

BARRIERS TO QUALITY HEALTHCARE FOR EAST AFRICAN FAMILIES AS IDENTIFIED BY EAST AFRICAN WOMEN

A PARTICIPATORY ACTION RESEARCH STUDY CONDUCTED BY

City Heights Hope

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EXECUTIVE SUMMARY

City Heights Hope is a network of approximately two hundred women. Most of its members are Somali with a small but committed contingent of women from Ethiopia and Eritrea. This group formed in the Summer of 2009 to address the "food environment" for East African families. Since then this group has grown in its strength and influence. Umoja-East African Community is a much newer group, having formed within the past year. It is made up of families who speak Swahili and come from six different countries. Together, a group of 23 women [17 from City Heights Hope; 6 from Umoja] developed and conducted a survey of more than 200 East African women refugees living in San Diego concerning barriers to quality healthcare for East African Families. The average age of women interviewed was 36 to 40 years old; 83% had children, the number of children ranged from one to ten with four being the average. More than half (59%) of the respondents arrived in the United States in 2000 or later. Most of the women (71%) speak Somali, 15% speak Swahili, 7% speak Amharic, 4% speak Arabic, 3% speak Tigre, and only one respondent reported English as her primary language. While many of the women (42%) spoke more than one language, very few spoke English as 80% reported that they understood little or none of the English they hear. Very few of these women were provided with interpretation (approximately 19%) or translated material (approximately 6%) when they accessed the healthcare system.

The key finding of the study was how poor the level of communication is between the respondent and her healthcare provider. Two-thirds (65%) reported that they understood their doctor poorly, 62% reported that their doctor understood them poorly, 59% reported that they understood the provider's aftercare instructions poorly, and 65% reported poorly understanding their medications. The low quality of communication seems to have an impact on both the quality of care and the quality of service provided. Women who don't speak English reported being misdiagnosed nearly twice as often as those who do speak English. Additionally, women who don't speak English reported having to return to the doctor for the same symptoms more than women who did speak English. While having the same doctor at every visit did improve the situation slightly, it did not overcome the negative impact of the language barrier. As for quality of service, it was found that women who don't speak English wait significantly longer to see to see the doctor than women who do (1 hour and 58 minutes as compared to 49 minutes).

The conclusion of this research is that the quality of the healthcare provided is directly related to the quality of communication between the healthcare provider and the patient. Without a mutually satisfactory resolution to the language barrier there can be no quality healthcare. While addressing other issues such as childcare, transportation, having the same doctor each visit, etc. would have some impact, neither any one nor all combined can overcome the negative impact of the language barrier on the patient-provider relationship.

RECOMMENDATIONS

Once the data were collected, and analyzed it was presented to the women who conducted the survey for interpretation. Based on these results, their experiences conducting the survey, and their own experiences, they developed the following recommendations for addressing the language barrier. These are:

1. All signs in providers' offices and pharmacies in our languages
2. Face-to-face interpreters who are native speakers in our language

3. Female interpreters for female patients
4. Female doctors for female patients
5. Be able to make appointments by phone
6. Have interpretation arranged prior to our appointment
7. All written material (including application) in our languages
8. Assistance in our own language with all forms
9. Assistance with transportation
10. Place and materials for children in doctor's office
11. Hire and train members of our community to be interpreters
12. No one waits more than 30 minutes in the waiting room for the doctor

These recommendations are meant to be the foundation for a dialogue within the broader community regarding the issue of real access to quality healthcare for those represented by this study. It is only through such a dialogue where clients, providers, funders, etc. sit as authentic partners that a long-term, sustainable solution to this issue can be developed.

INTRODUCTION

This research emerged from a California Endowment funded project that was designed to improve the health of East African families living in and around the City Heights neighborhood of San Diego. Using a place-based approach,¹ the project began by organizing women from East Africa to address their "food environment." The women who first came together were Muslim, mostly from Somalia with a small but continuously involved group of women from Ethiopia and Eritrea. The women's religion is important to note because their children's access to foods that meet the standards of their religion, i.e. halal foods, is one of their primary concerns. The first task of the new group was to conduct a participatory photography project that involved a group of six women and fourteen girls between the ages of fourteen and eighteen. These women and girls took pictures of their "food environment" which were then used to identify their perspective on access to healthy, culturally appropriate foods. What was identified, however, was deeper than food. From this work, both the mothers and the daughters identified the cultural gap between them as the central issue of concern. Food is but one of the main stages where the conflicts arising from this cultural gap are being played out.²

Having raised this issue, the group began to focus its energy on ways to address this gap. The group began conducting mother-daughter cooking classes. These were a core activity that allowed the mothers to teach their daughters traditional dishes and allowed the daughters to explore new foods with their mothers. Nutrition education was embedded in these classes so that the women could learn how to prepare healthy meals using the foods available to them, i.e., American food. The bond that developed as a result of these classes served to close the cultural gap. In addition, a small group of Somali college students planned and implemented a summer program that served nearly 100 elementary and middle-school children. The program used volunteers from the community and focused on the children learning their culture and getting healthy food and exercise. As this work was being accomplished, the group formed its identity, City Heights Hope, and began to develop a sense of competence and confidence. They learned to speak up and articulate the issues and concerns for their community and they demonstrated the capacity to develop and carry-out programs to address those concerns. They also earned a reputation in the broader community as an organization that represented the interests of East African women. It was, in fact, this reputation that became a motivating factor behind the formation of Umoja-East African Community, an organization of mostly Swahili speaking people. These residents, arriving more recently and coming from at least six different countries, saw the strength in City Heights Hope and wanted to emulate them. Because of cultural and linguistic differences, the people involved decided to form two organizations rather than converge into one.

The development of City Heights Hope and Umoja provides an exemplar of successful place-based practice. The process involved taking the California Endowment's concerns about access to healthy and culturally appropriate foods for East African refugees and using their resources to build the community's capacity to assess the issue and develop and implement a plan of action for itself. By the end of the second year the focus of the groups, especially City Heights Hope, broadened to include concerns about access to quality healthcare. It is important to note the changes in the level of the participants' involvement in the community throughout

¹ There are two very broad ways to conceptualizing approaches to social problems, i.e., person-based and place-based. Person-based, the more traditional is focused on creating behavior change within the individual, place-based practice is focused on changes within the environment.

² Institute for Public Health (March 2010). City Heights Wellness Center Advocacy Project Final Report. Graduate School of Public Health, San Diego State University.

this process. Their first acts were to address things that directly affected their lives, i.e., their relationship with their children. As they began to successfully address those concerns through the programs they created, they began to have the space to address larger, more systemic issues such as access to healthcare. In their monograph, *Why Place Matters*,³ the California Endowment lays out the theory behind place-based practice. In particular, it states that "local residents have significant insight into what problems are most critical to address, what community strengths can be used to improve the health and community conditions, and what strategies and solutions will be most effective (p. 7) ." The development of City Heights Hope and later, Umoja, validate this claim. Strengthening their relationship with their children is the most critical issue and developing ways of teaching their children about their history, their culture, and their religion is the strategy identified as the most effective solution. Having established themselves, the participants are now ready to address the larger issues. The research reported here is their statement about what is most critical in having access to quality healthcare and what steps need to be taken to assure that access.

