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**BETWEEN THE LINES: SOMALI WOMEN AND MEDICAL
INTERPRETATION EXPERIENCES**

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degree of Master of Science in Health Policy and Management

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Introduction

Since 2001, the number of Somalis living in the state of Maine has increased substantially and that growth is expected to continue. Many of these resettled families are made up primarily of women and children from low income backgrounds with little to no formal education. They are often marginalized because of their ethnic and religious backgrounds. They also face language barriers that make it difficult for them to communicate their medical needs to their medical providers.

As an interpreter for Somali women in Lewiston, I witnessed first-hand how language affects access to medical care from making an appointment to filling out prescription to comprehending discharge instructions. Yet, I found many traditional Somali women in the Lewiston community avoided formal interpreter services offered to them for free. I was frustrated and puzzled by the behavior of Somali women who for a variety of reasons chose to use friends and family members including children to act as medical interpreters. These informal or ad hoc interpreters were unfamiliar with medical terms, inaccurately summarized what was said, added their own opinion, omitted sensitive information and frequently breached patient confidentiality. The ad hoc interpreters appeared to do little to reduce the communication barriers and often caused misunderstandings that led to unnecessary testing and other errors that delayed care and may have in fact, directly influenced the quality of care.

The health and wellbeing of Somali women in Lewiston is important because these individuals often are the ones that hold families together in the Somali community. That is why I am deeply concerned by the use of friends and family members who have not been assessed for fluency in the Somali language as interpreters. I believe harm may come to Somali women as a result of gaps in communications and cultural misunderstandings. I think it would be useful to understand Somali women's needs and what are the impediments to their use of interpreter services. A study on interpreter use among Somali women is greatly needed so that medical providers can address their unique health care needs.

Problem Statement

Many studies have investigated the health care experiences of Somali women. However, there is little research that looks at Somali women's experiences with language barriers and their

language preferences. In my capstone, I explore language barriers in the health care system from the perspective of non-English speaking immigrant Somali women with children living in the Lewiston-Auburn area. I am studying this topic to better understand the impact language has on the healthcare decision making process of Somali women. I try to identify what characteristics and behaviors make possible the use of professional interpreter services and its associations with good communication and quality medical care. This Capstone includes the influence of Somali women's background, cultural beliefs, trust in Western Medicine, understandings of patient and doctor roles, knowledge of patient rights, views on self-advocacy and experiences with different types of interpreter services to guide my research. The aim of the study is to offer medical providers, administrators, and professional interpreters insights on the needs of a growing population. Additionally, it is evident that little research has been done on this topic and healthcare organizations may recognize the need to improve language support for Somali women.

Background

Limited English Proficient Population

The U.S Census Bureau estimated one in five Americans or around 61 million people spoke a language other than English at home in 2011 (Ryan, 2011). Of these, about 23 percent had limited English proficiency (LEP), meaning they were able to speak limited English or not at all (Ryan, 2011). Immigrants, the fastest growing demographic group in the United States, accounted for most of growth in the LEP population. These demographic changes increase the demand for language services in both large urbanized states, as well as, rural ones like Maine. Although immigrants form a smaller proportion of Maine's population compared to the national average, certain areas have experienced large growth in their immigrant populations (Ryan, 2011). Since 2001, the number of Somalis living in the state of Maine has increased substantially. It is difficult to obtain the exact number of Somalis living in the state as many are undercounted, but an estimated 3,500 Somalis have resettled in the Lewiston area alone (Huisman, 2011)

The Somali Population

Ethnic Somalis are the majority population of Somalia, North Eastern Province of Kenya, Ogaden region of Ethiopia and the republic of Djibouti. They have historically been nomads, but settled in urban areas after the 1960s. Although Somalis share similar language, culture and religion, they have always been divided along clans who fought over resources. In 1991, fighting broke out between clan based militias, the state collapsed and Somalia has had no functioning government to this day. Nearly a quarter of a million Somalis died as a result of the civil war and famine (Menkhaus, 2010). The situation in Somalia has been described as one of the worst humanitarian crisis in the world (Checchi & Courtland, 2013). Millions of Somalis have fled to refugee camps in Ethiopia, Djibouti and Kenya leaving everything they had behind in the hopes they would be able to return to their home country when conditions improved. However, the civil war has persisted and as a result millions of Somalis have endured decades of living in refugee camps. Some of the Somalis were admitted to the United States under refugee status and settled in Minnesota to form the largest Somali community in the country (Goza, 2007). Secondary migration has seen Somalis spread out across the U.S. and resettle in places like Lewiston. Because of the violence, famine and massive internal displacement in their country, the United States, and subsequently, Maine will continue to see a large influx of Somalis due to their refugee status and U.S. immigration policies that allow family reunification (Akiwumi & Estaville, 2010).

Somali Women

In past Somali culture, men have held all the power and made all the decisions with women responsible for taking care of the home and children. For those most familiar with gender equality, it is hard to comprehend the profound gender inequality in Somali culture. In Somalia, women rarely receive an opportunity to obtain formal education or work outside the home and have a low social status. The Somali civil war has significantly changed the lives of Somali women. Many Somali women experienced trauma such as sexual violence, torture, and loss of relatives (Gardner & El Bushra, 2004). As they resettled in America, many Somali women had to adjust to living in cities, working outside the home for the first time, and making decisions for their families. There has been a major role reversal with large numbers of Somali women now

head of households because their husbands and other male relatives are dead, missing or unable to come to the U.S. As a result, the Somali women experience significant challenges in the United States and continue to struggle with the language, culture and lifestyle, often without the support a large extended family.

