



Section 3: Barriers and Case Studies.

BARRIERS TO CARE

- 1. Providers and receptionists unable to distinguish between Latinos and Maya (or unaware of the differences).** This is relevant to the toolkit because misidentifying the Maya creates multiple problems in regards to patient care. The Maya have their own languages and traditions that differ from Latino cultures. They also have a unique history and background that is relevant to their overall health and wellness.
- 2. Limited use of interpreters in Mayan languages.**

There is a crucial need for trained Maya medical interpreters. Some but not all Maya speak Spanish. They may try to communicate in Spanish but often lack the proficiency to understand as well as might appear to the observer. Few Maya interpreters have professional or medical training. Without an adequately trained interpreter, Maya may not understand their diagnosis or their treatment plan. (See the final section on the Interpreter's Network for detail.)
- 3. Patients that are illiterate or have low literacy in Spanish and English have difficulty understanding materials and completing lengthy, complicated paperwork.**

Many Maya in Guatemala lack of access to education, resulting in high levels of illiteracy or limited literacy skills. This creates challenges for filling out paperwork, reading prescriptions, and understanding one's illness or diagnosis. Some clinics have forms translated into Spanish, but for Maya who do not read, this is not helpful. Financial constraints, unfamiliarity with U.S clinic procedures, and educational gaps cause many Maya to postpone clinic visits until their situation is critical. This creates a heightened stress level for patients during their initial clinic registration. Literacy is also a major issue when providers need written permission to perform certain procedures.

4. The use of children or family as interpreters.

Many parents have their children interpret for them. This is not ideal because it can be scary for a child to hear medical diagnoses and information can be lost or mistranslated easily. By law, hospitals and clinics must provide interpreters and should not use children.

5. Waiting too long to seek care—especially expectant mothers

Families usually seek care at the hospitals or clinics only if it is urgent because of high costs, lack of trust, unfamiliarity with local customs, discomfort with clinical surroundings, or because they are unsure of the health benefits.

6. Patients not returning for follow up appointments

This may be due to the cost of appointments, preference for alternative care, transportation issues, a history of bad experiences, or miscommunication regarding the appointment date.

7. Confusion between patient and receptionists regarding last names

Initial confusion occurs because many of the Maya, as customary in Maya villages, take only first names for the entire name, which in the Spanish style numbers four. For example, it is possible to have the name: Juan Juan Juan Juan, or Juan Francisco Antonio Lucas. In addition, Maya wives keep their maiden names and take their husbands "last" names. This may confuse hospital staff; thus, names are entered into the computer incorrectly, files are lost or difficult to locate, babies are miss-named, and Maya feel less respected.

8. Unknown date of birth

Many of the Maya living in the United States lived in Guatemala during the civil war. They may have been born during the war or lost family in the violence. Therefore, some of the Maya do not know their birthdates. They may give an estimated date when questioned, or be unable to answer. This can lead to frustration or suspicion by the healthcare provider.



9. Difficulty obtaining complete medical history and family history information

For the reasons stated above, many Maya do not know their complete medical history. Some records may still be in Guatemala or they may not have any.

10. Conflicting information being given by midwives or other traditional healers

Some Maya choose to see a traditional healer and use traditional medicines before going to the doctor, as this is custom in their homeland. Occasionally, information or medicines differ from that of western medicine.

11. Differing health practices and definition of health

In the Maya tradition, everything is connected: mind, body, and nature. This world view carries over into the Maya concept of health. Maya diagnoses may blame an illness on something in the natural world or on supernatural causes. Likewise, traditional treatments are likely to involve prayers along with natural remedies. Understanding that Maya patients may conceive of their illness and treatment in a holistic way is crucial to providing them with quality care.

12. High cost of care

To someone who is familiar with healthcare costs in the United States, a \$200 clinic charge for an initial prenatal check-up is reasonable and most would agree that the services are worth the money for peace of mind that one's pregnancy is progressing well. However, for a Maya woman with limited funds and little experience or knowledge of modern medical practices, these fees may seem exorbitant. The cost of seeing the local Maya midwife is only five dollars per visit. The Maya women may understand this difference in cost, but not the difference in care value.

13. Long wait times

Many Maya report waiting extended periods of time for care in clinics and emergency departments. Because of these lengthy waits, Maya sometimes feel they are being discriminated against.