PURPOSE OF STUDY

The purpose of the study was to identify barriers to healthcare for East African families living in and around the City Heights neighborhood of San Diego from the perspective of East African women. While there have been a number of studies of health related issues for refugees in San Diego County since the arrival of people from Vietnam in the late 1970s, a literature review conducted by UCSD in 2007⁴ showed only one of the six studies that focused on refugees in San Diego County was designed to examine barriers to accessing healthcare. UCSD's literature review was part of a larger study that did look at the issue of access for the major refugee groups in San Diego. Two additional studies have been conducted in San Diego since the UCSD study; one focused on the Somali Bantu and the other on Somali refugees.⁵ While these two studies do mention barriers, their focus was on the healthcare needs of those communities and not issues of access. This study is the first to directly address the issue of access and it is the only study that tells the story from the perspective of the refugee herself.

PARTICIPATORY ACTION RESEARCH

The data presented here is the result of a Participatory Action Research (PAR) study. PAR differs from academic research in that it is led and conducted by the people affected by the issue being researched and is designed specifically for the purpose of informing the type of action needed to be taken to address the issue being studied. What makes PAR both unique and necessary is that it provides data that typically do not exist, i.e., an assessment of the policy from the perspective of those targeted by the policy. In addition, because of who is conducting the study, the PAR approach has the potential to include people often left out of studies of this type. Speaking metaphorically, every community has a kind of geology to it. Like the earth, there are layers, each with a different set of characteristics. Generally, four layers can be found in most communities. These are:

³ Bell, J., Rubin, V. (2007) *Why place matters: Building a movement for healthy communities*. Washington, D.C.: Policy Links.

⁴ Brouwer, K., Rodwell, T. (2007). *Assessment of community member attitudes toward health needs of refugees in San Diego*. International Health & Cross-Cultural Medicine, University of California San Diego.

⁵ See report prepared by Olga de la Cruz (de la Cruz & Associates), Hamadi Jumale (Somali Bantu Community of San Diego), Colleen Krause (International Rescue Committee), Hamadi Madisa (Somali Bantu Community of San Diego), and Amy Pan (Institute for Public Health), August 2008; Institute for Public Health (January 2009). *Evaluation of Somali Elders health needs assessment survey*. Graduate School of Public Health, San Diego State University.

1. A top layer consisting of large institutions that have investments in the community but are not part of the community. This layer is inhabited by colleges, universities, hospitals, large national foundations, some federal and state programs, etc.
2. The next layer generally consists of local county and municipal government, some state-regional foundations, and some state and federal programs, etc.
3. The next layer is made up of nonprofit agencies that have programs within the community.
4. This bottom layer includes community-owned institutions⁶ as well as the unorganized members of the community. It is a broad band that ranges from relatively large, stable organizations to small, unfunded/underfunded community efforts and activities. This layer also includes those residents who live below the Clay Line and are rarely engaged in the public dialogue.

If you dig deep enough into the soil you will eventually strike a layer of hardened clay that makes it difficult to go deeper. The same thing happens within a community. If you go deep enough into a community you will eventually find the equivalent to the clay line. Those who live below this clay line tend to be people who lack of material resources to participate in the public dialogue, e.g., immigrants, refugees, people with incomes near or below the federal poverty line, disabled, etc. In addition, the conditions that block people from the public dialogue also make them the people least likely to be surveyed, interviewed, polled, etc. Research indicates that these are also the people who are most likely to be undercounted in the US Census. Without the resources to join the public dialogue and not being included in the research essentially means that the perspective of this important constituency is absent when policy is designed and implemented. Ironically, the people left out of the dialogue and research are often the targets of the policy being designed.

Cost of Participating in the Public Dialogue

Participating in the public dialogue is not free. While we don't tend to think of having to pay to become involved in the community, we do incur costs. These costs show up in gas for our cars to get to and from meetings and events, arranging childcare, minutes on our cell phones, pot lucks, etc. Most people don't think of these costs because they come out of their discretionary income, i.e., money left after one pays for necessities such as housing, food, healthcare, transportation, etc. In general, people living below the Clay Line either have no or negative discretionary income. They are often confronted with the choice between using the gas in their car to attend a meeting at their child's school or driving to work the next day.

This study was conducted by 23 women from at least six different East African countries, all of whom are refugees. These women created the survey and took it 210 women, 203 of which are included in the following analysis. The fact that 80% of those surveyed do not speak English and only one participant indicated that English was her first language demonstrates the ability of PAR to reach those typically left out. The surveys were written in English, Somali, and Swahili. In addition to those languages, some surveys were conducted in Arabic, Amharic, and Tigre.

THE PROCESS

The process began by having the participants describe their own experiences with the healthcare system. These discussions were held in separate meetings with the members of

⁶ A community-owned organization is one where the organization is controlled by the community it serves as demonstrated by a Board of Directors that has 75% or more of its membership made up of members of the community being served.

City Heights Hope and the women members of Umoja. Each meeting was run like a focus group with the facilitator asking questions and facilitating the discussion within the groups. The discussion centered on four main questions (see Appendix A for the protocol), i.e.:

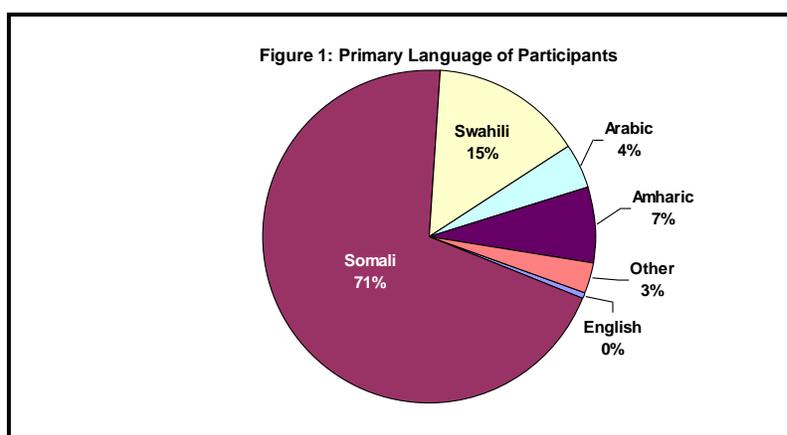
1. What does "healthcare" mean to you?
2. When do you engage it? Why do you engage it?
3. What happens when you seek healthcare?
4. How closely do you follow the healthcare provider's advice?

