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Healthcare and Language: Challenges Faced by Multilingual Patients in the US

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ABSTRACT

With the rising demand of access to healthcare language services can healthcare systems keep up? This thesis examines the federal laws regarding language interpreting services for limited English proficiency (LEP) patients, the challenges faced by LEP patients, how technology can aid in language interpreting, and how nonprofits are stepping up to support their communities. The findings outline that while there are laws mandating qualified language interpreters for LEP patients, these laws are not widely followed. As a result, children are often brought in to interpret, with negative impacts. LEP patients often have negative healthcare experiences—from long lists of testing to long waiting times, to not communicating or understanding their healthcare care plans. Technological solutions are still emerging. The solutions available have their own drawbacks from inaccuracy in language translation to regulation limitations. While there are community-based services available, they have limited resources, and it is simply not enough to be a long-term solution.

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Chapter 1 Introduction

When I think of my dream career, I think of a blend between healthcare administration, data, and technology. Growing up, I knew I always wanted to do something to give back to my community. After all, my name means “little helper/supporter.” In my early college days, I thought about one day creating a language interpretation program that would use volunteers to provide on-demand language interpretation. In return for their services, they would shadow health care providers to learn more about a career they were interested in pursuing.

My passion for language is deeply rooted in my upbringing as an immigrant child. Unlike my parents, I was able to pick up English because I was young and got daily exposure at school. Given this power, I would eagerly help interpret for my parents who are English language learners. As I grew up, I became more involved in this process of language interpretation. I would go with them to doctors’ visits and help them get access to quality health care. Over the years, there were many obstacles my parents had to fight because of their limited English proficiency (LEP). Their struggles deeply inspired me to pursue a career in healthcare administration. Many immigrant families go through the same obstacles my parents have. I have been gifted with the opportunity to be multilingual and have access to quality care, which is a basic human right. Because of my privilege and life experiences, I knew I wanted to do something meaningful with my career.

During my time at Penn State Abington, I got the honor of being Dr. Chamberlin’s student. The first class I had with her was in my first semester, Honors Globalization of English. I learned about the spread of English as a global language and how that impacted countries

where it was not their primary language. From that point on, Dr. Chamberlin and I bonded over our passion for language. Every year, I would try to schedule a class with Dr. Chamberlin because her passion for language is contagious. When the time came for me to pick a thesis topic, it was an easy decision. I knew I wanted to explore language barriers in healthcare. I wanted to learn more about healthcare laws and regulations, the patient's experiences, and how technology and non-profits have stepped in to better serve their communities.

While America is a multilingual country, the mindset many have is monolingual. This mindset can be seen in healthcare. Everyone should have access to the care they need, but those who do not speak English well face major challenges. In the next chapter, I will be reviewing the current state of healthcare language access laws. I want to explore what the law mandates and how the changes came to be. In chapter three, I will dive deeper into the challenges faced by LEP patients, the realities of language barriers and physician-patient communication, and the harsh reality of child language brokering. Following that, chapter four will review the interpretation services available. This includes the current state of services and what changes technology can bring and some of the drawbacks with futuristic solutions. In chapter five, I will review prominent community-based organizations that are serving their ethnic communities in Philadelphia. I will also give an insider perspective on the role the Children's Hospital of Philadelphia plays. And finally, in chapter six, I will conclude my thesis and give a look ahead.

Chapter 2 Healthcare Laws & Immigrants

Federal Laws

The United States of America does not have an official national language. It is also known as the melting pot, the land where immigrants can live and prosper. Throughout the 1800s and the latter half of the 21st century, America has seen a continual uprise in the number of immigrant settlements. Before there were any federal laws on overcoming healthcare language barriers, immigrant communities would settle together to form their own linguistic enclaves where services were provided in their native tongue (*The Evolution of Medical Interpreting*, 2019). An ethnic enclave is known as a racially segregated neighborhood typically located in an urban setting, also known as a cultural community. Similar to the ones from the past, some enclaves today still offer health services that benefit immigrants. In a study published by the *Journal of Ethnicity & Health*, it was found that the Chinese American enclave in California had an advantage for married Chinese American women who had colon cancer (Kcomt & Gorey, 2020). This group had a 23.3% greater survival rate than Chinese American women who did not live in enclaves. This is due to the advantage of gaining private medical insurance from their spouses. This decreased their treatment wait times and increased their surgery and follow-up treatment options. Furthermore, Chinese American enclaves are associated with better self-reported health and consumption of less processed and lower fat foods (Kcomt & Gorey, 2018). In a study in the *Journal of Immigrant Minority Health* (Viruell-Fuentes et al., 2012), researchers found that in the Latino enclave community in Chicago, Spanish-speakers and foreign-born community members benefitted from Latino-specific resources that allowed them to navigate the

healthcare system. The higher concentration of cultural communities resulted in lower rates of obesity, lower consumption of fatty foods, better access to healthy foods, and an increase in health care access. It must be noted that this study also found that such enclaves were not helpful for US-born Latinos as they experienced a block in social and economic opportunities (Viruell-Fuentes et al., 2012). Overall, these studies point out that linguistic and cultural understanding are an important component of healthcare.

As healthcare moved away from enclaves and became more centralized, LEP patients were forced to turn to healthcare providers for language interpretation. Healthcare organizations would use their bilingual staff as untrained interpreters—to orally translate medical communication. At this time, children often became the default interpreters. The Refugee Act of 1980 led to an increase in Southeast Asian refugees who spoke Vietnamese, Cambodian, and other languages rarely heard of in the US. With there being no ethnic enclaves, those refugees faced major linguistic and cultural barriers when accessing healthcare. By the late 1980s, advocates for these Southeast Asian refugees and other newcomers turned to the legal system to provide LEP patients with language access (*The Evolution of Medical Interpreting*, 2019).