14. Childcare availability

Often Maya women do not have access to childcare and must bring their children with them to doctor's appointments and hospitals. Some even have their children with them while they are giving birth. Lack of access to childcare limits women's access to healthcare.

15. Maya may not admit to being indigenous because they believe they may be treated worse.

Discrimination and prejudice against the Maya people is common in Guatemala. After suffering this treatment in their home country, many Maya are apprehensive about how their Native American heritage may be perceived in the United States.



CASE STUDIES

CASE EXAMPLES

The following case examples highlight specific incidences of misunderstandings and miscommunications between Guatemalan Maya people and the U.S. systems of health care and social services. Language and cultural barriers are the prime culprit in each of the instances under study. These cases took place in the Southern United States. All of the names have been changed. Case examples came via direct testimony from the people involved.

PREGNANT OR NOT?

Luisa went to the county health department and was told that she was three months pregnant. She received an ultrasound picture of the baby she was carrying. Later, she began to have pain in her abdomen. She went to the hospital. Luisa waited for six or seven hours until she was finally seen by a doctor. Around 3 or 4 am, she was examined and given medication to help her pain. An interpreter on the phone told her she had “an abortion” (miscarriage). She returned home, not understanding exactly what happened—she had never experienced bleeding, only pain, and so she was confused. The next week she began to “feel something,” as if she were pregnant. She returned to the clinic and the woman translating told her she had never been pregnant. Luisa and her husband still do not know what happened because they did not speak English or Spanish well at the time. Even though an interpreter was provided, it was not adequate to clarify the situation for this family. Did she have a miscarriage? Was she ever really pregnant? The questions still bother this couple, over three years after the incident occurred.

CAR ACCIDENT LEADS TO EMERGENCY ROOM CONFUSION

Juan and his 2-year-old daughter were in a car accident. Juan said he immediately called his wife Maria to come to the scene to be with their daughter. The police arrived and Juan stayed behind to answer questions as his wife and daughter got in an ambulance and went to the hospital. Juan is from Guatemala and speaks Spanish and Chuj but his wife speaks only a little Spanish. When they arrived at the hospital, Maria was told to sign some release papers. Since she does not read English or Spanish, she did not understand what she was signing but assumed it was permission for the doctors to examine her daughter. However, the doctors then began to examine both the Maria and the daughter. Maria wanted to tell them that she was fine and that she was not even in the accident but she could not communicate with the medical staff. Following the accident, Juan and Maria received a bill for \$1,500 from the hospital. It was itemized and showed expenses for both the daughter and Maria. Juan has been trying to explain to the hospital that his wife met them at the scene of the accident but was not in the accident and therefore did not need the tests the hospital ran. Juan was frustrated that the hospital did not know the accident details and did the tests on the Maria when she did not need them. He is also very concerned about his hospital bills and his inability to pay.

SURGERY SHE CANNOT EXPLAIN

Julia had some pain a few weeks after delivering a child. She went to the doctor and was told she had a "stone". She had to have surgery to have it removed. However, the problem and procedure were explained to her by a Spanish interpreter in Spanish. While she and her husband understand a little Spanish, they do not understand all of the nuances of the language or the medical terminology; hence, they were unsure of the details of her problem and the procedure. She expressed that while they understand Spanish better than English, they still do not speak Spanish that well. The result was that Julia had a surgery she could not explain for a reason she did not understand.



SEVERE, ONGOING ILLNESS OF A CHILD

Lydia's daughter was sick for two months. Because she was born in the U.S., she had insurance and Lydia and her husband could take her to the doctor. They did so three or four times over the course of the two months, but she was still sick. The doctor did nothing for her. Finally, the parents took her to someone from Guatemala who had knowledge of "Maya medicine" and she got better. She said, "We have Maya medicine. That's why when we get sick, we don't take the kids to the doctor because the doctors don't do anything for the kids. We have medicine that can make them better."

ARRESTED FOR CHILD MOLESTATION

A young male Mam Maya speaker had been waiting for his clothes to finish in the laundrette. Allegedly he touched the hair of the small girl child, who screamed, causing the child's mother to call the police. Unable to speak or communicate, he spent more than four years in a mental health facility; his identity and native language was unknown. However, when a Mam interpreter was brought to him after the four years, he began talking profusely and identified his home and family in Guatemala. When asked by the interpreter why he had touched the girl's hair, he replied "her hair was pretty." [The meeting with the interpreter was witnessed by one of the principal authors of the Toolkit.]