These discussions provided a description of the interaction between these women and their healthcare providers. The single largest issue raised in both groups was language. Both groups clearly stated that the lack of competent interpreters negatively affected the entire experience with the healthcare system. While the two groups developed their descriptions separately, they were essentially identical. The only difference between the two groups was that members of Umoja raised concern about the pharmacies as well as the doctors and the members of City Heights Hope did not. The second step in the process was to present the descriptions back to each group to validate that the description was an accurate statement of their experience. It was in this part process that the issue of pharmacies was brought to the members of City Heights Hope who fully agreed that they were a major concern. See Appendix B for the description produced.

After the groups developed their description of their experience the process moved to developing the survey. Prior to developing specific questions, the participants in each group received training on how to conduct research, including topics such as validity, reliability and generalizability. With an understanding of these concepts, the groups addressed the broad question of whether the experiences they described were unique to them or were they common throughout the community. It was at this point that each group developed a set of questions that would show whether the broader community shared their experiences. From the questions generated, a survey instrument was developed and presented back to both groups together. Together the groups worked through the draft survey and produced a near final version. The participants received training on how to conduct surveys and then pilot tested the survey by each participant conducting at least one survey with a friend who would provide feedback on the questions and their comfort with answering them. After the pilot test, the survey was finalized. Each participant then pledged to conduct the survey with at least ten people using convenience and snowball sampling techniques. The surveys were conducted between January and March of 2012.

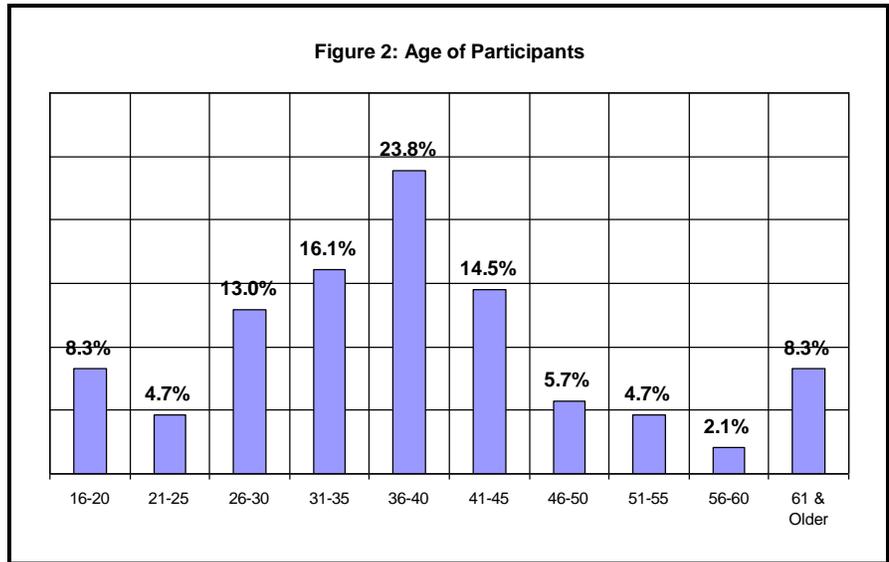
THE FINDINGS

Who: As stated earlier, 23 women surveyed 210 women refugees from East Africa now living in San Diego. Of the 210 surveys collected 203 are included in this analysis. Seven surveys were not complete enough to be included. The surveys were produced in three languages, i.e., English, Somali, and



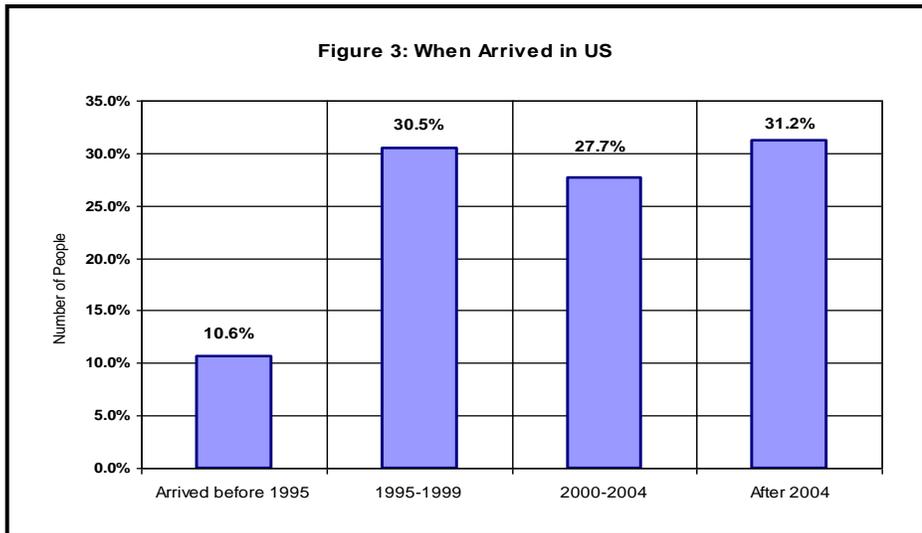
Swahili. Of the 203 surveys, 43% were in English, 43% in Somali, and 14% were in Swahili.

Regardless of the language of the survey, the interview was conducted in the language of the person being surveyed. While the survey did not ask where the participant was from, it did ask what languages they spoke. As can be seen in Figure 1, most of the participants (71%) spoke Somali. Swahili (15%) was the next most frequently spoken language followed by Amharic (7%), Arabic (4%), and then Tigre (3%). One participant reported English has her primary language.



Because the women who created the survey felt that it was a problem to ask the participants to state their age directly, it was reported in intervals of five years ranging from 16-20 to 61 or older. The distribution of ages can be seen in Figure 2. The participants' mean age fell in the 36-40 year old category as did the median and mode.

As can be seen in Figure 3, more than half of the women surveyed (58.9%) arrived in the United States in 2000 or later. Almost a third of the participants (31.2%) arrived after 2004. The median year is 2001 indicating that half the women arrived before 2001 and half arrived after.

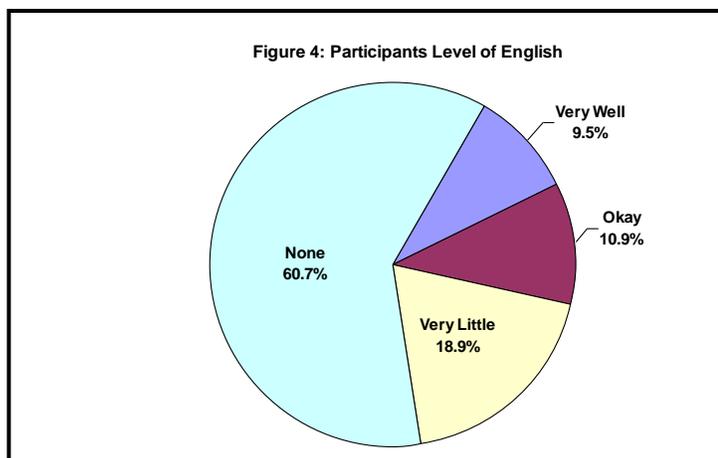


Participants reported living within over 30 zip codes throughout the County. Just over half of the participants (55%) lived within the zip codes of City Heights and the surrounding area (92105, 92115, 92102, 92104). Most of these (37%) lived within 92105. The next most common zip codes were from the Southeast area (92114, 92113) and Lemon Grove at 9% and 7% of the participants respectively.