The very first US federal law that prohibited discrimination based on one's race, national origin, or color for any federal-funded programs was Title VI of the Civil Rights Act of 1964. This law prohibits any form of discrimination whether it is direct or indirect considering timeliness, quality, or quantity of services provided, as well as; and the types of benefits or aids that are provided (U.S. Department of Health and Human Services, 2013). This was a major milestone for the United States in trying to provide access to quality services without undue discrimination. Thirty-six years later, on August 11, 2000, the President of the US signed the Executive Order 13166, also known as, *Improving Access to Services for Persons with Limited*

English Proficiency. It requires all federal agencies and federal-funded programs to examine services they provide and assess what services need to be provided for English language learners, so they too have the same access to services (U.S. Department of Justice, 2022). The Executive Order also requires each federal agency branch to create a LEP plan to increase language access. Refer to Table 1 (Appendix, p. 32) to see the U.S. Department of Health and Human Services' (HHS) Equity Action Plan Issued April 2022 (Limited English Proficiency, n.d.). The chart was published in a document that highlights the ten elements of language access strategy and policy. It is important to note that HHS requires a qualified interpreter, not children, family, or community members, to interpret. It is also mentioned that language access services will be free of charge (Limited English Proficiency, n.d.).

Ten years after the passing of Executive Order 13166, the Patient Protection and Affordable Care Act (ACA) of 2010 was passed. Under Section 1557, the Office of Civil Rights enforces the prohibition of discrimination patients on the basis of "...race, color, national origin, age, disability, or sex (including pregnancy, sexual orientation, gender identity, and sex characteristics)..." when providing health care coverage. During the Biden-Harris administration, this section was updated on July 25, 2022 to "...promote gender and health equity for communities of color, women, LGBTQI+ individuals, people with disabilities, persons with limited English proficiency (LEP), and older people" (U.S. Department of Health and Human Services, 2023).

Under the HHS is the Office of Minority Health, which houses the National Culturally and Linguistically Appropriate Services Standards (CLAS Standards). Their intention is to eliminate health disparities, improve quality, and advance health equity by outlining what health care organizations need to do. The principal standard is to "Provide effective, equitable,

understandable, and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy, and other communication needs” (U.S. Department of Health and Human Services, n.d.). There are three subgroups: (1) government, leadership, and workforce; (2) communication and language assistance; (3) engagement, continuous improvement, and accountability. Under the first subgroup, the goal is to recruit, promote, educate, and sustain organizations for health equity practice through policies, resources, leadership, and governance. The second subgroup focuses on language needs for those with LEP by providing language assistance at no cost and in a timely manner. To make this more accessible, there should be signage in all service areas and qualified individuals should be used as interpreters. The final subgroup focuses on collecting and maintaining accurate demographic information for quality improvement measures. There should also be ongoing assessment of current practices to ensure they are culturally and linguistically appropriate. The findings should be communicated to all stakeholders (U.S. Department of Health and Human Services, n.d.).

US Immigrants

As of 2019, more than 44.9 million immigrants live in the US, making up 13.7 percent of the country’s population (Camarota, 2012). The number is growing much slower than in the past due to the Covid-19 pandemic, Trump administration policies and deportation, backlog in processing where nine million are waiting for their green cards, and half a million are seeing delays with student, travel, and work visas (Watson, 2022). In 2010, there were 40 million immigrants, a 28 percent increase from the year 2000 (Camarota, 2012). Since the 1970s, when immigrants were rapidly increasing, there have been a major shift in US immigration laws and

economics. The top countries of immigrants as of 2019 include Mexico, India, China, The Philippines, El Salvador, Cuba, Vietnam, Dominican Republic, Korea, and Guatemala.

According to the 2019 US Census, roughly 78 percent of people ages 5+ reported speaking English, and the remaining 22 percent spoke other languages at home. About 46 percent of the total immigrant population is considered to have LEP. Refer to table 2 (Appendix, p. 33) to view the top language breakdown (Batalova et al., 2021). As of 2020, the top languages spoken by resettled refugees include Arabic, Ukrainian, Russian, Kiswahili, Spanish, S'gaw Karen, Kinyarwanda, Dari, and Tigrinya (Batalova et al., 2021).

Compared to the 69 percent of US born citizens who have private health insurance, roughly 58 percent of US immigrants have private health insurance. While 36 percent of US born citizens have public health insurance, only 30 percent of US immigrants have public health insurance as of 2019. With the implementation of the ACA, health insurance coverage has improved. From 2013 to 2017, uninsured immigrants reduced to 20 percent from 32 percent (Batalova et al., 2021). With the recent changes to legal mandates, foreign-born patients and LEP patients now have protection against discrimination and help with healthcare insurance. Despite these trends that favor health equity, immigrants still face communication barriers.

Chapter 3 The Patient Experience

Introduction

Despite federal laws intended to prevent discrimination today, linguistic minority patients continue to be without proper language services, which causes a disruption in access to quality care. The ACA requires facilities who receive federal funding to provide language interpreters to those with limited English proficiency, and doing so enables the nation to move towards providing adequate access to quality health care for all Americans. However, there are challenges that need to be solved, despite the ACA. For starters, the lack of language services can result in errors in communication, which can cause significant health disparities (Olani et al., 2023). An example of this can be seen through the following excerpt:

“...I had a patient who underwent a surgery to remove an anomaly on her lung. We then performed chest tube for her. To remove the chest tube, we gave them an appointment with the help of ad hoc interpreter, and they went home. We believed that they have understood everything we told them. But they came back after 3 months, long time after their appointment date with a very critical condition, and a surgery was performed for the second time. We were blamed for not properly informing the patient about the follow up. Had we professional interpreter, problems of this kind could not happen” (Olani et al., 2023).

Another problem that arises is that due to dissatisfaction from healthcare visits, patients may stop seeking medical help altogether.

