR vaccine adherence in Washington State. This is a significant gap as Somali tend to have very large families ($x = 4$ children), making the severity of risk within the pocket community very high, and increasing the chance they will impact the health of the general population.

(Gahr et al., 2014)
Psychological impact of Refugee Story

• Impact of war on populations is catastrophic,  
  Low level of trust in non-community members and systems
• For any public health intervention to be effective the specific psychological state of the community must be understood:  
  establish trust between the community and the health educators. 
  educators recognize the importance of stigma in this population.

Health Education: tea&Talk

• A strategy for culturally acceptable intervention:  
  Low stigma health topic then high stigma topics  
  Allows for a higher participation rate  
  Fosters trust
• Use culturally acceptable resources like the WHO Letter on the Islamic Legal Scholars' Verdict on the Medicinal Use of Gelatin Derived from Pork Products, which approves the use the porcine gelatin for consumption in vaccines.
Limitations of the Study

- This cohort represents a specific geographic and socio-economic group. We do not claim that they represent the entire Somali community.
- Qualitative study and did not collect statistical data on the actual percentage of adherence to MMR vaccination nor the actual rates of ASD in the Somali community.
- Solely includes Somali mothers, and our attempt to reach out to fathers was not successful. Future studies will need to include fathers to allow us to better understand their attitudes and impact vaccine adherence.
- Very small sample size, can not validate themes as drivers of behavior. Survey needed to validate behavioral determinants to be used in health education proposed tea& Talks.

These are gaps that need to be filled.
Thank you

To the Immunization Action Coalition of WA Quarterly Meeting

To my three advisors Drs. Kasprzyk, Heyer & Duerr who believed in me kept on saying
  “research is hard don’t give up”

To my amazing partner and founder of the Somali Task Force  Farhiya Mohamed
Decline in MMR vaccination rate in the MN Somali community

2004:
- 91.1% of Somali children had MMR

2010:
- 37% Somali children had MMR vaccine

MMR vaccine coverage declined 54%

Driving Factor

MMR vaccines cause ASD