Literature Review

Federal and Maine Law

Under Title VI of the Civil Rights Act of 1964, it is illegal for organizations receiving federal funds to discriminate against someone based on race, color or national origin. The Supreme Court ruled in *Lau vs. Nichols* in 1974 that the national origin clause in Title VI ensures non-English speakers are provided access to language support. In 2000, President Clinton issued executive order 13166, "*Improving Access to Services for Persons with Limited English Proficiency*" to ensure organizations receiving federal funds were complying with Title VI. The executive order mandated federal agencies to create guidelines for organizations and medical providers receiving federal funds under Medicare, Medicaid, State Children's Health Insurance Program, Hill-Burton and other programs. In spite of the law and guidelines that threaten fines and loss of federal funding, most hospitals, physician's offices, insurance companies, pharmacies, and non-governmental organizations still fail to publicize right to language services at no cost, translate health materials or provide interpreters to LEP patients (Youdelman, 2008). The main issue today is that while 80% of hospitals report treating LEP patients on a regular basis, most are not reimbursed for the full cost of providing these language services (Hasnain-Wynia, Yonek, Pierce, Kang, & Greising, 2006). As a result, many states including Maine have enacted laws and regulations that expand on federal statutes (Maine Department of Health and Human Services, 2014). Maine is currently one of the few states nationwide that reimburse health care providers that offer interpreter services to LEP patients (Chen, Youdelman, & Brooks, 2007).

Implications of the Literature

The negative impact of language barriers and the benefits of professional medical interpreters on the quality of care have been documented through three previous systemic reviews of the literature. The first review of the literature was conducted by Flores et al. (2005), and examined

36 articles according to communication issues (quality of the medical interpretation, adequacy and type of interpret services and interpreter error), patient satisfaction with different types of interpreters (ad hoc, telephone interpreters, and no interpreter), and health care processes (use of services, complications, and outcomes). The second review was done by Karliner et al. (2007), which considered 28 articles that compared the performance of professional interpreters and ad hoc interpreters in terms of communication (errors in communication, and comprehension of diagnosis and treatment plan), utilization (preventative care, ED visits, hospital admissions, and number of diagnostic tests), clinical outcomes (diabetic management, diagnosis of mental illness, and rates of various medical procedures like cesarean sections), and satisfaction with medical care (patient and provider). The third review was done by Bauer and Alegria (2010), which further researched the benefits of professional interpreters in comparison to ad hoc interpreters in psychiatric care. The researchers examined 26 articles according to psychiatric assessment and diagnosis, treatment, and patient-provider interaction. The evidence from the literature indicates that language barriers have a significant impact on the quality of medical care LEP patients receive. Flores et al. (2005) found LEP patients had poor access to medical care and were less likely to receive evidence based care. Compared to English speakers, LEP patients were less likely to have a regular source of care and received fewer preventative services such as physical, dental and eye examinations as well as cancer screenings and immunizations. Furthermore, LEP patients had poor management of chronic conditions such as asthma and diabetes than those with no language barriers.

According to Karliner et al. (2007), language barriers prevent medical personnel from being able to obtain accurate patient histories and symptoms. The consequences are expensive diagnostic tests, invasive procedures, misdiagnosis and delays in care. As a result, LEP patients are more likely to be hospitalized, have longer hospital stays and experience more medical errors with greater chance of death. In one study of six U.S. hospitals, nearly half of LEP patients experienced medical errors that ended in physical harm (Divi, Koss, Schmaltz, & Loeb, 2007). The problem was attributed to communication failures caused by the use of family members, friends, staff and other untrained individuals who have not been assessed for language proficiency. Often times, medical providers do not call for professional interpreters due to time constraints (Diamond, Schenker, Curry, Bradley, & Fernandez, 2009).

In one nationwide survey of pediatricians, more than half reported using ad hoc interpreters in their regular encounters with LEP patients (Kuo, O'Connor, Flores, & Minkovitz, 2007). Ad hoc interpreters increase the likelihood of interpretation errors and worsen the language barriers for LEP patients. The literature shows ad hoc interpreters make more errors due to their omission of important information, inaccurate translation or paraphrasing and adding of personal opinion (Jackson, Nguyen, Hu, Harris, & Terasaki, 2011). In one study that looked at medical interpreting errors, the researchers found ad hoc interpreters acted as gatekeepers and omitted fifty-two percent of information between LEP patients and their medical providers (Flores et al., 2003). Notably, one particular problem with ad hoc interpreters, especially minors that interpret for relatives is they are often embarrassed to discuss topics such as sexual issues, reproductive health, drug usage, and other intimate matters. Furthermore, the use of ad hoc interpreters in certain areas like psychiatry contribute to patient harm. According to Bauer and Alegria (2010), patients that used ad hoc interpreters were more likely to be misdiagnosed, less likely to have continuity of care and were at greater risk of suicide. In one study, the inability of ad hoc interpreters to accurately translate psychiatric concepts and provide patient symptoms and behaviors hindered the treatment of mental ill LEP patients (Hagan et al., 2013). It is clear from the evidence that ad hoc interpreters contribute to communication failures between patients and their medical providers.