“I have previously faced several terrible incidents related with language barriers. I am still facing the same problem. I am deciding that I will never come back. My health problem could be highly contagious or whatsoever, but I prefer dying in my bed than coming back here. Due to the problem of language barriers and the associated maltreatment I faced, there were times I even thought of holding electric wire to commit suicide” (Olani et al., 2023).

Furthermore, with unclear communication, small details are often left out, as in the following case:

“You see the existence of this problem mostly at the outpatient department when patients come for follow-up treatment. How the patient has been taking drugs could be completely different from how it was prescribed by the physician. This could be especially related to the amount prescribed and the sequence with food that the drug is prescribed to be taken. The patient may report that he had been ordered by the physician to take the drug after 30 minutes while the correct prescription from the physician may say 30 minutes before having food. These problems happen regularly” (Olani et al., 2023).

In a study published in the *Journal of the National Medical Association* (Sheppard et al., 2014), researchers found that a staggering 70 percent of Latinos have experienced discrimination when seeking care which then delayed their treatment. The most common forms of discrimination experiences were (1) providers not listening to them and (2) discourteous treatment from providers (Sheppard et al., 2014). The National Survey for Children’s Health found that people coming from non-English primary language homes went to fewer preventive

health care visits (Goenka, 2016). According to another study, Asian immigrants who have lived in the US for ten-plus years have a stronger relationship between their chronic conditions and language discrimination. Their risks include hypertension, obesity, diabetes, mental disorders, and depression. Overall, they feel lower levels of self-esteem, satisfaction with life, and lose social connectedness with their community (Yoo et al., 2009). As for DACA recipients, they may feel alienated from the healthcare system, which significantly impairs the group's health outcomes (Woofter & Sudhinaraset, 2022). These problems are severe and preventable, and they necessitate attention to better communication and physician-patient relationships.

Physician-Patient Communication and Relationships

The discrimination experienced by those with limited English proficiency is often the result of miscommunication and cultural differences that might impede a good physician-patient relationship. According to *Current Opinion in Pediatrics*, “High-quality care requires clear communication between clinician and patient, and language barriers adversely impact clinical processes and outcomes” (Goenka, 2016). In emergency rooms, linguistic minority patients are often dissatisfied with their care. Those patients are also less likely to visit the same hospital again. Due to the language barriers, it has been reported that pediatric patients experience longer wait times, have higher utilization of diagnostic testing, and are more likely to return within 72 hours (Goenka, 2016).

One of the most publicized cases on the importance of language interpretation services occurred in the 1980s in Florida. An 18-year-old unconscious male was taken to the ER and his LEP family tried to explain that the patient may have experienced severe food poisoning. In

Spanish the term used is “intoxicado”. Without a language interpreter the family informed the doctor “intoxicated, armBURger.” The doctor assumed that the teenager overdosed because the family mentioned “intoxicated.” Thirty hours later, the doctor ordered a neurology consult as the patient’s eyes deviated. It turned out the patient suffered from a stroke and was bound to a wheelchair. This medical error led to a \$71 million settlement and a tarnished career for the doctor (Children’s Hospital of Philadelphia, 2018).

Understanding culture in communication also plays a vital role in medical interpretation. A patient could smile and say “yes” to show they are paying attention to their doctor, but that shouldn’t be taken as them understanding what the doctor is saying. Similarly, a patient may avoid certain communication cues, which are considered normal in America, but disrespectful in other cultures. Just as one word can change the meaning of an entire sentence, one cultural barrier could cause a major medical error (Children's Hospital of Philadelphia, 2018).

According to a study published in 2023 by *BMC Health Services Research*, approximately 80 percent of health assessments that healthcare providers make are based on the explanation from patients, while 20 percent are drawn from lab tests. A lack of effective communication could result in preventable medical errors, increased hospital stays, ethical dilemmas, weak patient-provider therapeutic relationships, and patients who feel less confident in or ashamed of their experiences. Physicians in the BMC study admitted to ordering a list of lab tests to help find the problem due to language barriers. This means patients incur a financial loss when language barriers are present (Olani et al., 2023).

In the book, *The Spirit Catches You and You Fall Down* (Fadiman, 1997), Lia Lee and her family, who were Hmong refugees to America, experienced the harsh realities of language and cultural barriers in healthcare. Lia was the only sibling to be born in a hospital assisted birth

and had a birth certificate that included the time and date. In Hmong culture, the placenta is buried under the house because it is believed the soul returns to the placenta after the person dies. However, with Lia's birth, the placenta was taken and incinerated to lower the risk of Hepatitis B from spreading. When Lia was diagnosed with epilepsy, her family saw it as *quag dab peg*, which in Hmong culture means a bad spirit took Lia's soul. Although Lia was in pain and disabled, her condition was seen as a blessing because the Hmong believed Lia was now the host for a healing spirit, or a *neeb*. During the first three ER visits, there were no interpreters to help communicate Lia's condition. By the fourth visit, Lia's English-speaking cousin joined to explain the seizures. The family was given medicine to help with Lia's condition, but the family's distrust towards the rude doctors (who had no respect towards Hmong traditional healing methods) and Western medicine resulted in them not being administered. Lia was taken into foster care for some time due to the family not administering medication, which the family believed was altering Lia's spirit. Eventually, Lia returned home after her family showed they could give the medication to their daughter. During that time, Lia was taken to Minnesota to see a *tvix neeb*, a Hmong shaman. During the four-month period, Lia only experienced one seizure. While the family believed this was the result of *tvix neeb*, her doctors saw this as the result of regular medicine administration. After some time, Lia experienced a terrible seizure and went into septic shock. She was declared brain dead and spent nearly two weeks in the hospital. When the Lee family requested all medications to be stopped and to take Lia home to die, they were given a paper to sign that said she would be ready in two hours. The family thought the document said she would die in two hours. Lia's dad took her from the hospital bed and was stopped by security and escorted back. Once home, Lia's family began practicing Hmong healing practices to cleanse her body of the medicine. Lia continued to defy her doctors'

expectations and her condition subsided; she had a healthy weight, and lived for twenty-five years. Lia's mother was with her twenty-four hours every day—she believed that was the way to protect her daughter from the foster system. What was once believed to be Lia's child abusers, were now considered to be exemplary care givers in the eyes of Lia's care team (Connolly, n.d.).

