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Translating health care: Stories from refugees, providers, and friends

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Abstract

Drawing on interviews and participatory observation, this article weaves stories of *translating healthcare* told from the perspectives of refugees, health care providers, and friends. The research finds that while literal translations of documents and information are important to the health care process for refugees of New Americans, cultural translations of concepts like *health care* and *preventive care* are perhaps even more important. That translation, however, is not simple or literal either; refugees and New Americans may resist, or remain suspicious of, these concepts even once understood. Friends of refugees can provide an important role in helping with cultural and institutional translations, and their role should be considered as part of a culturally-centered approach to healthcare, as outlined by Dutta (2008). Note: all participant and researcher names have been changed in order to protect human subjects.

“The introduction of the voice of the subaltern participant in the discursive space elucidates the interaction between structure and agency” (Dutta, 2008 p. 248).

Introduction

Fargo, North Dakota and to a lesser extent its neighbor city, Moorhead, Minnesota—separated only by the Red River of the North—have become a small but important resettlement location for refugees from around the world. Bosnians, Bhutanese, Somalis and Southern Sudanese, as well as many other citizens of the world, have been resettled to Fargo-Moorhead by the United States Department of State and the Office of Refugee Resettlement, working in conjunction with Lutheran Immigration and Refugee Services and its local affiliate, Lutheran Social Services of North Dakota. According to Singer and Wilson’s (2006) comprehensive analysis of US resettlement patterns, Fargo-Moorhead resettled 4,348 refugees between 1983 and 2004, about .3% of refugees in the US, the 70th largest total number. Because refugees have left their home

countries under great duress, and may have spent 5, 10, 15 or more years in refugee camps, they often come to Fargo and other locations with little or no financial resources, limited English skills, sometimes poor health, and frequently some symptoms of post-traumatic stress disorder. Not surprisingly, Morris et al. (2009) suggest that “health or health care” may be “the most important issue facing refugees during their initial years” (p. 530).

As educators, professional communicators, and friends who sometimes accompany refugees to medical appointments, we have learned to appreciate the services available in Fargo and respect the service providers for doing so much in difficult circumstances, but we also began to wonder what else needs to be done to more effectively *translate* health care to refugees, in both the literal and more metaphorical dimension of that term. This study is our first attempt to understand the complexity of the health care situation for all involved. Our study investigates three groups of people: refugees, also called New Americans, a term with less negative connotations, although we will use them interchangeably throughout; health care providers or health care support staff, who serve the New American communities; and a group not much studied into which both researchers fall, friends of New Americans in the community. Pipher (2003) calls such friends *cultural brokers* explaining that “schoolteachers, caseworkers, public health nurses, and American friends can help New Americans make intentional decisions about what to accept and what to reject in America” (p. 80). Investigating health care with these populations allows us to get a number of views on the health care system vis-à-vis the refugee population. Integrating interviews with providers and stories of New Americans with our own stories from contexts when we accompanied them to health care settings provides a layered data set and helps to eliminate bias that might attend if only one type of individual were the research focus.

This layered data collection works in conjunction with a culture-centered health care communication frame. As Villagran et al. (2008) explain, “although many communication models offer culture as a barrier to effective communication, the culture-centered approach to health communication highlights the voices of marginalized people as a central force in health-care decision making” (p. 206). We are not, therefore, simply collecting stories. We are also listening for agency and empowerment, or disempowerment, of New Americans. We assume that refugees have health-care values that do not match American health-care values, and that their agency as individuals coming from different cultures needs to be respected and honored rather than corrected or dismissed. By allowing the voices of New Americans to be heard, the community of providers, friends, and communication specialists will gain a more nuanced cultural understanding of differing versions of health. The challenge of *translating* health care can be understood as not simply a problem of literal translation, and even more that a cultural translation; it can be understood as a translation and preservation of agency and power.

Background

According to the “History” page on the Office of Refugee Resettlement (ORR) website, post World War II resettlement of refugees was handled primarily “by private ethnic and religious organizations.” After the fall of Vietnam, and the challenge of dealing with hundreds of thousands of refugees, Congress passed The Refugee Act in 1980, subsequently professionalizing the resettlement process (ORR). Immigrants to the US have typically come through diverse metropolitan centers, but resettlement efforts since the mid 1990s have expanded

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to small and mid-sized cities: Utica, NY; Fargo, ND; Erie, PA; Sioux Falls, SD; and Binghamton, NY, to name a few. Refugee resettlement happens throughout the United States, now running between 60,000 and 75,000 refugees a year based on the last four years (Russell & Batalov, 2012), but in cities like Utica and Fargo, New Americans make up 86% and 76% of the foreign born population (Singer & Wilson, 2006), presenting unique challenges for small and mid-sized cities going through linguistic diversification.