In contrast, the use of trained professional interpreters has led to improvements in communications and a better quality of care for LEP patients. In a study of large emergency departments in Massachusetts, researchers found professional interpreters were far less likely to make interpretive errors of clinical significance that harmed patient care (Flores, Abreu, Barone, Bachur, & Lin, 2012). According to both Flores et al. and Karliner et al, LEP patients that used trained professional interpreters had better understating of their diagnosis and treatment plan. They were less likely to use the emergency room for non-emergency care. They were more likely to visit their primary care doctor, obtain appropriate preventive care (vaccinations, rectal exams, and mammograms), discuss sensitive issues, schedule follow-up appointments, adhere to medication regiments and better manage their chronic diseases. They were also more likely to obtain referrals to specialists when needed and understand informant consent. The use of professional interpreters was associated with better health outcomes because they had better knowledge of medical terminology and were more likely to translate words or concepts

accurately than ad hoc interpreters. Furthermore, the availability and use of professional interpreters has improved LEP patients' satisfaction with care.

The benefits of professional interpreters are also shown in psychiatric care. According to Bauer and Alegria, the use of professional interpreters in psychiatric settings greatly enhances the quality of care for LEP patients with mental health problems because they were more competent and less likely to compromise patient confidentiality. Access to professional interpreters improves psychiatric evaluation (obtain accurate patient history), increases patient disclosures of sensitive issues (delusions, obsessions, hallucinations and other symptoms), enables follow-up visits and increases adherence to recommended treatment. Without the presence and use of professional interpreters, LEP patients with psychiatric disorders receive poorer quality of care that exacerbates their mental health problems.

Despite the strong evidence in the literature that indicates professional interpreters should be used at all points of contact between LEP patients and their medical providers, they are often unavailable or underutilized. In one study, researchers found only fifty-six percent of U.S. pediatricians used professional interpreters (DeCamp, Kuo, Flores, O'Connor, & Minkovitz, 2013). A parent that does not speak, read or write English cannot make sound medical decisions for their child nor give informed consent. The usage of professional interpreters is not perfect and does not solve the whole language barrier, but the evidence clearly indicates it is better than the alternative.

A brief search of any newspaper or law journal quickly highlights what happens when there is communication failure between doctors and LEP patients. The stories of patient death and multimillion dollar settlements reinforce the importance of providing language support. Although the reviewed literature is limited by the general focus of the majority of studies on Spanish speakers, the review suggests that the use of professional interpreters make effective communication possible by reducing medical errors, increasing patient satisfaction and improving treatment outcome. In contrast, the literature indicates ad hoc interpreters are more likely to make interpretive mistakes that contribute to medical errors and poor health outcomes. The literature is unclear why LEP patients often use ad hoc interpreters even with the availability of interpretive services for free and laws mandating the use of professional interpreters. Thus, this capstone author will contribute to the current state of knowledge by examining why Somali

women in the Lewiston-Auburn area decline the use of professional interpreters and suggest methods to increase the appropriate use of medical interpreter services.

Analytic Framework

Since language affects almost all aspects of everyday life, Martinez provides a useful framework to considering the challenges for LEP patients in the U.S. healthcare system. Martinez's four dimensions include interaction barriers, information barriers, acceptance barriers and performance barriers. The first dimension is described as, "barriers of interaction that block face-to-face communication with healthcare providers and health educators" (Martinez, 2010, p. 69)." On the interaction barrier level, there is always an intermediary person between an LEP patient and his medical provider that prevents him from being able to accurately share his medical history and concerns about diagnosis and treatment. The result is then the silencing of the LEP patient's voice and passive acceptance of others decisions. The second dimension refers to, "those barriers that ensure that health information is unevenly distributed across linguistic populations ((Martinez, 2010, p. 70)." On the information barrier level, LEP patients are unable to access material in various health topics such as exercise, nutrition, preventative care, and new medical drugs because it is always in English. However, the information barrier extends beyond the healthcare system and into the wider society where LEP patients are disadvantaged when trying to access the health information available in the radio, television, newspapers, magazines and other media outlets. As a result, the information barrier prevents LEP persons from finding the health information they need to change their behaviors and lifestyles habits to improve their health. The third dimension is the, "barriers of acceptance that block the emergence of intersubjectivity between patients and clinicians ((Martinez, 2010, p. 70)." On the acceptance barrier level, the linguistic and cultural differences prevents providers and LEP patients from being able to accept the role and intent of the other. The miscommunication and cultural misunderstandings are likely to create distrust. As a consequence, medical providers may overlook LEP patients concerns and view them as less deserving of care, which has direct impact on treatment. Finally, the fourth dimension which is described as the, "performance barriers that alienate patients from the level of control needed to successfully manage disease and promote health (Martinez, 2010, p. 71)." On the performance barrier level, LEP patients are unable to navigate various healthcare settings (clinics, hospitals) and deal with several providers (nurse, doctor, therapist, pharmacist, etc.) to obtain the diagnosis and treatment needed. Therefore, LEP

patients are forced to passively accept medical care without understanding the consequences, which leads to poor health outcomes. While Martinez's four dimensions of language barriers provides some context and guidance, there may be other obstacles that LEP patients confront when navigating the health care system.