Because language barriers can be detrimental to the physician-patient relationship, out of despair, patients often bring in their children to help with interpretation. This is a sad reality, as proven by the numerous examples given thus far because while there are federal laws, they are not heavily regulated. The laws mandate a qualified language interpreter be present, but unqualified children are often brought in because of the lack of language services readily available at healthcare facilities.

Language Brokering: (not the answer!)

Child language brokers are children who are brought in to translate or interpret for their adult family members or anyone who does not speak the local language (Crafter, 2018). Children are not qualified for medical language brokering as they do not possess the maturity, knowledge, or cultural contexts required in medical communication. Furthermore, the act of language brokering for a family member can take an emotional toll on the child. In a longitudinal study of 604 Mexican American adolescent language brokers, (Benner et al., 2020) it was found that children who serve as language interpreters were more susceptible to discrimination such as being treated poorly and then performing poorly in school. Language brokering exposes the child's minority status and accent. From these negative interactions, children may internalize the interactions causing a decrease in motivation for language brokering and impacting academic

performance in terms of learning goals, grades, and engagement with school. The long-term effect of such discrimination and academic decline results in high school dropouts. This then leads to more individuals earning lower annual incomes and living below the poverty line (Benner et al., 2020).

In another study, 159 health class students from a high school in a Midwest metropolitan area were surveyed on their experiences as language brokers and how that impacted their academics (Ball et al., 2016). 86 out of the 159 students indicated they helped their families with healthcare related tasks. Table 3 (Appendix, p. 33) shows the results (Ball et al., 2016). The most common tasks performed by adolescents are speaking with healthcare providers, reading and understanding prescriptions, and researching healthcare information online. Those same students also reported the emotions they experienced when language brokering. Table 4 (Appendix, p. 34) shows these results (Ball et al., 2016). The most common negative emotions experienced are nervousness and stress. Such negative experiences mean these adolescents are at a greater risk of using alcohol and marijuana to find relief. Although there are experiences of calm, confidence, and determination, the most common emotions experienced are nervousness and stress (Banas et al., 2016).

In that same study, 24 out of the 86 participants indicated they missed school to assist their families with language brokering. Of the 24, 79 percent reported missing 1-2 classes while 21 percent missed 3-4 in an academic year. While 66.3 percent of the students who missed class reported it did not affect their ability to complete their schoolwork, 27.5 percent reported that they missed schoolwork 1-2 times. Another 2.6 percent reported missing 5 or more assignments (Banas et al., 2016). This is concerning because these students have pressure to perform well in school to achieve their academic and career goals. But along the way, they experienced setbacks

with language brokering that can lead to substance use and mental health issues. To ease their struggles, a third of the participants “Wanted a website where they could ask questions about healthcare tasks, obtain healthcare information in English and their family's language, and/or read about or watch videos about healthcare tasks” (Banas et al., 2016).

From the studies mentioned above, it is evident that child language brokering is not the solution to the healthcare language barrier. Children are not qualified to be language interpreters as they do not possess knowledge of medical terminology. Multilingual children often expose their minority status through language brokering, making them vulnerable to discrimination. Furthermore, when children are providing language interpretation for their families, it often comes at the cost of missing classes and schoolwork. Children often internalize their negative experiences, which leads to anxiety and poor life choices such as substance abuse.

Chapter 4 Interpretation Services

Introduction

The previous chapter has shown that even though the law prohibits family members from acting as language interpreters, it is still widely practiced. When a family member is assigned as the language interpreter, the patients might hide their illness or medical history. Conversely, the family member might not tell the patient the severity of their medical condition such as end stage cancer; or they may oversimplify the situation and make the patient neglect the precautions the physician has ordered (Olani et al., 2023). A possible solution to this problem rests with the emergence of technology, which may bring hope for a viable alternative based on remote services and artificial intelligence.

Local Changes

To combat language challenges, many local health organizations have taken action. In Philadelphia, Main Line Health Chief Nursing Officer and Senior Vice President, Barbara Wadsworth, DNP, RN stated, “It’s really important when patients come into the hospital that we can communicate with them in their primary language” (Main Line Health, 2019). Overseeing the language services program for the organization, Main Line Health was able to address the needs of their patient communities through various interpretation services. Main Line Health offers remote video and live interpreters through the Stratus app, so they have coverage around the clock. As a result of this change, both patients and providers have reported satisfaction from

diagnosis to treatment to surgery. Their decision for this change comes from over 15 years of established research that professional interpretation services better facilitate verbal and nonverbal communication needs (Main Line Health, 2019). Jefferson Health, based in Philadelphia, also provides interpretation services to all patients. And patients who are hard of hearing or deaf can request assistive devices (Jefferson Health, n.d.).

Future Advancement

The cost of hiring certified medical interpreters can get costly fairly quickly. In a magazine article published by the *American Psychological Association* in 2020, it is estimated that face to face interpreting fees can range from \$45 to \$150 an hour. This range also depends on the language involved. Video interpreting can range from \$1.95 to \$3.49 per minute, and sometimes there is a minimum number of minutes required per session. Telephonic language services are often the least expensive and typically cost from \$1.25 to \$3 per minute (American Psychological Association, 2020, p. 92).

With that being said, there is hope in the future for technology to step up and assist in language access for LEP patients. One example of such advancement is Vital, an AI powered doctor to patient translator that turns medical terminology into 5th grade reading level plain language, refer to Table 5 (Appendix, p. 35) to see an example. This tool can translate doctor's notes, discharge summaries, radiologist reads, and test results. In addition, it is free for the public to use (Landi, 2023).