In 1997, Lutheran Social Services (LSS) and the US State Department began resettling Bosnian, Sudanese, Hmong, Somali, and other refugees in the Fargo-Moorhead area. They estimate that “in Fargo and West Fargo, Lutheran Social Services has resettled approximately 4,000 refugees from 35 countries” (p. 5). While the *Lost Boys of Sudan* have been the most visible resettlement group in this community because of national media coverage like Sara Corbett’s (2001) article “The Long, Long, Long Road to Fargo,” the four largest resettlement groups according to data provided by LSS New American Services in Fargo are Bosnians (1484, but none since 2004); Bhutanese (810, all since 2007); Somali (749, ongoing since 1997); and Sudanese (486, ongoing since 1997). The current populations of all these groups are larger than these numbers due to secondary migration and family growth. Because the community was previously homogeneous, and because the diversity of the refugees resettled presents multiple translation and interpretation challenges, the researchers believe the complexity of translation and interpretation needs to be better understood and documented and eventually addressed.

Barriers to health care, such as insufficient translation and interpretation services among refugee communities have received critical attention both in the United States and in other host countries like Australia and Norway.[i] Even within the Fargo context, some research suggests that refugees experience impediments to accessing appropriate health care. Julie Semlack et al. (2006) explain that “should a refugee have an immediate health concern, the problems of navigating the health care system can exacerbate the health problem” (p. 56). The Lugar report (2010) written for the Senate Committee on Foreign Relations, corroborates this claim: “the language barrier often impedes the ability of refugees to navigate local health care systems with a potential wide impact on the general public health.” Our research expands upon these observations; we investigate how language difference, health literacy levels, and cultural attitudes affect access to and willingness to use health care services for the New Americans who currently reside in the Fargo-Moorhead area.

While the refugee population in Fargo-Moorhead receives health care at varying rates, they are not able to fully participate in the health care communication process. Full participation would mean that they could exercise agency in health care decisions. Dutta (2008) explains how “Agency refers to the capacity of cultural members to enact their choices and to participate actively in negotiating the structures within which they find themselves” (p. 7). While long-time residents of the US often struggle to negotiate the health care system, New Americans have the added barriers of language, transportation difficulty, and cultural difference, at times compounded by poverty, making their ability to perform agency in health-care settings quite limited. As Villagran et al. (2008) explain “at the heart of the culture-centered framework for health communication is the goal to raise the level of agency for the members of the marginalized population” (p. 204). Our research aims to indicate both the barriers to and

successes in providing New Americans in Fargo with health care that allows them agency, rather than merely addressing essential health needs.

Because large data sets in questionnaire form miss some of the nuance of health care, stories became the best way to tease out barriers faced by New Americans. Maynes et al. (2008) explain that “personal narrative analyses have been designed pointedly to introduce marginalized voices into the record” (p. 6). Stories from individual New Americans allow their voices to become part of the health care conversation, working toward the culture-centered framework and increased agency that Villagran describes. Bosticco and Thompson (2008) add that narrative can “provide information to health practitioners about the experience of a particular health problem or illness population” (p. 50).

For our purposes, narrative unites different groups who have access to parts of the story about health care for New Americans in Fargo-Moorhead. One aspect of our design here is to access refugee narratives in order to better understand them as a population; even though their health-care needs are often very different, the barriers they face may be similar. As Maynes et al. (2008) clarify, “studying *whole persons* is key to the distinctiveness of personal narrative approaches” and it “involves an epistemological strategy that sees individuals *both* as unique and as connected to social and cultural world” (p. 10). The stories collected work toward understanding the complexity of the individuals, in addition to their membership in the category of New Americans or health care providers or friends of refugees. Finally, giving space to narrate allows subjects to work through any language barriers in their own time. The refugees / New Americans we interview can effectively communicate in English now, but they sometimes refer to a time when their English skills were not as strong. For this reason, during the refugee interviews, we ask participants to relate stories about the health care situations they have experienced since moving to Fargo-Moorhead.