Habermas's communicative action theory is used as the second framework to better understand language barrier and interpretive services (Habermas, 1987). In his theory, Habermas distinguishes between the "System" and the "Lifeworld". According to Mishler (1984) who applied Habermas theory to healthcare setting, the "System" refers to the voice of medicine which includes institutions (hospitals, clinics), medical professions (doctors, nurses), and scientific knowledge (treatment of disease). On the other hand, the "Lifeworld" consists of the voice of the patient shaped by his culture, relationships, and experiences. In this interpretative framework, the interaction between the "System" and the "Lifeworld" can be distorted by the different roles of interpreters. As part of the "System", professional interpreters often act as representatives of the medical providers and communicate to the LEP patients the medical provider's norms and agenda. Consequently, the professional interpreter can distort communication, reinforce the power of the medical providers and silences the voice of the patient. Alternatively, ad hoc interpreters can better understand the LEP patients' complex issues, place them within the context of their wider life and aid medical providers to understand the nature of their illness. Furthermore, ad hoc interpreters can advocate for the LEP patient and help them understand their own diagnosis and treatment so they can be involved in the decision making process. Drawing on Habermas's framework, this author hopes to better understand how LEP patients interact with the healthcare system and the roles played by different types of interpreters.

Methods

In-depth individual interviews were conducted with six non- English speaking Somali women with children living in the Lewiston-Auburn area. Their ages ranged from 27 to 50 years of age and all have lived in the U.S. for several years. None of the women spoke English, but some were fluent in Swahili, Amhara and Arabic. The participants were invited to participate through the local Islamic center where the majority of Somali women in the community meet to pray and discuss issues. All participants in this study were volunteers and did not receive monetary

compensation. The interviews were conducted between March and April of 2014 with the help of the researcher's sister Ubah Sheikh. The interviews took place in each participants home to protect their privacy and for convenience as some of the women lacked transportation. The interviews were conducted in Somali and recorded. Before the start of each interview, a written summary of the research project in Somali was provided, and also read out loud to each participant. A written informed consent was obtained. The specific questions for the interview were developed after conducting the literature review and approved for the study protocol by the Institutional Review Board (IRB) at the University of Southern Maine.

During the interview process, all the participants were asked ten guiding questions about their experiences of the health care system and views on different types of interpreters in order to identify overlapping themes. In addition, participants were encourage to discuss other topics relating to their interactions with medical providers, staff and others, and to share specific examples. The interview responses were transcribed, checked for accuracy and coded to preserve confidentiality using pseudonyms for each participant. In addition, transcripts were reviewed with participants to minimize error and to better understand their perspectives.

After a qualitative analysis of the data, five themes emerged from close reading of the interview transcripts. All the themes that emerged from the interviews appear to relate to the broad topics covered by the literature review. In the following section, my findings are presented.

Results

Finding #1- Interpreter Services

All the women interviewed had experienced interpreter errors that caused them emotional pain and physical injuries. Idaho, a 27 year old mother of three who has been in the United States for ten years had suffered greatly due to interpreter error. When Idaho first arrived in the U.S., she was pregnant with her first child who was born prematurely and delivered by C-section. The baby boy spent several weeks in an intensive care unit before she could take him home. Idaho was given written discharge instructions in English that informed her she should not get pregnant again until she was healed completely and cleared by obstetrician. However, Hawo, Idaho's interpreter, merely informed her she should not get pregnant. Idaho who has no formal education and was not familiar with contraception ended up pregnant again before she was completely

healed. She was advised by her doctors to not continue with the pregnancy. Idaho decided to have her child, but Hawo incorrectly informed the doctor that Idaho did not want to continue with the pregnancy. Recalling her story, Idaho was in tears.

I signed a sheet of paper without knowing what it was. The interpreter never explained it to me. I was taken into a room, had a tube placed in my arm and went to sleep. I then awoke in a different room with a new a doctor and nurse I have not seen before talking to each other. I slept in that room until the next morning when Hawo came in, told me I was no longer with child and that I could go home.

There was miscommunication between Idaho and Hawo throughout their dealings. Coming from different parts of Somalia, Idaho recalled the difficulty she had trying to understand the Somali dialect Hawo spoke.

I had trouble understanding Hawo whenever she spoke. Some of the words she used made no sense to me. So I just nod my head when I was in the doctor's office because I did not want to cause trouble for her or appear stupid.

Following the termination of her pregnancy, Idaho had difficulty getting pregnant for several year and had to turn to fertility treatment. Most profoundly, Idaho grappled with crisis of faith and faced depression that almost broke up her marriage.

Like Idaho, Springville had a negative encounter with an interpreter when her new infant was born prematurely. The child was taking several medications, but Springville who does not read or write in any language could not understand the instructions. The interpreter never properly explained to her how to give the medications, which resulted in the infant returning to the hospital. When the infant was treated, the hospital refused to discharge him and instead reported Springville to the Department of Health and Human Services. DHHS threatened to take away the child.

I did what Hargeisa told me to do, but my child never got better. So I took him back to the hospital and they made him better. But when I wanted to take him they refused and called the State on me. My husband was so frightened that he ran to the mosque crying and asked for help. He came back with five men from the community who spoke English well.

The failure of Hargeisa to explain to Springville how to correctly give medication nearly killed the infant and caused blame to be placed solely on Springville. Without immediate assistance from members of the community, Springville would have lost her child to DHHS.