Eighty-three percent of the women had children with the number ranging from one to ten. The average family size was four as was the median number of children.

Language: As noted above, 71% of the women surveyed speak Somali, 15% speak Swahili, 7% speak Amharic, 3% speak Arabic, and 3% speak Tigre. A large percentage of the women (42.8%) speak more than one language. While many women were fluent in more than one language, few women were fluent in English. Participants were asked to rate how well they understand English. The ratings were:

- Very well: Understand 90% or more of what I hear
- Okay: Understand about half of what I hear
- Very Little: Understand almost nothing of what I hear
- Not at all: Understand nothing of what I hear



As can be seen in Figure 4, 60.7% reported not understanding English at all while 18.9% reported understanding very little. Combined, 79.6% of the women surveyed reported understanding almost nothing or nothing of what they hear. Only 9.5% reported understanding almost all of what they hear. These numbers become very important when considered along with the questions about the quality of communication between the patient and the doctor. Table 1 shows the responses to questions related to the quality of communication between the patient and her doctor. As can be seen, 65% of those surveyed rated their level of understanding of the doctor as "poorly." Similarly, 62% reported that they thought the doctor understood them poorly, and 59% reported only poorly understanding the doctor's instructions. Further, 64% reported poorly understanding the medications that were prescribed to them.

Question	Very Well	Adequately	Poorly
How well do you understand your doctor?	12%	23%	65%
How well does your doctor understand you?	13%	25%	62%
How well do you understand what you need to do after leaving the doctor?	13%	28%	59%
How well do you understand the medications the doctor prescribes?	10%	26%	64%

The low level of understanding reported is not surprising given that 81% of the participants surveyed reported that they were not provided with interpretation, 94% reported that they were not given written materials in their language, and 95% reported not getting information about the medication prescribed in their language. In addition, 68% of the respondents reported being asked to sign forms that were in a language they didn't understand. These results are similar to the findings of the UCSD study⁷ mentioned earlier that states that "Language was mentioned

⁷ Brouwer, K., Rodwell, T. (2007). Assessment of community member attitudes toward health needs of refugees in San Diego. International Health & Cross-Cultural Medicine, University of California San Diego.

during every interview as a strong barrier to healthcare access. . . Participants also mentioned the lack of interpretation services (oral) and availability of translated (written) health information as a barrier to accessing preventive services." Similarly, focus groups with members of the Somali Bantu community found that language issues "were brought up frequently throughout the focus groups. Women reported difficulty communicating with their doctors and other providers."⁸ A study involving Somali elders also reported language as a barrier and that most patients were not offered interpretation.⁹

Almost three quarters of the participants (73%) said they asked for help when they didn't understand their healthcare provider and 27% said they did nothing and just acted like they "didn't even see the doctor." Similarly, 61% of the respondents who didn't understand their medications asked for help. Only 10% reported that they didn't take the medication but 29% said the just guessed at the dosage. Ninety-three percent of the people asking for help in understanding their doctor and 92% asking for help understanding their medication asked family members. While data were not collected on which family members were asked, anecdotal evidence as well as prior research suggests that it is most typically their children. Of the people who were asked to sign papers they didn't understand, 79% said they sign them anyway while 10% said they refused to sign the papers. Only 1% reported asking for help.

The critical nature of the language barrier in healthcare is well known. While there is no shortage of studies related to this issue,¹⁰ there still seems to be no system-wide response that has been successful in addressing it. Several factors have been suggested as to why there has been no such response. These typically include the cost and complexity of addressing the issue on a wide scale. A recent evaluation of community clinics in San Diego, however, suggests that there might be an additional reason, i.e., a belief among providers that the existing interpretation system is adequate to meet the demand. An evaluation of language access among the community clinics in San Diego stated that "A majority of clinic providers/staff interviewed (65.5%) felt that the clinic's efforts to address language access needs are highly effective."¹¹ A perception clearly not supported by the data reported here and in other studies. A potential explanation as to why the providers have such a different perspective than the respondents lies with the staffing of the clinics. It is not unusual for these clinics to have staff fluent in Spanish and/or Talalog who are called upon to interpret without additional training or compensation. The result is that the burden of low English proficiency shifts from the patient to staff at the clinic. The evaluation states that, "Utilization of existing staff who have not been trained to provide interpretation was reported by all clinic providers/staff." While this practice may make things easier for the patient, it places a burden on staff who are, in most cases, medical assistants. These staff have reported that this practice is "challenging as they are often pulled from their other responsibilities" and that they "often have difficulty understanding the medical terminology the doctors use and identifying the appropriate words in the translated language."

⁸ See report prepared by Olga de la Cruz (de la Cruz & Associates), Hamadi Jumale (Somali Bantu Community of San Diego), Colleen Krause (International Rescue Committee), Hamadi Madisa (Somali Bantu Community of San Diego), and Amy Pan (Institute for Public Health), August 2008

⁹ Institute for Public Health (January 2009). Evaluation of Somali Elders health needs assessment survey. Graduate School of Public Health, San Diego State University.

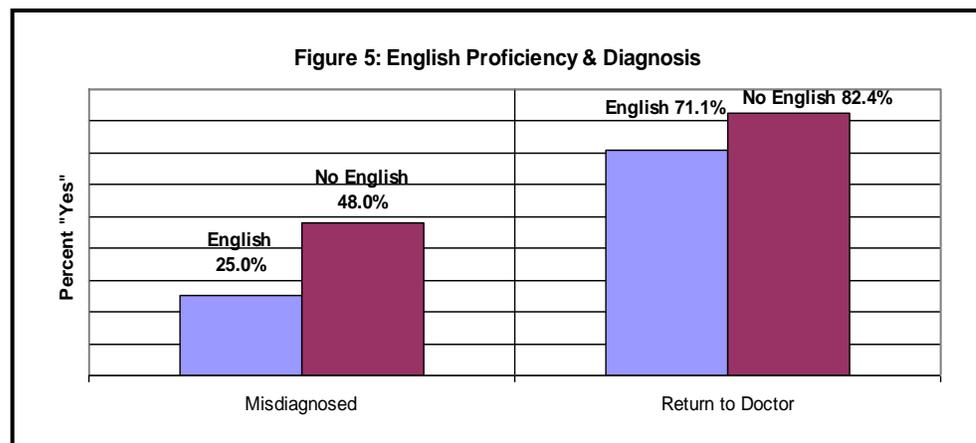
¹⁰ Jacobbs, E.A., Agger-Gupta, Niels, CChen, A.H., Piotrowski, A., & Hardt, E.J. (August 2003). Language barriers in health care settings: An annotated bibliography of the research literature. Los Angeles, CA: The California Endowment.