One way that Fargo might be a useful case study is that some of the New Americans become service providers in health care fields after they receive an education. This trend of giving back to the organizations and communities that helped them transition into the United States could be a useful way to extend the possible benefits of small community size and person-to-person communication. In our interviews, one subject graduated with a BS in Nursing in 2011, the other will graduate with a BS in Community Health in 2012. The struggle for Fargo-Moorhead health care providers includes the increasing diversity of languages and cultures in the recently resettled populations; if the more established, not-so-New Americans are from entirely different cultures and speak different languages, they cannot provide the translation and explanation like they can for refugees from their own part of the globe. Fargo must learn to balance its strengths with new challenges and decreasing funding.

Refugee stories

To gather refugee stories, we conducted informal one-on-one interviews with two refugees from different African countries of origin, Emma and Seth, asking them to tell their stories about health care. One was an acquaintance of the researchers; the other they met for the first time. Questions were designed to solicit stories from participants, in order to let them expand on what is important to them. The questions included definitional issues, like “What did ‘health care’

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mean to you when you first got to the United States” as well as policy questions like “what changes to the health care system in Fargo would be most beneficial for New Americans?” The interviews lasted about an hour and allowed the participants freedom to elaborate on points they made both in the interview session and via email message after the interview had ended.

Our two primary interviews elicited similar stories. For these two, and by reasonable extrapolation most other refugees from Africa, health care was sought only when one was sick. Both had received medical care in their home country or in a refugee camp, but the concept of an *appointment* was new to them. Going to a medical facility meant lining up and waiting as long as needed; the providers in Africa would triage and treat the most serious cases first. The concept of an “appointment,” Seth said, needed to be explained by an American friend, the kind of cultural translation that appears to be a crucial part of medical translation.

The two interviewees had different experiences with documents and translators. Emma, who could speak French as well as her mother tongue and some Swahili, was frustrated by translators in Fargo who claimed to be able to speak either French or Swahili, but spoke in a dialect which she could not understand. Because of their poor command of the language, from her point of view, she also distrusted their ability to understand medical concepts. Seth arrived in America with passable English skills, an obscure mother tongue, and a smattering of African languages with regional dialects. He interacted with the healthcare system primarily in English but acknowledged that whenever he was given a document with too many words, a document that was too dense (true of many medical documents, as well as the IRB Informed consent form we gave him), he found an oral explanation from an American friend to be helpful.

Both agreed that an American friend or what Pipher (2003) calls a *cultural broker* is essential to good health care. “Anyone with an American friend is better off,” said Emma. She told the story of a family who had an American friend they could not understand, but this friend took them to all the appointments, helped them with every detail of their lives. She said that without a doubt New Americans get better treatment when they attend medical facilities with a cultural broker. The dynamic includes more responsive staff, but Emma said that New Americans would also trust the system and relax when accompanied by an American friend. Fear and distrust dominate New American views of western medicine; Emma said that many New Americans will not show their fear during an appointment, but they will throw out the medicine they receive as soon as they leave a facility.

Our two primary interview subjects have been in the United States 14 and 11 years respectively, and are now working in the health-care field. Not surprisingly, both have come to trust and understand health care. Seth talked extensively about how he learned about nutrition through his education. When he and fellow refugees arrived, they ate only meat, and they regularly ate fast food, thinking that their much needed weight gain was healthy. They consumed gallons and gallons of pop, and the pounds just kept coming. He now understands the importance of a well-balanced diet and exercise; going to the gym was a concept entirely foreign to him before arriving in the US. As a community health professional, he understands *health care* as health and wellness, emotional, spiritual and physical health. Both he and Emma agreed that most refugees, regardless of length of time in the US, do not understand health care in such broad,

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expansive terms. Emma related stories of families receiving traditional medications from home and refusing to take their children to local health care facilities.