Friends of my husband fought for us. Unlike Hargeisa, they were so kind towards us. They stepped in and spoke to the hospital and DHHS officials for us. Thanks to them I was able to take my child home.

In recalling the interpretation errors that caused them many problems, all the women were especially angry over the refusal of the interpreters to admit their mistakes and take responsibility. The interviewees were sure interpreters rarely lost their jobs and if they did, they went to another agency and went right back to interpreting in the same medical facilities. They were mad at how their lack of English proficiency prevented them being able to talk to medical providers and stop bad interpreters from working with patients so they could not harm other people.

Finding #2- The Interpreter- Part of the System

The interviewed women did not trust professional interpreters because they worked for agencies that had contracts with the medical provider or they were directly paid by the hospital. They found it hard to work with interpreters because it appeared to them that the interpreters “were on the side of” the medical providers. Charlotte, a 40 year old mother of four, had kidney problems and needed a transplant. While she waited for a new kidney, she went through dialysis. Charlotte had difficulty with one of the nurses who she said treated her badly. She told her interpreter, Yusuf, that she did not want to work with that nurse any more. Yusuf did not tell anyone of Charlotte’s request and she had to continue to endure that particular nurse. Charlotte reported that the nurse repeatedly swore at her and that she could recognize the profane words.

Rebecca was horrible to me. I always had to wait a long time before my treatment began. She would give me dirty looks. I knew she said bad things about me. I was most bothered by Yusuf siding with her instead of supporting me.

Many interpreters work per diem and try to establish working relationships with doctors, nurses and administrators so they will be requested personally when in need of an interpreter. As a result, interpreters may seek to please the medical provider and strive to maintain a good

relationship. In Charlotte's case, she was able to get a better nurse because her brother stepped in to interpret for her when it was clear Rebecca was verbally abusive.

I had my brother with me one time. He overheard Rebecca making fun of my dress. She was telling another nurse the reason I was covered head to toe was because I was so ugly and obese. She also said I did not deserve to receive a new kidney. My brother reported Rebecca to her boss. I never saw her again.

In many negative situations, it required family, friends and other ad hoc interpreters to intervene in support of the women. Charlotte was eventually assigned a new nurse because of her brother's intervention. It was the same thing for Ohio, a 49 year old diabetic patient and mother of five children. She has frequent contact with medical providers because she suffers from multiple chronic illnesses and several of her children have asthma. Ohio complained of always being rushed by her interpreter because the doctor wants to see the next patient. Even when she has questions, her interpreter will pay attention to the doctor and follow his lead.

Many interpreters have cut me off while I was talking. They were rude. They will say hurry up the doctor wants to see other patients. They always promised to explain things to me later on when the doctor has left, but they never did.

For Ohio and the rest of the interviewed women, the paid interpreters often told them that if a doctor does not ask about a problem then they should not say anything. However, when the women disregarded their command and informed the doctor of their problem, the interpreter would become annoyed and decide not to translate for them. The women would, for example, speak about a medical problem for a minute and hear the interpreter speak with the doctor briefly. Ohio recalled the numerous times she felt what she was saying was not being accurately communicated to her doctor.

I went to hospital because I was having back problems. I carefully explained my problem to the doctor, but my interpreter did not explain to the doctor what I was saying. If he had I would have gotten medication for my back pain. Instead the doctor recommended physical therapy, which I did not want to do. The interpreter just sided with the doctor and told me to not argue with the doctor because he knew what he was doing.

When being seen by their doctor, the women had different expectations concerning the medical encounter. The women reported thinking pills will cure their ailment and that they did not have to do much else. When they did not receive pills, but instead were told to rest and stay hydrated or go for physical therapy to manage chronic back pain, they assume they are getting second-rate care. The women misunderstood the purpose of their treatment because the professional interpreters did not adequately explain to them the standard of care for their particular disease and that some medical conditions can only be managed and at times without the need for medication.

From their perspective, the women believed medical providers stereotyped them, viewing them as traditional and therefore ignorant persons incapable of understanding their medical treatment. The women perceived professional interpreters as wanting to emphasize their similarities with the American medical providers adopted the latter's negative attitudes towards them. They thought professional interpreters discounted their opinions and concerns to validate their own position. In addition, the women highlighted they did not begin using professional interpreter services despite their prejudices, patronizing and arrogance. The women only decided to go with ad hoc interpreters after repeated problems with professional interpreters.

Finding #3- Advocacy

The participants in the study acknowledged that their lack of English prevented them from being able to advocate for themselves. They expressed similar frustrations about the indifference of professional interpreters. According to the interviewed women, there were many times when medical issues could only be resolved or managed after non-medical issues were dealt with. Kentucky, a 40 year old mother of six children, has a daughter with Down syndrome. Her daughter was born premature and was in intensive care unit for many months. She required surgery to fix a heart problem, physical therapy to walk, and speech therapy to learn to communicate. Kentucky, who has no formal education, was totally confused about all the medications her daughter took, the numerous medical treatments she had and the visits with various specialists located all over the place. Kentucky recalled in the interview confronting two main problems. First was professional interpreters were not always available when they were needed. Secondly, the paid interpreters could not help her navigate the complex health system

and social services to obtain the care her daughter needed. Kentucky had to rely on an old friend who was aware of her situation and could be there for her the whole time.