¹¹ Harder + Company (October 2007). Language access evaluation project. San Diego, CA: Council of Community Clinics

An additional point regarding language has to do with the relationship between proficiency in English and length of time in the United States. A Pearson r correlation indicates a weak, but statistically significant ($p < .05$) relationship between the two (0.21), suggesting that people's English skills may improve slightly over time. However, it is important to note that the question respondents refused to answer most frequently was "What year did you arrive in the US?" When asked why they didn't want to answer, they most often cited their embarrassment over how long they were in this country and how little English they spoke. This would suggest that most of the people who did not respond to the question of when they arrived are not proficient in English. If they were to be included in the calculation, they would most likely reduce the correlation indicating that the relationship is even weaker than reported here. This point is important because if, as this data suggest, people's English skills do not improve over time, then we are talking about needing resources for interpretation for many years to come. Research on brain development and learning a language supports this suggestion. The general consensus is that languages are best learned sometime between the ages of seven and thirteen. While there is less consensus on the issue of adults learning a second language, the general sense is that the older the person, the more difficult it is to learn a language. Given the average respondent is between the ages of 36 and 40 and most do not speak English, the findings of this study and the research on language indicate that these women are not likely make any significant gains in their English proficiency. All of this points to an issue that will not be resolved without taking intentional action and an investment of resources.

Quality of Care: Respondents were not asked directly to rate the quality of care they received. However, there were several questions in the survey that addressed this issue. It should be noted that such a question was not asked because many of the women who developed the survey felt that people would be uncomfortable answering such a question, fearing it would negatively affect their relationship with their doctor.

A significant number of respondents (43%) reported that they had been misdiagnosed by their doctor. While 80% of the respondents reported having to go back to the doctor because they were not getting better, 65% of them reported that this "hardly ever" happened. However 26% reported that this happened "very often." The data reported above on the proportion of people who rate the quality of their communication with their healthcare provider as poor must be considered relevant here. While these data do not directly connect the two, there is some relationship. Figure 5 shows the possible impact of English proficiency on the quality of the care. When the respondents are separated into English and non-English speakers¹² some important differences appear in their responses to the questions

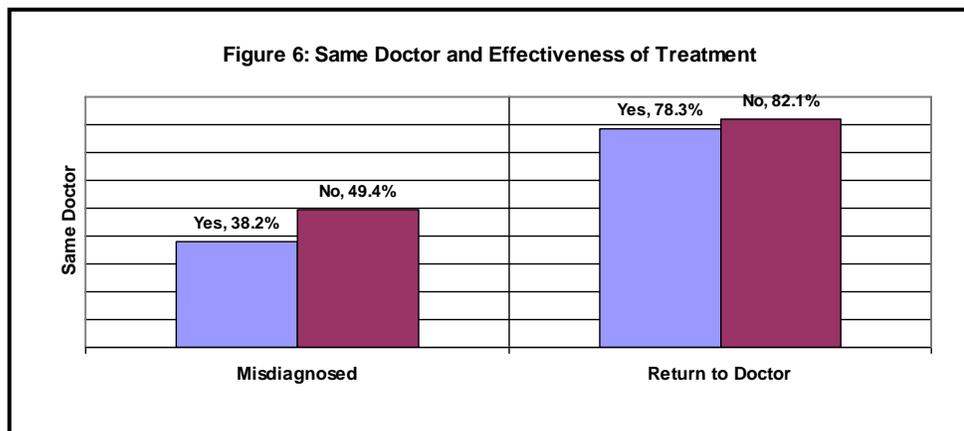


¹² For this analysis respondents who rated their level of understanding of English as "Very Well" or "Okay" were considered English speakers while respondents who rated their level of understanding of English as "Very Little" or "Not at All" were considered non-English speakers.

related to diagnosis and effectiveness of treatment. As can be seen nearly twice as many non-English speakers (48%) reported being misdiagnosed than English speakers (25%). Non-English speakers reported needing to go back to the doctor for the same condition (82.4%) slightly more than the English speaking respondents (71.1%). The evidence here is consistent with the research and suggests that the level of English proficiency can have an impact on the outcome of the client-doctor interaction.

Another issue that may affect the quality of the outcome is whether or not the patient sees the same doctor at each visit. Almost half (47%) of the respondents reported that they did not see the same doctor at each visit. If you look at the questions of misdiagnosis and effectiveness of treatment in

relationship to having the same doctor you find that, as shown in Figure 6, there is some differences between those with the same doctor and those not. However, the effect is much less than that of English proficiency.



Together, the responses to these questions indicate language is more important than having the same doctor in determining the quality of communication between the doctor and patient. The pattern of responses to the questions concerning the quality of communication supports this suggestion. A comparison between those reporting seeing the same doctor at each visit and those who see a different doctor at each visit on their ratings of their level understanding the doctor, the doctor understanding them, and their knowing what to do after seeing doctor shows little difference. As can be seen in Table 2, the participant ratings are almost the same regardless of whether or not they see the same doctor every time.

The ratings of the quality of communication range from 0 to 2. A rating of 0 indicates that the level of understanding is poor, a rating of 1 indicates the level of understanding is adequate and a rating of 2 indicates the level of understanding is very good. The differences here are not statistically significant.

Quality of Communication	Same Doctor	Different Doctor
Patient Understands Doctor	.44	.48
Doctor Understands Patient	.53	.50
Patient Understands Doctor's Orders	.58	.53

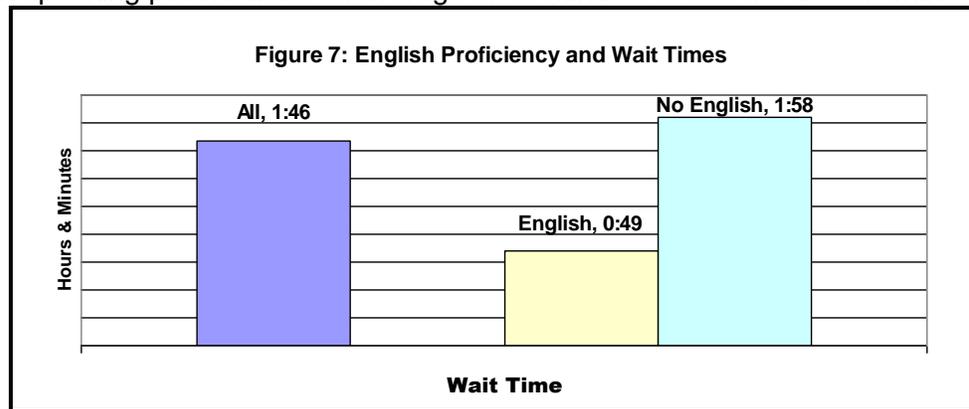
While the data presented here is far from conclusive, it strongly suggests that language is the critical variable in determining the quality of the relationship between the doctor and the patient. While other issues have some impact on the doctor-patient relationship, the evidence presented here strongly suggests that creating a quality relationship cannot happen without resolving the issue of language.