Emma and Seth tell stories of coming to a western understanding of health care, but we also hear in their stories continued resistance of others to western medicine. Both perspectives need to be valued. If we include nutrition and exercise/fitness in the broad definition of preventive care, the interviews with Seth and Emma corroborate the claims from health care providers in our study and previous research that refugees do not include these concepts for preventive care in their understanding of health care. Morris, et al. (2009) corroborate Seth and Emma, explaining that providers complain that “many refugees resettled in San Diego are not fully accustomed to the idea of preventive care, such as annual medical, vision, and dental exams; they elaborated that refugees often wait to seek care until conditions are severe” (p. 535). The reiteration by “all refugee serving organization participants and health care providers” (Morris et al., 2009 p. 535) suggests that providers recognize the behavior as cultural or at least situational. Yet the providers both in the San Diego context and in Fargo do not seem to ask refugees about why preventative care might be unexpected or taboo. Certainly, they do not intend to change their own assumptions that preventative care is the best way to manage health. In the cultural model provider by Dutta (2008) and elaborated by Villagran (2009), the patients’ agency takes precedence, but these providers do not integrate patient understanding of preventative care into their views or their care plans. Instead, caregivers either complain about refugee lack of understanding and/or attempt to convince New American patients about the importance and appropriateness of preventive care.

To really work with this knowledge, it would be useful to understand whether they have ever been exposed to the idea of fitness as preventive care or if they have simply been unaware of such ideas. Wood et al. (2008) suggest “this growing awareness of the need to give voice to the national or international ‘other’ has also potentially altered the ways that researchers think about the ontological and epistemic dimensions of health communication and medicinal public practices” (p. 431). If, in fact, New Americans reject the concept of preventive care for religious or cultural reasons other than simple lack of information, then communicators and providers could change their responses to their situation. Preventive care may also be a way of interpolating New Americans into systems they would prefer to avoid. The idea that preventive care is always an absolute good or always the best way to approach health care might be further questioned depending on the variable responses from New Americans. More information about the reasons for avoiding preventive care is needed, and refugee voices should be integrated into providers’ understanding about patient needs. For example, how useful is nutritional information that focuses on counting calories rather than providing nutrients to refugees who have been underweight for decades? Providers sometimes hear New American resistance to treatments or preventive care, but a cultural approach asks them to value and understand that resistance rather than dismissing it as lack of understanding.

Health care provider stories

We conducted interviews with three providers who work with New Americans at various stages in resettlement: a designated refugee nurse who does initial screenings; the manager of interpreter services at a major medical provider; and a director of the faith ministry at the same

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provider. While we asked some specific questions, the interviews remained open-ended to let the participants move toward the subjects they deemed important. The stories told reveal institutional pressures and actions that curtail patient agency, a network of support that may or may not support personal agency, and one example of a strong assertion of agency by a New American. Jimmy Rowe and Jeff Paterson (2010) articulate a principle of communication that *culturally competent* health care providers should strive for: “Culturally competent, patient-driven communication, through which the provider acknowledges the patients’ individuality, strengthens human dignity and validates equality in health care” (p. 334). We listened to the stories with this principle in mind.

The existence of a refugee nurse position would seem to create a welcoming and respectful environment. The position is funded by a federal grant from the Office of Refugee Resettlement within the U.S. Department of Health and Human Services, and the grant allows the refugee nurse’s facility to focus on refugee needs specifically and keep their special circumstances in mind while creating programs and assessment tools. Such special attention, however, lasts only for the first eight months during which time health care insurance coverage is provided by the federal government. Once adult New Americans settle into the community and, with luck, find jobs or educational opportunities, their health care coverage runs out quickly, and they are even more likely to be uninsured.

According to the refugee nurse, the initial screening is the first health professional contact with New Americans after their arrival. The refugees have already undergone intense health screenings required for eligibility prior to entering the United States. She explains how this initial post-resettlement contact with patients usually begins with a checklist of vaccinations, tests, and questions that the provider feels compelled to complete. While patient ideas about their health care needs are minimally addressed, they cannot be the focus in this initial screening, which is the main health care gate-keeping stage for refugees resettled in Fargo-Moorhead. As the nurse describes it, during this appointment the professional has two aims: to “make sure they [refugees] are healthy for themselves and community” and to refer them to any specialists if necessary. Making the community part of the equation suggests that patient’s needs are not the only issue in the early stages of providing health care. Initial health screenings, even though performed by a thoughtful and responsive refugee nurse, are by their very nature *not patient driven* and run the risk of sending unwelcoming messages.

The definition of healthy early in the resettlement process is established by the medical field rather than by the New Americans themselves. The *CDC Domestic Guidelines* suggest that HIV “Screening should be performed on all refugees unless they decline (opt out)” and the refugee nurse confirms that intake includes HIV testing. Considering the expense and difficulty with accessing retroviral drugs, it seems troubling that HIV screening is an early priority. While drugs are temporarily made available to refugees who receive a positive HIV test, that status may make it difficult to obtain insurance coverage or other health care in the future, and positive results could end with social costs that health care providers do not see, although they are willing to acknowledge that such costs might exist. It would be useful for refugees to be able to express health concerns first at these screenings, but they do have a chance to do so at some point.