I was overwhelmed when my daughter was born. She had so many problems and had many appointments with different types of doctors. My main problem was I lived in Lewiston and a lot of the specialists were in Portland.

In Kentucky's case, helping her daughter required more than taking her to medical appointments. Kentucky had to deal with housing, transportation and babysitting issues. Kentucky does not drive, can't afford a taxi and her husband can't take off work without being fired. So unable to bring her daughter to Portland, she missed numerous appointments and reports being threatened by DHHS with the loss of custody of her daughter.

I needed documents from doctors to give to Portland Housing Authority and DHHS so I could get a house in Portland. Moving to Portland was the only way I could take my daughter to all her appointments. The problem was the interpreters would not help me. They would just tell me their job was to interpreter during visits not to run after doctors for documents and write letters on my behalf.

The interviewed women believe the role of professional interpreters should go beyond enabling communication between patients and their medical providers. They believe professional interpreters should advocate for them, but frequently felt they were worried of angering medical providers. In addition, the participants thought professional interpreters were not as helpful as ad hoc interpreters because working per diem meant they need to pay attention to the clock and move on to the next patient. The result, according to the women, were professional interpreters who fill their schedules back to back leaving no time to explain things in detail or advocate for patients.

Arizona, a 45 year old mother of four children, gave an account of her struggles to get a homecare nurse for her son. Initially, she thought she could care for him, but realized quickly she was over her head trying to manage her son's colostomy bag, post-surgery recovery, medication regimen and physical rehabilitation. Arizona's goal of getting a homecare nurse to visit her son was hindered by the continuous change of professional interpreters. Every time she visited a hospital, clinic or DHHS she would have a different interpreter that was not familiar

with her case and she would have to explain her situation all over again. As the paid interpreters were interested in seeing as many patients as possible, it was difficult to get the interpreters to help her deal with multiple organizations, fill out numerous paperwork and speak with various officials in the midst of trying to understand and manage her son's complex health problems.¹

My son had 7 surgeries. He had a bag attached to his stomach because he could not go to the bathroom. He has mental problems. I needed help from a nurse otherwise he would have to go to a group home. Trying to explain my situation to many different interpreters and get them to be on my side was hard. All of them were interested in moving on to the next person who was easier to deal with.

As was the case with all the other participants, Arizona had problems that went beyond health matters. She wanted the professional interpreters to speak forcefully on her behalf. She assumed that, they would not advocate for her for fear that may offend someone and reducing their own potential income. As a result, Arizona had to use her sister and a close friend to travel with her to meetings, appointments, obtain documents and make her case to the right people to get the nurse and treatments her son needed.

Finding #4- The Gossip Mill

The main concern of all the participants that was quite surprising was fear of becoming part of a gossip within the larger Somali community. The concern about the potential embarrassment and, humiliation due to the disclosure of their personal and health problems kept many women highly suspicious of professional interpreters. None of the participants trusted a professional interpreter to maintain patient confidentiality. Kentucky recalled several times she heard people speak badly of her because she has a daughter who has Down syndrome.

I have heard many times people call me a bad woman because I have a daughter that has Down syndrome. They think I am responsible for how she was born. I am now so paranoid about what others say about me.

Kentucky was especially concerned about how often what she discussed with her doctor was known by people in the community. She even confronted several paid interpreters but they always denied having anything to do with the gossip.

I once confronted the interpreter about how everyone in the halal market knew I was with child when I have not even told my husband. You just can't trust anyone to not talk about you. That fear forces you to not be totally honest with your doctor when the interpreter is in the room.

Though a lot of the gossip may be insignificant, at times the gossip can seriously damage family unity and lead to community rejection. One of the interviewees, Ohio, reports community rejection as a result of gossip concerning her son's medical condition. The teenager contracted hepatitis C through exposure to contaminated blood while in Kenya. Ohio believes that a paid interpreter told members of her mosque her son was a drug user and had AIDS.

I had people avoiding me and not coming to my house. I was devastated when I brought food to the mosque because it was my family's turn and no one ate it. It took a long time before anyone believes my son did not have AIDS and that the interpreter is a liar.

The significance of potential gossip is particularly frightening to the female study participants. Their reputations matter because disclosure of their fertility problems, health issues with their children and other personal matters negatively impacts their social standing in the community and subsequently, their daughters' prospects of marriage. Kentucky expressed concern about how the many false rumors about her could harm her eldest daughter's marriage prospects.

Because I use to be okay with paid interpreters before I knew better they were able to share so much of my personal information with everyone. Now that my daughter is of marriageable age, she has few suitors even though she is religious. I think many suitors worry my daughter will bear unhealthy children.

Besides the concern over the breach of patient confidentiality by paid interpreters, the participants stressed there appear to have been no consequences over the disclosure and violation of their personal information. One reason is that the women lack the time and language skills to make formal complaints to language service agencies and medical providers about certain interpreters. Should the paid interpreters share private health information, this information becomes fodder for gossip that spreads through the cafes, restaurants, and stores throughout the Somali diaspora. All the participants have family and friends living around the United States and

have heard accountings of the private discussions they had with their medical provider retold to them word for word from areas as far away as Minneapolis, Seattle and Columbus.