Quality of Service: As with the Quality of Care, respondents were not asked to rate the quality of service directly. However, there were two sets of questions in the survey that did relate to

this issue. One set of questions asked about accommodations for children in the doctor's office. The second set of questions asked about the time it took to get an appointment and how long one waited to see the doctor.

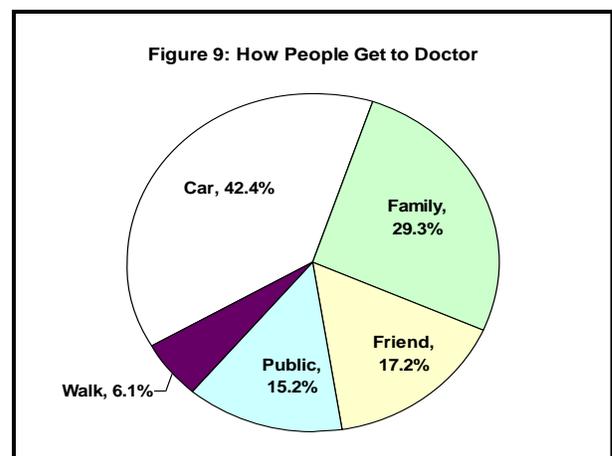
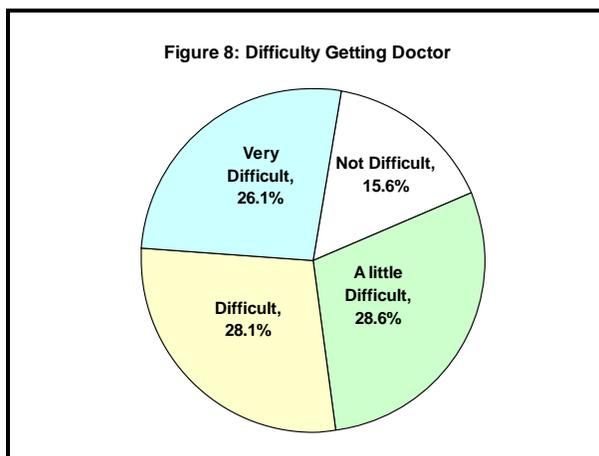
As stated above, 83% of the respondents have children. Of those, 61% reported that they took their children with them to the doctor. Most of these women (85%) gave "lack of childcare" as the reason for bringing their children. Almost three quarters (71%) reported that the doctor's office had no accommodations for the children. Given that these women are waiting an average one hour and 55 minutes and that half are waiting over two hours, it is reasonable to assume that the lack of accommodation for children has a negative impact on the quality of service.

The long waits to see the doctor was raised at every meeting focused on the quality of healthcare. Most women identify the lack of interpreters as the reason for the long waits. The data presented here supports that perception. The average wait time for all respondents was one hour and 46 minutes. The importance of language can be seen when the wait time for English speakers is compared to the wait time on non-English speakers. As can be seen in Figure 7, the English speaking patient waits an average of 49 minutes to see the doctor while the non-English speaking patient waits an average of one hour and 58 minutes. This difference is statistically significant at the .0001 level. In addition, the correlation between English proficiency and wait time is $-.45$ ($p < .001$), indicating that as one's level of English proficiency goes up, the amount of time they wait to see the doctor goes down. As with quality of care, language again emerges as the critical variable in the quality of service. The data here reinforce the conclusion of the section on language, i.e., it is not possible to provide true quality care without resolving the language issue.



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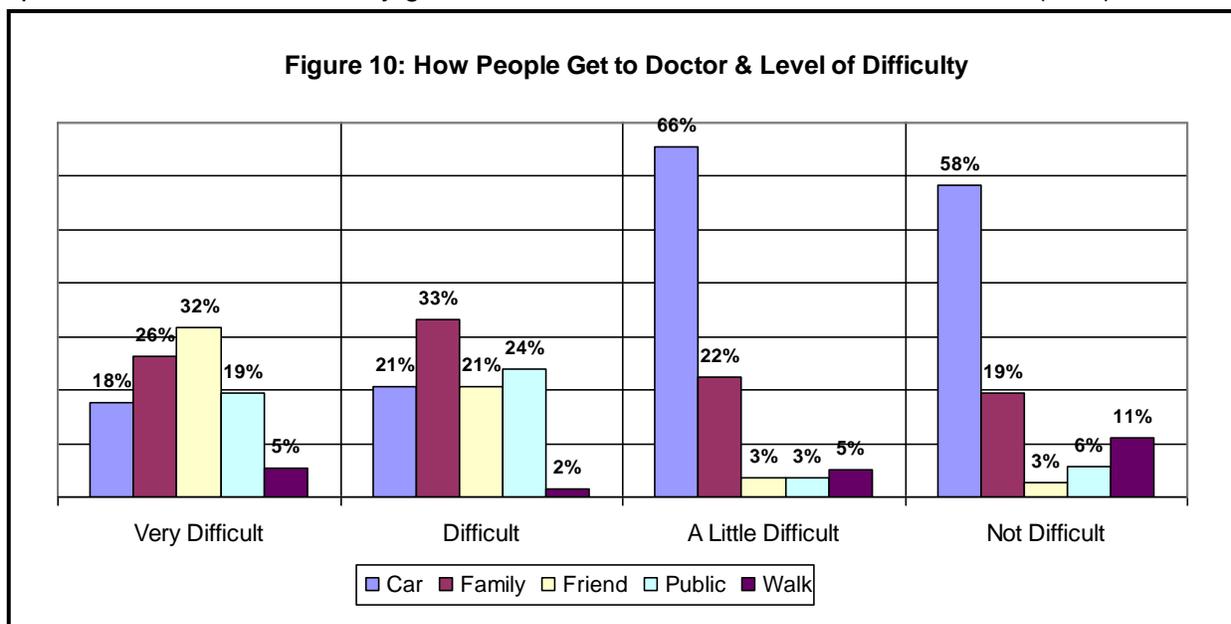
External Issues: The issue of access to healthcare is a complicated one, one affected by



many factors in addition to language. The participants in the study were asked to rate how difficult it is for them to get to the doctor. As can be seen in Figure 8, 15.6% of the people said is not difficult to get to the doctor while 26.1% said is was very difficult.