Technology as Hope, With Limitation

Currently, there are many free translation tools available, a more popular one is Google Translate. But how effective and accurate are these tools? There is much more to language translation and interpretation than simply changing the words from one language to another. In a pilot study published by *JMIR Diabetes* in 2016, researchers experimented and compared three certified Spanish and Chinese translators with Google Translate to see how accurate Google Translate is on translating health educational information. From the experiment, it was noted that (1) Google provided greater rate of accuracy when translating in Spanish from English than from English to Chinese; (2) the likelihood of incorrect translation increased when the English sentence required higher levels of comprehension. The study concluded that “...miscommunication through translation is possible given that words often have different meanings depending on the context in which they are used...” (Chen et al., 2016).

In another study published by the *JAMA Network* in 2019, it experimented with Google Translate by translating 100 ER discharge instructions (647 total sentences) related to medication changes and common ER complaints. The study had the language translated from English to Spanish and English to Chinese; in addition, there were bilingual translators who translated the text back to English. The findings were that 92 percent of the sentences were accurately translated in Spanish and 81 percent in Chinese. However, these minor inaccurate translations can lead to potential clinical harm (Khoong et al., 2019).

Not only are there limitations to language translation and interpretation due to a lack of cultural context, but HIPAA laws also need to be followed in healthcare. Some of the challenges include:

- **Data storage and transmission:** Google Translate works by sending the information entered to the servers to process the text and return it in the requested language. During this process, Google may store protected health information (PHI).
- **De-identification:** HIPAA mandates that any PHI should be de-identified when it is not used for treatment, operations, or payment. There is no guarantee that tech companies properly de-identify such information.
- **Trackers:** Cloud services like Google come with trackers that collect user data for targeted advertising, improving service quality, etc. If Google Translate is embedded into patient portal, then there is a risk of sensitive user data being transmitted, which violates patient privacy (*The Risks of Using Google Translate in Healthcare Websites and Patient Portals: A HIPAA Perspective, 2023*).

Technology in healthcare language access is still emerging. There are numerous challenges that need to be addressed such as inaccurate translation due to missing cultural contexts. Since healthcare as an industry is heavily regulated, using technology means encountering HIPPA violations. Without addressing these changes multilingual patients are left with limited options for language services. Perhaps only one option remains: community-based services. Will they fill in the missing gap?

Chapter 5 Community Based Services

Introduction

While there are laws to help facilitate language barriers in healthcare, and technological aid is still emerging, there are many obstacles faced by many patients that deteriorate the quality of care. From language barriers to cultural barriers to navigating the healthcare system, nonprofits are trying to fill in these gaps by serving their communities. With their limited funding, their impact is limited as well. While there are numerous organizations that help patients access quality care, this chapter will focus on prominent nonprofits in the Philadelphia region and how they attempt to fill in the gaps.

Philadelphia is a prominent city for immigrants and LEP families. Pew's 2018 report found that more than a quarter of Philadelphians have foreign-born parents or are immigrants themselves. In 1970, only 6.5 percent of the residents were foreign-born and by 2018, that number rose to 14 percent. The language scene is also diverse in Philadelphia with 23 percent of the population speaking another language at home. The top countries of origins for Philadelphians as of 2017 include (in order): China, Dominican Republic, Jamaica, India, Vietnam, Haiti, Mexico, Ukraine, Albania, and Korea (North and South) (Lowe, 2019). In 2023, the City of Philadelphia announced that it was a Certified Welcoming city by Welcoming America. Philadelphia is the fourth city in PA to gain this certification and one of the 18 across the US. The Welcoming Standards takes several years to meet and is a multisector effort that includes the mayor's office, law enforcement agencies, local organizations, the education sector, and many more stakeholders. During the self-assessment and in-depth audit of the policies,

services, and programs, Philadelphia earned 92 out of 100 points. The average for Certified Welcoming cities is just 55 points (Joinville, 2023). As a Welcoming city, Philadelphia has several nonprofit organizations that serve immigrants, including those focused primarily on healthcare.

Greater Philadelphia Asian Social Service Center (GPASS)

Greater Philadelphia Asian Social Service Center (GPASS) is a nonprofit dedicated to assisting Philadelphians with resources, bridging language and cultural barriers, enriching lives, and sustaining a diverse community. The organization provides outpatient counseling (group and individuals) for mental disorders and treatment for substance use. They have a SAFE (Stop Addiction ForEver) group to support patients, which accepts most insurance and has appointments and walk ins. They also provide a Medication-Assisted Treatment (MAT) program for those suffering from opioid and alcohol addiction. GPASS also provides affordable, reliable, and compassionate home care for independent living environments. This service is offered to family caretakers who need additional help with non-medical services. Examples include personal care, companionship, respite care, homemaking, and self-administered medication (Greater Philadelphia Asian Social Service Center, n.d.). As reflected in their name, this organization understands the connection between socio-cultural issues and health.

Philadelphia Health Partnership (PHP)

The Philadelphia Health Partnership was created in 1997 as a merger between Trustees of the University of Pennsylvania and Pennsylvania Hospital (Philadelphia Health Partnership, n.d.). Their mission is to serve Philadelphia residents who face barriers in healthcare. They strive to end healthcare disparities, racial injustice, and engage with the community to advocate for policy changes (Philadelphia Health Partnership, n.d.). Their work can be divided among four categories: nurture, connect, advocate, and lead.