Finding #5- Professionalism

All the participants shared concern about the prejudices of professional interpreters. Despite sharing the same religion and language, there are profound cultural, class and regional differences among the Somali people. Often times, the paid interpreters belonged to the urban middle class prior to the Somali civil war. In contrast, the majority of non-English speaking U.S. Somalis were nomads or lived in rural communities. Along with this class difference, there is often a gender difference as many of the professional interpreters are men. In addition, there is strong clan based kinship among Somali people. As various clans continue to fight throughout Somalia, that conflict spills over to the diaspora where many raise money to help their side in the civil war. With this social and historical context, it is possible that there are paid interpreters who cannot separate their personal views and professional duties. The interviewed women recalled professional interpreters swearing at them, looking down on them, and even threatening them.

During her interview, Ohio described how several years ago, a paid interpreter swore at her after she asked him to help her fill out documents after her appointment with her doctor was over. At issue is that at the time of interpretation services, Ohio's clan and that of the interpreter were fighting in central Somalia.

He swore at me. He told me he was not going to do a favor for a woman whose clan was killing his. I tried to explain to him the conflict back home had nothing to do with me, but he would not listen. Sometimes you can't escape clan problems even in Maine.

Besides clan based prejudices, gender discrimination is a huge issue within the Somali community. All the women brought up in their interviews that most paid interpreters are men and treat them differently because they are women. The participants found the male professional interpreters patronizing and felt that the interpreters preferred to deal with their husbands rather than them. According to Charlotte, she got tired of paid interpreters because they always viewed her as incapable of understating anything and wanted her husband to make all the healthcare decisions.

A lot of the male interpreters don't like to deal with women. They are arrogant. They don't get in this country things are different. Women can do things outside the house. A woman can make decisions for her family.

A third problem discussed by the participants was perhaps the most alarming in the entire study. All the women had personally experienced situations where professional interpreters with filled schedules accepted jobs and sent someone else to interpret in their place. However, the persons they sent were relatives who did not speak English or Somali well enough to provide accurate interpretation. Springville recalled going to the emergency room last year with her daughter. The nurse called for an interpreter, but instead of showing up, the interpreter sent her younger sister in her place. The younger sister showed up, interpreted for Springville and got her elder sister's timesheet signed.

I was surprised to see her. She lied to the nurse about who she was. I let her interpret for me because I did not want to wait and spend any more time in the emergency room.

The women in the study talked at length about the lack of professionalism amongst professional interpreters. They believe professional interpreters create a bad image for themselves by engaging in questionable practices, which leads others to question their character and trustworthiness. Additionally, the participants expressed concern that the lack of accountability when professional interpreters violate the rules prevent good communication with LEP patients and possible cause emotional and physical harms.

Discussion

The Somali Language

Analysis of the responses from the participants indicates that both patients and professional interpreters are greatly handicapped because there is no single standardized Somali language that all Somalis can understand. In the past, the Somali Language Commission which existed prior to the civil war tried to create a uniformed written and spoken Common Somali based on the northern dialect. The Commission standardized grammar, coined new words, published dictionaries and promoted Common Somali in schools, newspapers, radio and television (Warsame, 2001). However, the Commission's effort to create a Common Somali failed because

the majority of Somalis are nomads who also live in Djibouti, Kenya and Ethiopia and are largely illiterate.

Today, the lack of a language commission has led individual Somali writers, teachers, professionals and religious figures in the horn of Africa and throughout the diaspora to create their own words to translate foreign terms and concepts. The new words and expressions enter the spoken Somali language, but without consensus through formal education and broad popular usage, they take hold only in specific places. For instance, a word for infection in northern Somalia can mean inflammation in other parts of that country. The result is confusion and miscommunication between Somalis allegedly speaking the same language. When faced with such a state of affairs, the use of ad hoc interpreters is the best choice according to the participants in the study. Because English medical terms and expressions are not easily translated into Somali, there is often a need for paraphrasing to explain them. Many times it is ad hoc interpreters who are of similar cultural background and speak the same dialect that are able to provide a detailed explanation of diagnosis and treatment because they use words, expressions, and metaphors that the participants understand. The linguistic differences among Somali speakers are further complicated by clan animosities as discussed in the next section.

The Clan

Although Somalis share the same ethnic background, they do not share the same culture. The Somali community is greatly divided along clan lines. In the participants' views, clan connections were vital for their survival back home and continue to shape their lives here in the United States. For all the women interviewees, living in Maine has increased the importance and influence of their clan. The consequence is a small Somali community that is highly fragmented to the point where people use separate mosques, cafes and civic organizations due to clan animosities. The significant mistrust among Somalis then spills over to the relationship between paid interpreters and patients. During the interviews, the participants talked at length about paid interpreters that were rude, angry and uncaring towards them. They felt most paid interpreters controlled the agenda during medical encounters, interfered in decision making, and even purposely obstructed their access to medical care. The lack of professional conduct displayed by paid interpreters caused participants embarrassment, fear and anxiety and made them hesitant to talk about their problems. All the interviewed women pointed out their expectation of paid

interpreters is relatively low because they readily share their personal information with the community. Since they have no confidence in most paid interpreters, it often results in lack of respect for all professional interpreters and an unwillingness to use them for their medical appointments. In the participants' views, ad hoc interpreters are more caring, compassionate, respectful, and trustworthy than professional interpreters and better advocates for them.