MINOR INJURY BECOMES POTENTIALLY FATAL

Because traditional care is tried first and expense is a major factor, minor injuries can turn into major problems. A 19-year-old yard worker with a major finger infection developed potential life-threatening complications. He injured his finger with a weed-whacker, and his finger became infected with major swelling. He had no public or private insurance, so he tried a variety of traditional remedies. Later at the hospital he was advised that without surgery he would lose the finger and the infection could spread and even result in death.

CHILD REFUSES TO EAT SCHOOL LUNCH

A Maya child in Florida would not eat the school lunch given to him each day. He was new to the United States and he spoke neither English nor Spanish, hence he was unable to communicate why he refused. Teachers and staff became forceful in their insistence that the child eat. However, the boy was unfamiliar with foods like milk, cheese, and peanut butter; he found these things repulsive and nauseating since he did not grow up consuming these types of foods. His inability to communicate his reasons did not stop the forceful reactions by the school staff.

BELIEFS ABOUT CHILDBIRTH CAN CONFUSE PROVIDERS

Maya believe that warm food produces the mother's milk, but in the hospital, the new mother was given only cold milk. The doctors wanted her to drink lots of ice water and take prescription medicine, but she felt that was bad for her and her baby. She feared that the child would sicken with digestive problems, swelling of the chest, and chills. The mother herself might become ill.

NON-VERBAL MISCOMMUNICATIONS: THE MOTHER WHO "REJECTED" HER CHILD

The baby had been taken away from mothers when hospital staff believed that the mother had shown a negative attitude toward the child rather than being loving and attentive. The mother had been afraid of causing illness in the child because she was imbalanced after birth, thus she was in fact showing her love for the child by refusing to demonstrate what the hospital staff thought should be correct maternal behavior.

NON-VERBAL MISCOMMUNICATIONS: THE MAN WHO "DOMINATED" HIS WIFE

Medical staff complained that Guatemalan men dominated their wives to the point that women would not speak during appointments. It was thought that the women were not allowed to speak, and they suspected abuse might play a role. Investigation showed that nearly all Guatemalans in the local area were Maya; and approximately 50% of the women spoke no or very little Spanish; and no English.



RESULTS OF FOCUS GROUPS SPECIFIC TO WOMEN

LANGUAGE AND LITERACY

Women have difficulties expressing their problems to doctors and nurses, understanding their diagnosis and treatment options, knowing what medicines they are taking, why they are taking them, or the correct dosages. Some of the women or their husbands understand and/or speak Spanish, but not always well. Luisa said, "Sometimes we say we understand, but we don't understand." The Maya women expressed a great need for someone to help explain medication use to them, and stressed that their number one healthcare need was to have someone who speaks their language interpret for them.

The hospital claims to provide interpreters (in person or over the phone) to anyone who needs translation services. However, this was not the case described by the women. They have to wait long periods of time for the Spanish language interpreter to be available. If the interpreter is busy, the Maya women have to wait. Some of the women said that several times a Q'anjobal-speaking interpreter was provided for them over the phone. In one case, the woman's husband was able to make it known to the hospital staff that she needed a Q'anjobal interpreter. This allowed the hospital to obtain the correct interpreter.

Luisa had to return to the doctor's office multiple times because she did not understand what was happening and the interpreter was not there. This situation led her to return to the doctor with her school-age daughter who speaks English. Her young daughter interpreted for her and she was finally able to understand what was happening. At another point in time, this same child was very ill and had to be taken to the hospital for treatment. Even though she was sick, she had to translate what the doctors and nurses were saying to her parents because no interpreter was available. Luisa saw her daughter's ability to translate as a wonderful thing. She feels it is a good opportunity for her daughter to get a good education in the United States and that her daughter must learn to speak English well. The woman stated that she likes her daughter to translate for her and always takes her to the doctor with her now.

The issue of language difficulties also carries over into the written paperwork that the women must complete at doctors' offices and in hospitals. Because the women do not speak English and few of them read or write in any language, it takes a very long time for them to complete paperwork. While confronting the difficulty of filling out paperwork in a foreign language, the women were usually in labor and experiencing pain while trying to do this.