The goal of “nurture” is to promote optimal health (cognitive, physical, and social-emotional development) of children from 0-5 years, and influence well-being across their lifespans to support a pathway of success. Priorities include fostering nurturing parenting/caregiving, advancing perinatal health, building collaboration between pediatric care and early childhood systems, and amplifying family voice in early childhood policies, programs, and systems. Some of the grantees include Attachment & Biobehavioral Catch-up (ABC), CHOP PolicyLab, Education Law Center, and Legal Clinic for the Disabled (LCD) (Philadelphia Health Partnership, n.d.).

The goal of “connect” is to improve access to equitable and responsive care, address health disparities, and support community-based groups that support changes to meet the needs of divided communities. Priorities include delivering (1) culturally, racially, ethically, and linguistically appropriate care to address various health needs, (2) increase insurance and public benefit coverage, (3) and provide care management assistance. Some of the grantees include Community Legal Services of Philadelphia (CLS), Justice at Work, Nationalities Service Center, and Philadelphia Legal Assistance (PLA) (Philadelphia Health Partnership, n.d.).

The goal of the “advocate” is to initiate advancement in structures, systems, and policies to achieve health equity. Priorities include organizing community members who are affected by health disparities to voice for change and mobilize care providers and cross-sector stakeholders to join collectively on ending health inequity. Some of the grantees include Thriving PA, Children First, Pennsylvania Association for the Education of Young Children (PennAEYC), and Pennsylvania Health Access Network (PHAN) (Philadelphia Health Partnership, n.d.).

The goal of “lead” is to create a pathway for nonprofit organizations and health and human service organizations to support equitable health care. Priorities include increasing leadership opportunities for people of color and providing skill-building and educational opportunities for career advancement. Some of the grantees include Economy League of Greater Philadelphia, Leadership Exchange of Greater Philadelphia, and The Village of Arts and Humanities (Philadelphia Health Partnership, n.d.). All of these goals help this organization to achieve its mission of serving Philadelphia residents who face barriers in receiving quality healthcare.

Puentes de Salud

Puentes de Salud (Bridges of Health) promotes health and wellness of Philadelphia’s Latinx immigrant community by educating and empowering members to understand how to receive quality health care. Their purpose is to improve social determinates of health and provide social justice by educating members on services available for immediate services, and the social inequalities their groups commonly experience. They partner with public schools and universities to educate people of all ages. Alongside public schools and universities, they also partner with

governmental institutions and other nonprofits to address the structural, social, and economic conditions of this group that limits their prosperity. Some of the services provided include (Puentes de Salud, n.d.):

- **Medical care:** women's health, clinical care, and dental care
- **Holistic wellness:** behavioral health, food access, art and culture, medical-legal partnership
- **Education (3-18 years):** early childhood programs to high school programs

In the 2022 annual report, Puentes de Salud reported serving 6,300 members across all their services and age groups. They had a total of 7,780 clinic visits, which served 2,968 existing patients and 1,340 new ones, 1,628 dental visits serving 636 individuals, and 389 behavioral health visits by 198 individuals. In addition, they trained 250 volunteers in community health work and had 185 individuals engaged in educational programming (Puentes de Salud, n.d.).

Children's Hospital of Philadelphia

Ranked as the number one children's hospital in Pennsylvania and the Mid-Atlantic region by *U.S. News & World Report*, Children's Hospital of Philadelphia (CHOP) plays a prominent role in accessing quality care in the Philadelphia region. For eleven consecutive years, CHOP doctors have been recognized as #1 in the country (Children's Hospital of Philadelphia, 2023). The two programs I would like to highlight are the Language Services Program and the Refugee Health Program. The Language Services Program provides free aid and services to people with disabilities (sign language interpreters and written information in other formats) and

to those whose primary language is not English (qualified medical interpreter and written information in other languages). On their website, they have this information in twenty-three different languages: Arabic, Bengali, Chinese (Traditional), Deutsch, English, Filipino, French, German, Gujarati, Hindi, Indonesian, Italian, Japanese, Khmer, Korean, Nepali, Polish, Portuguese, Russian, Spanish, Turkish, Urdu, and Vietnamese (Children's Hospital of Philadelphia, n.d.). CHOP offers face to face, telephone, and video interpreting. When making a call to the hospital or CHOP providers, patients and their families can use CHOP Speaks Your Language service to use phone interpreting. They provide this service in thirteen languages: Spanish, Arabic, Bengali, Burmese, Mandarin, Cantonese, Vietnamese, Portuguese, French, Farsi, Haitian Creole, Korean, Polish, Somali, Russian, and Nepali. They also provide interpretation for deaf and hard of hearing individuals. Tools and services include ASL, amplified telephones, video relay services, closed captioning, and much more (Children's Hospital of Philadelphia, n.d.).

“Each year, almost 800 refugee families arrive in Philadelphia in search of freedom, peace, and opportunity for themselves and their families. The healthcare needs of these children are the same as, if not more extensive than, any child in the United States” (Children's Hospital of Philadelphia, n.d.). Of those 800, CHOP sees about 70-100 children annually (K. Yun personal communication, February 13, 2024). The services offered through this program include catching up on immunization, psychological assessment, and age-appropriate screening for developmental delay, infectious conditions, and adolescent risk behaviors. Physicians assess all factors including trauma, migration, and educational impacts. They eliminate health-related barriers such as helping children enroll in schools, helping families find a healthcare network, and having interpretation services available. To provide better quality care, the program partners

with HIAS, Bethany Christian Services, and Nationalities Service Center, all nonprofit refugee resettlement agencies. They do not allow child language brokering (Children's Hospital of Philadelphia, n.d.) and if funding is available, they offer a culturally informed Community Health Worker. The program's national impact is vast. They educate interpreters, clinicians, and resettlement agencies through conference workshops and webinars. They also created an Electronic Health Record (EHR) based tool to facilitate newcomer healthcare (K. Yun, personal communication, February 13, 2024).