Despite the problems described with intake screenings for refugees, the interview with the nurse suggested a generally positive situation for New American health care in Fargo-Moorhead. According to the nurse, the most important factor for success in the Fargo, ND context derives from the small size of the community. Caseworkers at Luthern Social Services (LSS), health care workers, and other providers in education and law enforcement know each other personally (or at least by name); therefore, they can exchange information quickly and deal with situations more easily than a larger, more complexly bureaucratic city. The nurse's stories suggest that unofficial networks maintain support for refugees where their needs might otherwise get ignored. Such networks could include those born American friends or cultural brokers as well.

While all three providers were generally and understandably positive about the role of meeting the health care needs of New Americans, one was willing to acknowledge that she had seen examples of some providers being unwilling to defer to patients' cultural differences, some providers communicating primarily with the interpreter rather than the patient, and treating an adult patient in a patronizing way. "Although we [in the health care system] have touched the surface on cultural understanding there is still quite a chasm," she acknowledged.

One story of strong agency assertion emerged during our interview. The refugee nurse related a story of a Somali woman in labor with a breach baby, refusing a cesarean section for religious and cultural reasons. In Somali Muslim culture, God wills the complexities of childbirth including the complications and outcomes for mother and child. With difficulty, they found one local obstetrician willing to perform a breach delivery vaginally, and both baby and mother lived. This example of extreme agency seems unlikely considering the middle class native speakers who are coerced into cesarean sections, but this woman was clearly able to negotiate the health system here and maintain her agency about how she wanted to give birth. Stories like this one, where a New American maintains agency despite the recommendations of health care professionals, are rare but hopeful.

For all of the successes of the health care programs for New Americans in Fargo, there are still challenges. Rowe and Paterson (2010) explain that "patients should have the opportunity to ask question, express concerns, and enter into dialogue with their providers" (p. 336), and our interviewee nurse affirmed that the New Americans she works with are often worried about and unwilling to question providers. She explains that "they don't question authority" in the same ways that Western born people do and that some refugees fear being deported if they are not healthy enough. For those reasons, the nurse works hard to help New Americans feel comfortable asking questions by reinforcing the concept of confidentiality and asking them many questions to facilitate their own inquisitiveness. She adds that the refugees are not familiar with preventive care.

Some of Rowe and Paterson's (2010) "suggestions to improve culturally competent communications" include "understand[ing] which cultural differences may exist" (p. 336) and "develop a basic understanding and knowledge of the refugee patient's cultural background" (p. 336). The nurse explained how this becomes important with older New Americans and addressing end of life issues. She went on to foreground difficulties, such as cultural taboos against telling ill people that they are dying, which contradict legal requirements to inform

patients they are dying. It seems that the multiplicity of people arriving in Fargo from diverse cultures would complicate providers' ability to know about the cultures they serve. Dutta (2006) suggests "The locally situated nature of health communication processes has become particularly relevant in the context of a growing awareness of the diverse ways in which meanings of health and illness are constituted in diverse societies and cultures" (p. 1).

This focus on local structures displays both a struggle and an opportunity in the Fargo-Moorhead context. Because the New Americans may not define health and illness as an American health care professional might do, one danger of research like this is imposing the researchers' definitions of health and illness on participants. If the nurse is correct and many New Americans do not believe in preventative care, perhaps they should not be asked to change their outlook on health to suit American expectations. On the other hand, as the nurse points out, the size of this community allows for more personal interaction and more willingness to listen.

Beyond the first contact with the refugee nurse, New Americans access health care at area hospitals and clinics. One of the largest hospitals in the region works to address language needs with interpreter services, and we interviewed the manager there. According to the Manager of Interpreter Services, their Fargo facilities held 4,183 appointments using face-to-face interpreters in July 2010-June 2011 and 3,903 appointments using phone interpreter services. For face-to-face interpreting, which is preferable to allow for gestures and body language for context, local providers have people with skills in 15 languages, but they must use phone services for the remainder of the 40 to 50 languages encountered each year. She explained Title VI of the Civil Rights Act, which states that

No person in the United States shall on the ground of race, color or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance. This includes discriminations based on an individual's ability to speak and/or understand English.