Two factors that directly affect how easy or difficulty it is to get to the doctor are transportation and whether or not you bring your children. Figure 9 shows the forms of transportation people reported using to get to the doctor. A significant number of respondents (42%) reported having a car while 46.5% relied on either a family member or a friend to provide transportation. Slightly more than 15% reported using public transit and 6.1% reported walking.

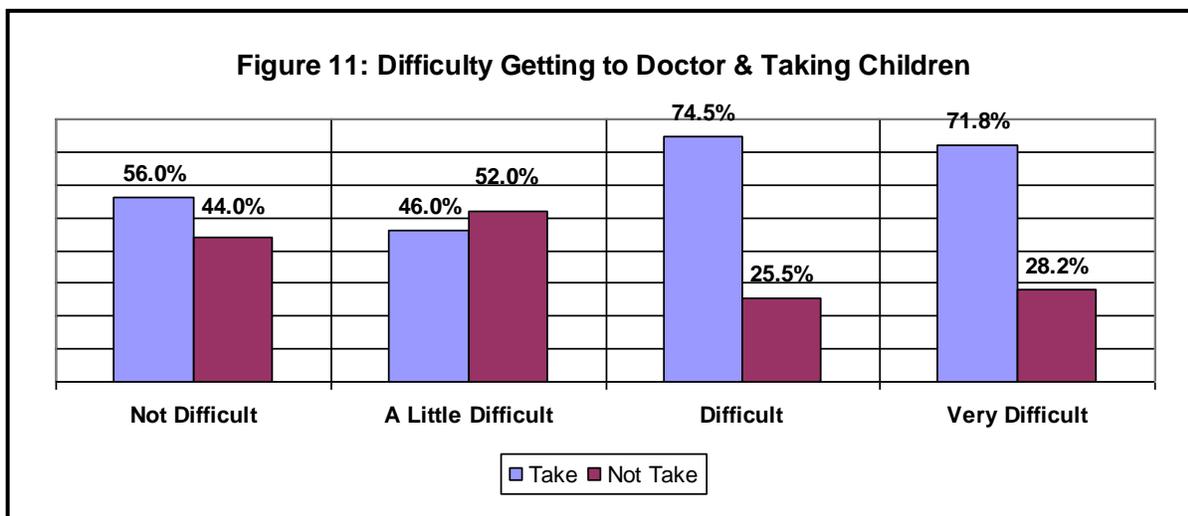
The data on the relationship between how one gets to the doctor and level of difficulty getting there suggests the obvious, i.e., those with cars have the least amount of difficulty getting to the doctor. Figure 10 shows the results of separating respondents based on the level of difficulty reported in relation to how they get to the doctor. As can be seen, well over half (58%) of those



reporting that it was "Not Difficult" and two-thirds (66%) of the people reporting that was just "A Little Difficult" had access to a car while only 18% of those reporting that it was "Very difficult" and 21% of those reporting it as "Difficult" had access to a car. Almost a third (32%) of those reporting that getting to the doctor was "Very Difficult" asked friends for a ride. The next largest number of people were those who received rides from a family member. With more than half (58%) of those reporting it "Very Difficult" getting to the doctor by relying on family or friend suggests that arranging such rides is not easy. These data also suggest that the use public transit contributes to the difficulty getting to the doctor. As can be seen, only a small percentage of those who reported that getting to the doctor was "Not Difficult" (6%) or "A Little Difficult" (3%) use public transit while 19% those who reported that getting to the doctor was "Very Difficult" or "Difficult" (24%) use public transit.

The second external issue affecting the level of difficulty getting to the doctor relates to whether the women bring their children with them or not. A comparison between the women who take their children and the women you don't on the level of difficulty getting to the doctor also indicates the obvious, i.e., it is more difficult for the women who take their children. As can be seen in Figure 11, nearly three times as many women who take their children with them reported that it was "Difficult" (74.5%) than women who didn't (25.5%). The pattern is similar for

women who reported that it was "Very Difficult" to get to the doctor. Of these women, 71% take their children while 28.2% do not. The difference in level difficulty getting to the doctor between the two groups of women, i.e., those who take their children and those who don't, is statistically significant ($p < .05$).



The two external factors assessed in this study, transportation and childcare, do to affect the respondents' access to healthcare. As with most things, those with the most resources, i.e., cars and/or childcare, are able to access healthcare with more ease than those without those resources.

Health Insurance: Most of the respondents in this study (85.6%) have health insurance. More than three quarters (77.9%) of those insured have Medi-Cal. Because most of the respondents are insured, the role of insurance as a factor in one's access to healthcare was not raised in this study. These data, however, should not be taken to mean that access to health insurance is not an issue. It is more likely that these women have greater access to Medi-Cal because their status as refugees. Surveys conducted in City Heights in mid-2009¹³ indicated that more than half of the respondents (51.2%) had no health insurance and that 70% of Latinos were without health insurance. Anecdotal evidence also indicates that, while the women in this study have health insurance, some of their children might not due their age. Age is also factor in this issue as the women without health insurance are, on average five years younger than women who do have insurance (33 years and 38 years respectively). This age difference is statistically significant ($p < .05$).

CONCLUSION

It is clear from the data presented here that language is a core factor in providing access to quality healthcare for the respondents in this study. While other factors have some affect on access to and the quality of care, language, or lack of English proficiency, is the primary barrier. There can be no quality healthcare without removing this barrier. The data suggest that the quality of the communication between patient and provider is poor and that this inability to communicate effectively negatively impacts the quality of care and service. In general, two-

¹³ See: Preliminary Report: Findings from the City Heights Building Healthy Communities House Meetings produced by the Mid-City CAN House Meeting Leaders, Sheila Mitra-Sarkar, William Oswald, and Jesse Mills. Published by Mid-City CAN.

thirds of the women reported that that they did not understand their doctor, their doctor did not understand them, they did not understand the doctor's aftercare instructions, and did not understand the medications they were given. It also shows that very few women were offered interpretation services and nearly everyone needing help sought it from their family, very often their children.

The quality of the communication was shown to affect the quality of care in that those who didn't speak English reported being misdiagnosed more than those who did. They also reported having to return to the doctor for the same symptoms more often. One of the concerns raised in the development of this survey was the affect of people not seeing the same doctor at every visit. The data suggest that there is some difference in the quality of care between those who see the same doctor and those who do not. However, the negative impact of the language barrier persists even when the respondent saw the same doctor at every visit. In terms of quality of service, respondents who did not speak English waited more than twice as long to see the doctor than women who speak English.

External issues such as transportation and access to childcare were shown to affect the level of difficulty respondents had getting to the doctor. As would be expected, those with access to a car and those with childcare found it less difficult to get to the doctor than those without.