Voices From the Field

While writing my thesis, I was interning at CHOP. I took this opportunity to meet with Gabriela Jenicek, Director of Operations for Patient and Family Support Services, and Dr. Katherine (Kate) Yun, MD, an attending physician in the Division of General Pediatrics and Refugee Health Program. During my interview with Gabriela, we bonded with our shared experiences of language brokering for our immigrant parents. Gabriela's story is unique, she immigrated from Czechoslovakia to Germany at the age of four and started language brokering by the age of seven. She also immigrated to the US later on in life and made great progress in the language services department at CHOP. My interview with Dr. Yun was heartwarming as well. She described the work that she and the team do for refugee families. They dedicate their personal time to care coordination for their patients.

Gabriela holds a master's degree in translating and language interpreting from Germany. She was hired by CHOP to build an in-house language access program because their volume of demand was not sufficiently met by the contracted service they used to have. Gabriela was

trained to be an interpreter for the European Union. In twelve years, Gabriela built a department that has 20 staff interpreters in the top four languages: Spanish, Arabic, ASL, and Mandarin. Annually, CHOP provides language services to about 80 languages and services at a volume of a quarter of a million. To meet those language demands, CHOP has contracted services that offer in person interpreters, who are reserved for acute and complicated situations, and video and telephonic services. Due to the costs, 60 percent of language services are done via telephonic interpretation. The contract service also offers 200 languages. In the past six years, CHOP added video interpretation, for which demand increased since the pandemic. Gabriela shared with me that CHOP started the CHOP Speaks Your Language program because patients would often call and get lost in the phone transferring because they couldn't communicate or CHOP staff outside of central access would often hang up. This service provides support to about 98 percent of families.

Gabriela told me “We are not allowed to use children...[or] family members...you are only allowed to work with professionally trained [interpreters]” (personal communication, March 6, 2024). She informed me that while this is a federal mandate, it is often not fully practiced in the industry and acknowledged both of our child language brokering stories as children of immigrant parents. Her team plants the seed in younger generations, as Gabriela likes to put it, by speaking about this topic and informing them of the realities patients face. Their department also has tight relations with refugee and immigrant organizations and grassroots community organizations to expand the community impacts. It was heartwarming to see the dedication Gabriela and her team has for offering language services to CHOP families. She said no one interprets for the money, they do it because of the satisfaction and relief they see on the patient's faces when they enter the room. As an immigrant twice in her life, Gabriela understands the

struggles of CHOP families when they miss access to resources due to language barriers (G. Jenicek, personal communication, March 6, 2024).

The same unwavering dedication was evident during my interview with Dr. Yun. She explained to me that the federal government decides how many refugee children come in, but of the children who are assigned to Philadelphia, there is "...often an effort to have children come to us at CHOP, if they are medically complex..." (K. Yun, personal communication, March 6, 2024). These include conditions such as congenital heart disease, cancer, intellectual differences, genetic difference, and much more. During CHOP's busy time, they see about 70-100 refugee children, who then become established patients at CHOP, if their families choose to reside in Philadelphia. Dr. Yun informed me that at any given time, their patient panel is 300+. Dr. Yun described some of the work her team does. She explained that when these refugee families arrive, many do not know how to read a map, administer medicine, or get a prescription from the pharmacy. Her team has seen many cases like these and while they are challenging to navigate, they guide the families with optimism and see progression in many families. Her team works with Gabriela's to provide language services. During the interview, Dr. Yun shared two very strong stories to describe the work of her team.

- About 10 years ago, there was a resettlement of Bhutanese families. When they arrived at CHOP, they requested a community health worker who would provide long-term hands-on coaching. This model was what the Bhutanese families experienced in their resettlement camps in Nepal. Dr. Yun's team was able to establish the program and find the funding for it.
- During Operation Allies Welcome, there were a large number of Afghan refugee children coming in with medically complex cases. Multiple other health systems provided 24/7

airport coverage. CHOP worked closely with those providers and gave hands-on support to ensure adequate care was provided in a timely manner. For example, ensuring Type 1 diabetic children received blood sugar monitors, making sure that children who needed transfusion were getting them on time, and including the support of CHOP's subspecialty care.

Dr. Yun and her team shared their experiences and findings from Operations Allies Welcome with the Office of Refugee Resettlement (ORR), a federal entity within HHS and with the PA Department of State because they played a significant role in providing the evacuation. She explained that people typically think these children are healthy, but in this evacuation, a large number were not. CHOP shared their findings so that a process could be in place for all the safe havens across the US to follow. This process would allow children access to the right care they need and assure that there is a proper, safe, and warm handoff for families. Dr. Yun shared that while this is a way for her and her team to pay it forward in life, it is not sustainable. There were many times when she would volunteer her personal time to care for refugee families and missed out on quality time with her family. While the team enjoys learning about the different cultures and seeing their patients thrive, it is coming at the cost of their personal time. She hopes that with extra funding, her team is able to onboard a case manager and community health workers who can go home with the families to role model and teach them so they can access quality care (K. Yun, personal communication, March 6, 2024).

Chapter 6 Conclusion

In conclusion, while there are federal laws that mandate qualified professional language translators and interpreters to be present with LEP patients, they are often not followed. Lack of adequate language service access affects the patients and their families as they do not receive quality healthcare services or access to resources. Vulnerable patients often stop seeking care or are too embarrassed to ask questions because they cannot communicate with their providers. Doctors have admitted to ordering more tests and labs because they do not understand their patients' concerns. This delays care and treatment and negatively impacts the health of LEP patients. Historically, immigrants would settle in enclaves to form a community, but soon turned to their children for language brokering. Although it is a common practice, it is illegal to have children translate or interpret for others. As a result, children are negatively affected, from facing discrimination to dropping out of high school.

As more awareness is brought to this topic, and technology is advancing in language services access, many local health systems have implemented programs to support their LEP patients. While technology is still in its infancy, the impact has been positive. There are future opportunities in this area with AI, however many challenges still need to be resolved for technology to accurately aid LEP patients. Nonprofits have stepped up greatly and their community impact is remarkable. To fill in the remaining gaps, they offer community support from educational classes to home care to advocating for change.