For her, this law means that they are required to provide an interpreter for any patients who request it and/or anyone they authorize. At the large hospital she represents, notices to this effect in several languages are posted in many departments. Despite this requirement and genuine efforts to fulfill it, the manager and all providers agree that language and lack of translation/interpreters remains a significant barrier for New Americans.

For this provider, professionalization of the interpreters themselves was a primary focus. In the open-ended interview, the provider addressed problems with standardization in the field of medical interpreting at length, and executing federal standards and requirements for all medical interpreters was a main goal. Fernandez (2010) makes a similar call to establish "national standards and certifications for health care interpreters" and our interviews with New Americans verified problems with language skills and health literacy deficiencies of medical interpreters in the Fargo-Moorhead community. What's not always clearly articulated in these discussions, however, is the importance of patient autonomy and agency. Any national certification program should value the culture-centered approach, emphasize the role of the provider and interpreter to

solicit questions and support the agency of the patient, and always strive to maintain the dignity and equality of refugees or other limited English speaking patients.

Friends' stories

Pipher (2003) clearly documents the importance of *cultural brokers* or *American friends*, including their role as brokers of America's complex health system. The researchers, through close involvement with refugees since 2005 (Ward) and 2008 (Kane) respectively, have seen interactions with the health care system through the eyes of professional communication and textual scholarship, noting over and over again the complexities of translation that is occasionally a literal problem, frequently a cultural problem, and sometimes a problem of agency.

Ward has seen and heard among many refugees the distrust of medicine articulated by Emma, he has shopped with New American families trying to navigate the complexities of grocery super stores, and he has heard them worry about excessive weight gain. He has heard families dismiss local health care provider's assessment of *Post Traumatic Stress Disorder* as simply another way in which in American doctors are trying to get rich. These families often refuse to buy expensive drug treatments prescribed to family members. He has seen the local health care providers baffled by a persistent headache, prescribe complex cocktails of drugs, including nasal inhalers mistaken by the New American as eye-drops, only to have the headache pass once this single mother of four finally stabilized after a very difficult resettlement transition.

He has also seen a young man get treated for diabetes, and a middle aged man who came to America as a paraplegic receive the amazing news that he was not in fact paralyzed, but severely atrophied. He is now on a simple exercise plan to help him walk again for the first time in over 20 years. The health care system struggles to understand the complexities of refugee lives and cultures, sometimes failing and re-enforcing the medical culture of over-treatment and expensive solutions, sometimes responding sensitively with simple, affordable exercise routines. The New Americans assert agency at times by refusing expensive care or treatments, and feel helpless at other times when their children are locked up for 72 hours of mandatory psychiatric observation or when nurses draw vial after vial of blood from their young, under-nourished children with no clear explanation why from the health care provider.

One simple story highlights many of the cultural and literal translation issues that come with being a friend of a New American. Ward arrived at the home of Ayan and Mohamed for a weekly visit only to find Ayan in terrible pain. A phone conversation with a more fluent speaker of both English and Somali helped Ward understand that Ayan probably had an abscessed tooth. The Somali cultural broker, in this case, said the Ayan would need to go to the free dentist on Tuesday (three days away), but Ward knew nothing of the free dentist and did not want to see his friend in such terrible pain. He took her to an emergency room, where the abscessed tooth diagnosis was confirmed, a shot for pain relief was administered, information about the dental service (\$25 for a visit) was provided, and additional pain relievers were prescribed. Ward helped Ayan fill the prescription, but what she really wanted was "Motrin," the cheaper, off-the shelf product, which they looked for while waiting for the prescription, but could not find. In retrospect, Ward' role as cultural broker had mixed results—he intervened against the

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recommendations of someone from Ayan's cultural group, and he helped relieve some pain, but he also inadvertently led Ayan to the more expensive drug solution.

Taking Ayan to the low-income dental service in Moorhead that Tuesday also illustrated the benefits and complications of American friend intervention. Ward was able to provide the frequently missing element in all services—transportation. There is no easy bus route from Ayan's home in Fargo to the dental facility in Moorhead, and Ayan and Mohamed don't drive or own a vehicle. Unfamiliar with this service, however, he didn't know that only 16 patients would be seen; luckily, Ayan was number 15. He hadn't communicated the \$25 cost to Ayan (she had heard free in the initial discussions), and she only had \$10 on her. Ward was able to cover this small cost. Patients, the intake document explained, needed to bring their own translator; Ward knows very little Somali, but the dental process seemed fairly transparent. Not surprisingly, this assumption turned out to be wrong.