Access to health insurance was not addressed in this study because most respondents had insurance. There is some evidence, however, that the issue may be larger than the data suggest. Respondents without insurance were significantly younger than those with insurance and some respondents indicated that, while they were insured, their older children were not.

The respondents in this study were 203 East African women with an average age of 36 to 40 years old. Just over half of the women arrived in the United States after 2000. Most of the respondents' primary language is Somali. The other primary languages included Swahili, Amharic, Arabic, and Tigre. While many of the women spoke more than one language nearly 80% did not speak English. Most women had children. The survey was developed and the data collected by a group of 23 East African women from at least six countries who used their own networks to reach the respondents. Because of the capacity of these women to reach deeply into their communities, the data presented here reflect the perspective of the women who are most affected by the language barrier described here. The foundation for any solution to this barrier lies within this perspective. This barrier cannot be effectively removed without the participation of those affected by it in developing the solution.

RECOMMENDATIONS

Once the data were collected, and analyzed it was presented to the women who conducted the survey for interpretation. Based on these results, their experiences conducting the survey, and their own experiences, they developed the following recommendations for addressing the language barrier. These are:

13. All signs in providers' offices and pharmacies in our languages
14. Face-to-face interpreters who are native speakers in our language
15. Female interpreters for female patients

16. Female doctors for female patients
17. Be able to make appointments by phone
18. Have interpretation arranged prior to our appointment
19. All written material (including application) in our languages
20. Assistance in our own language with all forms
21. Assistance with transportation
22. Place and materials for children in doctor's office
23. Hire and train members of our community to be interpreters
24. No one waits more than 30 minutes in the waiting room for the doctor

These recommendations are meant to be the foundation for a dialogue within the broader community regarding the issue of real access to quality healthcare for those represented by this study. It is only through such a dialogue where clients, providers, funders, etc. sit as authentic partners that a long-term, sustainable solution to this issue can be developed.

APPENDIX A

ACCESS TO HEALTHCARE –SESSION 1: DESCRIBING THE EXPERIENCE

1. What does "healthcare" mean?

- a. When I say "healthcare" what do you think of?

2. When do you engage it? Why do you engage it?

- a. Walk through the decision to go/not go for healthcare
- b. Are there things you won't seek healthcare for – what & why
- c. Are there things that keep you from going for healthcare – what & why?
- d. Are there things that would make it more likely that you would seek healthcare?
- e. Are there people in the community – outside the healthcare system that you go to for advice on health issues? Who and what do they offer?

3. What happens when you seek healthcare?

- a. Walk through what happens from the time you decide to seek healthcare?
 - i. Getting there
 1. Where do you go? Why there?
 2. Do you go to the same place every time?
 3. How do you get there?
 4. How difficult is it to get there?
 5. What makes it difficult to get there?
 - ii. At admissions
 1. Describe the lobby
 2. Describe the interaction between you and the intake person
 - a. What is asked of you?
 - b. Is language an issue?
 - i. No – how is dealt with
 - ii. Yes – describe challenge
 - iii. Seeing the healthcare practitioner
 1. Do you see a Dr, a Physician's Assistant, Nurse, other?
 2. Describe the interaction
 - a. Is language an issue?
 - b. How comfortable are you?
 - i. What makes you comfortable?
 - ii. What makes you uncomfortable
 - c. How well do you understand the healthcare practitioner?
 - d. How free do you feel to ask questions?
 - e. How much do you trust the healthcare provider you spoke with?
 - i. What makes you trust/mistrust the healthcare provider?
 - iv. Checking out
 1. Describe the interaction
 2. Are the instructions for next steps clear?
 3. Is language an issue?
 4. Are there other issues that interfere with checking out?

4. How closely do you follow the healthcare provider's advice?

- a. Why might you not do what the healthcare provider advises?
- b. What are the things that would stop you from following the advice?
- c. What are the things that make it more likely that you would follow the advice?

APPENDIX B

IMPRESSIONS OF HEALTHCARE: SUMMARY OF SOMALI & SWAHILI SPEAKING SESSIONS

The single largest issue raised in both groups was language. Both groups clearly stated that the lack of competent interpreters negatively affected the whole experience with the healthcare system.

Issues common to both groups were:

- That they rarely, if ever, fully understand what the healthcare provider is saying to them
- Having to wait up to six hours to see the healthcare provider because there is no one there who speaks their language. People who speak English, have interpreters with them or the system is prepared for them get treated first regardless of what order in which they arrive.
- Feeling disrespected by intake staff in particular
- That the present interpretation system is not working. The phones are problematic for several reasons, i.e.:
 - Very difficult to understand the person on the phone, particularly if the interpreter is not a native speaker of the language
 - Interpretation is often too literal, i.e., word-for-word, not concept-for-concept
 - Often told by interpreter that they are to sign the form in front of them, but the interpreter doesn't know what the form is
 - Interpreters are not seen as maintaining confidentiality
- That they often had to rely on family, friends, or strangers to interpret to them. Often people had to rely on children to interpret for them in highly inappropriate situations. Other times they had to rely on family members or strangers, making the situation extremely uncomfortable and sometimes affecting what actually gets reported to the healthcare provider.

Both groups were very clear that this language issue is a problem throughout the schools and the entire safety net and not just within the healthcare system. The only difference between the groups was that the Swahili speaking group identified pharmacies as an issue while the Somali speaking group did not.

Both groups identified lack of health insurance and transportation as barriers. The Somali speaking group reported that the language barrier reduced the probability that they would follow the healthcare provider's instructions after they left the office, while the Swahili speaking group did not. This difference may help explain why the Swahili speaking group has an issue with pharmacies, but the Somali speaking group did not. If the Somali speaking women are not following the instructions, they may never get to the pharmacy to have this issue.

Both groups reported that they rarely, if ever, see the same healthcare provider twice and that they felt that this lack of a consistent healthcare provider often resulted in a misdiagnosis. This misdiagnosis often led to the person needing to return to the doctor more than once for the same health issue.

In general, the Swahili speaking group trusts the advice of the healthcare provider while the Somali speaking group does not. Additionally, the Swahili speaking group was generally satisfied with the care they received from the doctor while the Somali speaking group was not. These differences are likely to contribute to the differences in the degree to which the women within each group follow the healthcare provider's advice. It should be noted, however, that the Swahili speaking group was clear

that, while they were satisfied with the treatment they received from the Doctor, they were very dissatisfied with the treatment they received from the rest of the people in the system.

The Somali speaking group reported that healthcare is more structured for the children and that this structure comes from the school system. Schools were the main contact between children and the healthcare system and children who don't attend school have less contact with the healthcare care system. However, while the group reported that this structure increased their children's access to health care, they were not satisfied with the quality of healthcare provided.

Submitted by Bill Oswald; 9-27-2011