The Role of Ad Hoc Interpreters

The role of the interpreter as an advocate was an important recurring theme in all the interviews. The participants in the study found it difficult to navigate the health care system with its complex referral patterns, payment methods and endless paperwork. These difficulties forced all the women to use family and friends as interpreters. As all the women have little to no formal education, and with paid interpreters unavailable at all points of contact with the healthcare system, family and friends play a crucial role in helping them get information and access medical care. According to the women, the presence of family and friends changed how they interacted with their medical providers. When they initially arrived at the U.S., the women accepted they had no choice but to use paid interpreters. They offered troubling accounts of being practiced on by medical interns and, having unnecessary laboratory and diagnostic tests done. In general, they report that their concerns and opinions overlooked because the paid interpreters do not serve as advocates. From their perspective, reunification with family and friends here made a huge difference. They no longer just get frustrated at medical providers and accept mistreatment. With friends and family members interpreting for them, they take action and seek out second opinions and pick medical providers that are respectful, competent and meet their needs. The active involvements and support of family and friends allows the women to be assertive, to ask more questions, to give comprehensive health histories and to understand essential health information. This active participation in their treatments allows the women to have better interactions with their medical providers, keep up with the flow of information and be part of the decision making process that leads them to make sound decisions regarding their health. As the Somali women interviewed report their dislike of professional interpreters and it is not uncommon to see children participating in ad hoc interpreting, study participants were if they use minors to interpret for them. All of the women answered no. The women pointed out they were careful to avoid putting minors in roles where they have to deal with delicate situations or even potentially

have power over them. They were all in agreement that the task of interpreting is complex and needs to be performed by adults.

Recommendations

The many risks of using ad hoc interpreters are well documented in the literature. Yet all the interviewed women in the study prefer ad hoc interpreters over professional interpreters. From their perspective, the benefits of using family and friends as interpreters were improved privacy, advocacy and availability of interpretive services in all situations. While the literature supports the use of trained professional interpreters for all medical encounters, the rules on their use is inconsistent. Furthermore, were medical providers to insist on the use of professional interpreters at all times, that would likely be ignored and cause problems. The practical choice is to incorporate ad hoc interpreters into the professional interpretive services when particular standards are met. Based on the literature review and study findings, this author has prepared some considerations and recommendations for medical interpretation services for non-English speaking Somali women. Of course, not all recommendations are relevant or appropriate for every given situation.

1. If a Somali women does not speak English, determine what type of interpreter she prefers and place it in her medical record.
 - Face-to-face interpreter
 - telephone interpreting
 - Ad-hoc interpreter
2. When a LEP Somali women schedules a medical appointment, simultaneously schedule a trained medical interpreter to reduce wait times and increase the likely use of trained interpreters.
 - Ideally, the interpreter should be someone she knows and prefers.
 - If possible, try to maintain continuity of interpreting by scheduling the same interpreter for follow up appointments.
3. If a Somali woman arrives for unscheduled visit or with an ad hoc interpreter, make her aware of the availability of free interpreter services.
 - Minors should not be used as interpreters. If it is safe to do so, delay consultation until availability of trained interpreter.

- When LEP Somali women are accompanied by an ad hoc interpreter, ask for permission to have a trained interpreter present during the clinical encounter. If the woman refuses to have the trained interpreter in addition to the ad hoc interpreter, have her sign a waiver form or reschedule appointment if there might be a safety issue.
 - If there is concern over abuse or other sensitive issues, have the provider speak with the LEP Somali woman alone through a trained interpreter and without the presence of the ad hoc interpreter
 - Use only trained interpreters when informed consent is required.
 - Make sure to provide translation of discharge instructions in both Somali and English.
4. Conduct assessment of the paid interpreter
- Recruit and train more female interpreters.
 - Test the bilingual proficiency and cultural competence of the paid interpreter.
 - Make sure he or she knows health and medical terminology.
 - Ensure that the paid interpreter observes the Code of Ethics, particularly in regard to patient confidentiality.
 - Make sure paid interpreter maintains professional behavior at all times
 - Obtain feedback from the Somali women to assess interpreter performance

Limitations

There are some limitations in the study. The majority of the articles in the literature review pertain to Spanish speaking LEP patients and some were outdated. More importantly, this author could not get the interviewed women to be more open even with the presence of his sister. Furthermore, gaining the trust of the participants would have taken further longer than the study permitted. Lastly, the small size of the study make it hard to generalize the findings as representative of all Somali women in the Lewiston-Auburn area.

Summary

The language barrier was described by all the participants in the study as one of the main obstacles to obtaining quality healthcare. The inability to speak English make it difficult for the interviewed women to navigate the healthcare system, understand their medical treatment, access health information, advocate for themselves and proactively look after their health. Although the reviewed literature recommended the use of professional interpreters to minimize the risk of medical errors, all the interviewed women preferred the use of ad hoc interpreters. The participants liked the ongoing relationship they had with ad hoc interpreters who share the same values and culture, and whom they trust to explain relevant clinical information, protect their privacy, advocate for them, be more available all through medical encounters, and offer emotional support. In the end, to make possible the frequent use of professional interpreters, it is important to combine formal training and professional accreditation with features Somali women desire like continuity of interpreting, advocacy on their behalf and feedback process to build trust and confidence.

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