In addition, as cultural brokers for refugees in the area, researcher-participants provide first-hand experiences with negotiating health care for and with refugees. Ayan had a terrible time with the initial X-ray—she had never had anything like the strip of film used in this facility put in her mouth before, and because the abscess was in the back left corner of her mouth, the dental assistant had to be aggressive in placing the film. The x-ray turned out to be only partially successful, but the volunteer staff was confident that the tooth was abscessed. For both the assistant and the dentist, they had a difficult time communicating *open* and *close* to Ayan, and with her being nervous and scared, Ward had a difficult time getting her attention and explaining with gestures. In retrospect it would have been two easy words for Ward to learn prior to the visit, and knowing what is known about Fargo-Moorhead's increasingly diverse population, it also seems not unreasonable that *open* and *close* could be provided in multiple languages on a single sheet, posted in each examination room.

The tooth was successfully extracted, no infection ensued, and in most respects this is a successful story of an American friend working with not just a single New American, but an individual and the larger refugee community, to navigate one aspect of the health care system. The availability of this dental service for any low-income individual is also a testament to the dental profession in Fargo-Moorhead and other communities with similar service. Ayan did exert her agency as she and Ward left the facility—she immediately spit out the gauze the dentist said needed to be left in for 30 minutes. She and Mohamed also continue to use a *miswak stick*—a hygienically processed and vacuum packed version of the tradition toothbrush-like stick used in many African countries—for their primary dental care

In another circumstance, Kane accompanied Meredith, a recent refugee from Congo to an eye appointment at a local hospital eye clinic. Her eyes had been tested in an academic setting, and her caseworker set up the appointment. When they arrived, Meredith was asked to fill out a Patient Race/Ethnicity/Language Questionnaire, offered in English only. The reception person explained in English that they wanted Meredith to fill out a form. The first question asks patients to “Please indicate in what country you were born” and includes a list of approximately 188 countries in alphabetical order, with options for *other* and *choose not to answer/declined/unknown*. In Meredith's case, despite having been in the United States only a

little over three months, her English is quite good, if not fluent. She was able to answer the question fairly quickly, and move to the questions on the following page. The second question proved more difficult and evinced an interesting response from the person behind the desk. The question reads, “Please indicate the race/ethnicity groups that describe you. (Select the groups that best describe you. Multiple selections are permitted.)” Meredith looked at the questions, the woman read or paraphrased only the first sentence of the question aloud, omitting the parenthetical addendum, and Meredith balked, looking at the options in what appeared to be confusion. The woman then prompted her by pointing to the “Black or African American” option but only reading the word “African” aloud. Hearing the term “African” prompted Meredith to mark that category. While Meredith ostensibly fits this category, she may not envision herself as part of a *race* or *ethnicity group* at all, and she clearly did not fully understand the question or its ramifications. The Board on Health Care Services at the Institute of Medicine suggests that *self-reporting* represents “the generally agreed-upon best way to define a person’s racial and ethnic identity” (two-three), and they suggest allowing patients to identify categories of their own.

Language became the issue to address, as it often does with New Americans. The rest of the questions on the form involved language preference and skills in English. As Villagran et al. (2008) maintain, “Language barriers impede access to health organizations, diminish the potential quality of health-care services, and increase the risk of unintended outcomes” (p. 207). This knowledge about Questions six and seven ask “Would you like an interpreter?” and “In which language would you feel most comfortable reading medical or health care instruction?” (Patient Race). Meredith indicated that “yes” she would like an interpreter and chose “Swahili” as the language she finds most comfortable. Yet, the woman behind the counter did not follow up with any interpreter or translation plan. After Meredith had completed and signed the form, Kane asked the woman if interpreters are indeed available. She said “no” and then went on to explain that she believed patients could get an interpreter if they requested one at the time they schedule the appointment. The reception desk workers did not seem concerned that Meredith was more comfortable with Swahili than the English, which was used for the entire visit.

This race/ethnicity/language form was the only form Meredith was asked to complete. There was no form concerning her health history, eye health, or other health forms despite this visit being her first to the eye clinic. Since both family and personal health history matters in assessing health care needs and in diagnosis, it seemed odd that such a form was not required. The intake nurse did ask Meredith important questions about family history (glaucoma, high blood pressure) once we entered the examining room, but usually such questions follow a written form.