EXPERIENCES WITH HEALTHCARE PROVIDERS AND HOSPITAL STAFF

Lydia told the story of a friend of hers who could not come to the focus group that day. She said that the woman had a problem with the *"finance people"* at the hospital. She has four children and the father *"is gone."* The woman is alone and has no one to help her care for the children. The hospital worker became very upset with this woman because all of her children were at the hospital with her. *"They were talking about her really bad and treating her like a dog,"* Lydia said. The staff person was saying, *"How are you going to feed them?"* The Maya women felt that this was unacceptable behavior from someone working in a hospital and they felt that the staff person did not have a right to talk to their friend that way. This story was shared as a plea for help in stopping this kind of treatment.

It is common for the Maya women to have to bring their children to the hospital with them when giving birth because they do not have another option for childcare. One of the women described a nurse threatening to call the police if *"they didn't get the kids out of there."* One woman expressed confusion when dealing with doctors. She said, *"Doctors are different. Some of them don't want noise, others don't care."*

Other women expressed the belief that doctors and hospital staff treat them differently because they do not speak English or because they do not have insurance. Several women said that the first thing hospitals ask you is if you have insurance or a way to pay. *"If you do not, then they don't care about you. The people with insurance get better service than the people who do not have a way to pay."*



MAYA HEALTH

The Maya women feel that to be healthy means that they do not have any pain, they are not sick and they do not have to go to the doctor.

The women said to keep their families healthy they wash fruits and vegetables before eating them, wash their hands, and keep their homes clean. They also said that their doctors had told them that children must eat fresh vegetables and healthy things.

PRENATAL CARE AND CHILDBIRTH

In seeking prenatal care, the Maya women wait much longer to see a doctor than is recommended by biomedical practices. Most of the women were about seven months pregnant the first time they went to a doctor. One of the women said she was only two months pregnant when she first went to the doctor, one was five months pregnant, and Anita did not see a doctor until she went into labor. The women said that money was the primary reason for their delay in seeking medical care during pregnancy. They said that all the doctor does is “check” the baby. The women did not believe that it was worth the money for the doctor to do a quick check. However, the woman said that they appreciate and like having doctors there to help them. They feel that childbirth is less painful for them because of this and that they feel less worried delivering in a hospital than they did in Guatemala.

Pregnant Maya women go to the hospital when they begin feeling labor pains. Some of the women said that when the pain started, they got medicine from doctors to help, but they did not know what kind of medicine it was. Luisa described a long needle that was put in her back while she was in labor. She said that the doctors and nurses explained it and its side effects, and told her what it was, but she did not know what it was called. When the other women were asked if they had received an epidural or anything like what Luisa described, all but one said they had rejected the procedure.

In Guatemala, after giving birth, the women and baby take a shower in very hot water in what they called a “temascal.” They described it as hotter than a sweathouse—

about 150-160 degrees. In the U.S., the women have found that they are offered cold drinks after delivery, but they do not want anything cold. The women said that after giving birth, everything they eat must be hot. Everything they drink must be hot. This cultural preference is hard to convey when language is a barrier.

COMMON ILLNESSES AND MEDICATION

The most common illness among Maya families was what they called “the flu.” Women said that their children get “the flu” when the weather changes. They know the children are sick because they cry a lot, have runny noses, and a fever. Other symptoms, such as vomiting, diarrhea, sore throat, etc. were not common illnesses in Maya families. Luisa did report that if women breastfeed their babies, their children do not get ear infections, but that if children are given store-bought milk they do get ear infections.

When Maya women or children become ill, they expressed that first they use “Maya medicines” to try to cure the illness. If that does not work, they go to the pharmacy and buy medicine. However, if a school-age child has a temperature over 100, the women said they have to take the child to the doctor because the school requires it.

The women expressed that obtaining traditional medicines is very difficult. They said that they can get some things at the Hispanic grocery store, but the Mexican herbs are different from what they are used to in Guatemala. Some special medicines can be brought from Guatemala, but airports do not allow you to bring plants into the country. The use of the “temascal” is also a common health method in Guatemala. The entire family would take a shower in the very hot water. However, there is no “temescal” here.

The women also described the differences in obtaining medication here and in Guatemala. There, they do not have to go the doctor to procure medicines. The pharmacist gives out medications that in the U.S. are dispensed by prescription only. In Guatemala, there is also access to plants with healing properties and their uses are taught to children by their parents from a very young age. In the U.S., the Maya have to go to the doctor to receive care and they are not used to this.