My internship at CHOP fell at the perfect time and was a dream come true! Similar to how my name means to help and support, CHOP has made it their mission to serve children and make positive contributions to the Philadelphia community. My time with CHOP has been

nothing short of fulfilling. To see the work they do and to contribute to it has been rewarding. I was able to relate to both interviewees on how rewarding their jobs are. Completing my thesis and my internship at the same time has been eye-opening. While I realize the gaps we need to fill in language access, I got to see in real time the work CHOP has been doing to serve its community. As I embark on this lifelong journey of making language access more accessible for LEP patients, I will also think back to my thesis and my time with CHOP. It is important I take my talent to a highly mission driven organization that focuses on helping provide quality care.

Appendix

Table 1: HHS Equity Action Plan

Barriers to be addressed	Medium term indicators (2 to 4 years)	Long term indicators (5 to 8 years)
<p>Access to in-language content through webpages, listserv announcements, & public outreach material</p>	<ul style="list-style-type: none"> ◆ Establish website accessibility guidance 	<ul style="list-style-type: none"> ◆ Agencies will post in-language webpages & annual add pages in frequently encountered languages ◆ Agencies' websites will link to in-language program information ◆ LEP visitors will find more online material in their language and information on how to obtain LAS
<p>Telephonic interpreter services</p>	<ul style="list-style-type: none"> ◆ Establish procedures for providing telephonic interpreter services 	<ul style="list-style-type: none"> ◆ Every agency will have Help Lines supported by telephonic interpreters ◆ LEP callers to Help Lines will successfully reach and obtain services from the desired office
<p>Program and benefit information in other languages</p>	<ul style="list-style-type: none"> ◆ Establish action plan for in language program & benefit information 	<ul style="list-style-type: none"> ◆ Every agency will translate and publish vital documents in non-English languages ◆ Every agency regularly updates already translated in-language program information ◆ Every agency will develop a mechanism for receiving document translation request
<p>Federal funding for recipients of HHS funds to provide LAS</p>	<ul style="list-style-type: none"> ◆ Establish how LAS funding can be distributed ◆ Establish goals for funding LAS 	<ul style="list-style-type: none"> ◆ Grant programs will aim to provide funding to help recipients provide language access services ◆ LEP visitors to HHS-funded/conducted programs will receive language access services at no cost

Table 2: Languages Spoken at Home

	Estimate	Share of All Speakers of Foreign Languages
Speak Language Other than English	67,802,000	100%
Spanish	41,757,000	61.6%
Chinese (including Mandarin, Cantonese)	3,495,000	5.2%
Tagalog (including Filipino)	1,764,000	2.6%
Vietnamese	1,571,000	2.3%
Arabic	1,260,000	1.9%
French (including Cajun)	1,172,000	1.7%
Korean	1,075,000	1.6%
Russian	941,000	1.4%
Haitian	925,000	1.4%
German	895,000	1.3%
Hindi	893,000	1.3%
Portuguese	846,000	1.2%
Amharic, Somali, or other Afro-Asiatic languages	590,000	0.9%
Yoruba, Twi, Igbo, other languages of Western Africa	589,000	0.9%
Other Indo-European languages	576,000	0.8%
Yiddish, Pennsylvania Dutch, other West Germanic languages	560,000	0.8%
Italian	540,000	0.8%

Table 3: Healthcare Language Brokering Task

Healthcare Brokering Task	Frequency of Times Cited (N = 86)
	Number (%)
Talking to their doctor or nurse	54 (62.8)
Reading their prescriptions	49 (57.0)
Looking up health info on the Internet	49 (57.0)
Talking to the pharmacist	37 (43.0)
Filling out medical insurance forms	28 (32.6)
Talking to the health insurance company	9 (10.5)
Finding a doctor	8 (9.3)

Table 4: Emotions Experienced in Language Brokering

Emotion	Frequency Cited (N = 86)
Negative emotions	
Nervous	38 (44.2)
Stressed	16 (18.6)
Scared	10 (11.6)
Sad	6 (7)
Alone	2 (2.3)
Angry	1 (1.2)
Ashamed	1 (1.2)
Positive emotions	
Calm	44 (51.2)
Confident	37 (43.0)
Determined	23 (26.7)
Proud	20 (23.3)
Happy	18 (20.9)
Strong	11 (12.8)
Excited	5 (5.8)

Table 5: Vital AI Powered Translator

The screenshot displays the Vital AI Powered Translator interface, which is split into two main panels. The left panel, titled "Medical Note", contains the following text: "PROCEDURE: XR Chest 1 View Frontal", "ORDERING PROVIDER: Justin Schragger", "INDICATIONS: Shortness of Breath (SOB)", "ADDITIONAL CLINICAL HISTORY: None.", "COMPARISONS: 01/01/2000", "FINDINGS: An anterior view at 1200 hours demonstrates cardiomegaly and vascular congestion. Bilateral infiltrates. No pneumothorax or large pleural effusion.", and "IMPRESSION: CONGESTIVE HEART FAILURE". At the bottom of this panel, it shows "3128 characters left" and "5 translations left", along with a "Translate" button featuring a double-headed arrow icon.

The right panel, titled "Translation" with a "BETA" badge, shows the translated text: "The chest X-ray shows an enlarged heart and fluid in the lungs. The doctor thinks this is due to congestive heart failure." Below this, a disclaimer states: "Medical summary from <https://vital.io/translate>. This tool has been evaluated by a panel of doctors, however errors or omissions can still occur. Use your original note and instructions from your care team as the ultimate source of truth." At the bottom of the right panel, there are options to "Rate this Translation" (with thumbs up/down icons), a "Copy" button, and a "New Translation" button with a refresh icon.

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