Kane then asked for a copy of the form without a patient name, and they provided her with one. The form in the appendix is a copy of that form with the provider information removed. When the reception desk employees had succeeded in printing one for Kane, they turned to other tasks. While Meredith waited for her name to be called, Kane asked her if she understood everything on the form, and she said, “no, it was confusing.” Her level of English allowed her to understand some of the questions but not all of them. When the intake nurse called Meredith back to the examining room, she requested that Kane accompany her, no doubt due to her English skills,

although she does not speak much Kiswahili. The two barriers to access appeared in this instance. Kane's presence with Meredith at the appointment connected to transportation difficulties; Kane provided transportation to a health care site in an unfamiliar part of town where it would have been difficult to take a bus. In addition, Meredith relied on Kane at the front desk, being somewhat unsure about what the form was asking her, but knowing that she understood the words on the form and what was being said by the employees behind the reception desk.

Once in the examining room, the intake nurse asked a number of questions and conducted an initial test of Meredith's sight. The ophthalmologist used drops to dilate her eyes, and while he explained that the drops might sting, Meredith was clearly surprised and unhappy about the amount of pain those drops caused. At this point, either the doctor or nurse could have explained about different reactions to the drops or talked about pain levels, and asking about what she was feeling or why it was scaring her. But they merely continued with the testing, evincing frustrated body language when Meredith took extra time to wipe tears away from her face, delaying the next process. Kane's presence probably kept Meredith from panicking, but reassurance that stinging can be intense or questions about what she was feeling might have helped her as well.

Conclusion

Our collected stories, considered from a culture-centered health care communication frame, reveal that concepts like *preventive care* need more than literal translation, that professionalization of interpreters is desired by all parties—especially if patient empowerment is part of the professionalization—and that cultural brokers and friends can play a stop-gap role in health care translation.

The cultural approach to health communication suggests that New American attitudes about preventive care should be attended to and integrated into decision making. On this issue, providers and New Americans had similar conclusions. Most agreed that attitudes about preventive care differ for some refugees, and that New Americans do not all understand or value the preventive approach for a number of reasons. More understanding about why some cultures eschew preventive care would add much to the conversation. If availability of providers and facilities or lack of resources are the underlying reasons for avoiding preventive care, then encouraging a cultural shift to take advantage of available providers might be warranted. But a more integral rationale such as respecting the bodily autonomy of seemingly able-bodied persons or other cultural concerns might be a space to allow medical professionals to better understand the health care needs and preferences of refugees.

More extensive training of translators, interpreters, and health care providers in a cultural approach to health communication might sensitize translators—who may share a language but not a culture with the patient—to the importance of empowering patients. Instead of merely telling a patient the recommend cure or medication, the translator might ask the patient if a particular treatment or practice is acceptable and relay important cultural practices or beliefs back to the provider to allow solutions through dialogue. Translators and interpreters might better serve New American clients through training that emphasizes patient agency as well as professionalization that gives them power to more effectively interpret patient needs back to

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health care providers.

A cultural approach would push providers, who already work hard to collect ethnic, language, and country of origin data, to improve those data collection systems based on input from the patients they serve and to use that data in development of programs and procedures. The Institute of Medicine has called for a standardization of data collection that would nicely complement professionalized interpreter services. The challenge in both these cases is containing costs and proving cost-benefit scenarios in an already too expensive health care system.

Friends or cultural brokers play a potentially valuable and affordable stop-gap role in translating health care for New Americans, but they too are subject to cultural misunderstandings and may prevent empowerment of New American patients, rather than enable it. Our own experiences have been mixed. We have been able to provide the all-important transportation piece of health care for New Americans, but we, too, are limited in our agency within a medical system that values privacy and protects against litigation.

The challenges of translating health care are literal and cultural; the solutions are difficult and expensive, but not insurmountable. Professional communicators may have a role to play in appropriate local settings. They may be more comfortable than health care providers in using a cultural perspective, may be able to facilitate non-textual document production, and/or facilitate small-scale translations. Certainly scholars interested in the intersection of health literacy, globalism and professional communication can find a worthwhile action-research agenda to be developed around issues of translating health.

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[i] See Pesata V., Pallija, G. & Webb, A. A. (1999), Sheikh-Mohammed, M. Macintyre, C.R.,