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Frances Chiu

March 20<sup>th</sup>, 2025

## Symptomatic Translation: Why Latinx Communities Seek Healthcare Abroad

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An abstract of a thesis submitted to the Faculty of Emory College of Arts and Sciences of Emory University in partial fulfillment of the requirements of the degree of Bachelor of Arts with Honors

Department of Spanish

## <u>Abstract</u>

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Healthcare is one of the most politically contentious discourses on the United States political stage, with widespread discontentment with a system that simply seems unable to provide for all 340 million people in the country. Often in political discourse, low-income immigrant communities such as the Latinx community are blamed for overburdening the system. However, interviews have revealed a surprisingly common decision among the Latinx community to seek healthcare outside of the United States, returning to their origin countries for most non-emergent care. Through a series of interviews with 12 people from a range of different backgrounds, I explore the reasons contributing to this phenomenon. Ultimately, I argue that a failure of translation on multiple levels creates an increasingly hostile healthcare system for Latinx people to navigate, interweaving my interlocutors' anecdotes with existing literature to outline three principal obstacles. In the first chapter, I examine language barriers and current methods of linguistic interpretation as factors contributing to discomfort in US clinical encounters, even for some fluent English speakers. In the second chapter I analyze cultural differences as another barrier to care, underscoring the ways in which principles of cultural competence are insufficient in negotiating this challenge. Finally, in the last chapter, I evaluate the US and Latin American health systems through the lens of Max Weber's bureaucracy, comparing my interlocutors' experiences in both, focusing on symptomatic translation, which I define as the translation of a patient's symptoms and complaints into a resolution. This study offers preliminary insight into the reasons contributing to this phenomenon and offers reflections on potential improvement for the US healthcare system.

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### **Introduction**

Healthcare in the United States is a complex issue at the center of social and political debate. The healthcare system, meant to serve millions of people, is seemingly dissatisfactory to all who encounter it—providers, patients, and families alike. Though this trend is seen across demographics, the Latinx<sup>1</sup> community, the largest immigrant community in the United States<sup>2</sup>, is uniquely positioned at the junction of healthcare inequity, linguistic barriers, and political discourse. The Latinx community has been documented to experience poorer health outcomes within the United States due to a variety of reasons, from lack of healthcare access to inadequate public health education. Additionally, some immigrant members within the Latinx community experience linguistic barriers in healthcare, struggling to communicate with healthcare providers despite the interpretation services provided. Finally, the Latinx community has been spotlighted as the center of political debate in the United States surrounding immigration and immigrants as they pertain to strain on systems such as the healthcare system. In recent years, some political discourse has linked the healthcare system's growing demand with immigration, blaming immigrants, particularly Latinx populations, for increasing demand and strain on the already overburdened healthcare system. However, anecdotally, members of the Latinx population have shared that they refrain from seeking healthcare in the United States, often

<sup>&</sup>lt;sup>1</sup> I recognize the critiques of using Latinx as a term, as it is used primarily in academic institutions and circles and, in many cases, is not how the people I interview would themselves identify. Additionally, my interlocutors come from a wide range of backgrounds, including people who were born and raised in Latin America and are, as such, Latin American. However, for the sake of brevity in terminology, I will use Latinx throughout this thesis to refer to my interview population.

<sup>&</sup>lt;sup>2</sup> Source: <u>https://www.census.gov/newsroom/press-releases/2024/population-estimates-characteristics.html</u>

opting to return to their home country in Latin America for everything from routine screenings to other concerns that arise, with the exception of emergent situations. This investigation seeks to elucidate the reasons behind this preference in Latinx communities for healthcare outside of the United States, proposing that the American healthcare system's failure to assist Latinx community members in accurately and expediently interpreting, navigating, and understanding linguistic, cultural, and bureaucratic borders is the primary driving factor.

This investigation explores translation as a concept applicable beyond linguistic challenges and barriers, and relevant to cultures and systems as well. While translation within the medical system encompasses the interpretation of communicated information from one spoken language to another, this is by no means the only form of translation impacting a Latinx patient's healthcare experience.

#### **Study Overview & Methodology**

This project initially began as an interview centered on chronic illnesses and conditions within the Latinx community, and how individuals integrated their personal beliefs and culture with institutional biomedical knowledge. However, the focus of this investigation changed as I began interviewing my interlocutors and discovered that many expressed similar frustrations with the US healthcare system and its inefficiency, sharing that they preferred to seek healthcare outside of the United States. This decision was fascinating to me, and I began a journey of exploring why and how my interlocutors had arrived at this preference. During this interview process, I also noticed my own biases and upbringing coming into play; as as my interlocutors criticized American healthcare providers, I often felt myself suppressing an instinctively defensive response; likely, this arises from my position as both the daughter of a US-educated and practicing physician, and a student interested in pursuing medical school in the future. Recognizing this, I felt it ever more crucial for me to investigate these questions, listening closely to my interlocutors' dissatisfactions and using this research experience as an opportunity to inform my future studies and eventual participation within the system.

I recruited interlocutors through friends, classmates, and other connections, asking people if they were interested in talking about their experiences with the healthcare system in the United States and abroad. I obtained consent verbally at the start of each interview, conducting the interviews in English or Spanish, depending on my interlocutor's preference. When my interlocutors consented to it, I recorded our interviews as voice memos on an encrypted device. I later used Vook.ai, an encrypted AI transcription tool, to create the first transcript draft before later reviewing it alongside the audio while correcting mistakes and changing my interlocutors' name to the pseudonym used for the remainder of the project.

Over the course of this study, I encountered a number of difficulties. Obtaining IRB approval was particularly difficult, with the whole process from initial submission to final approval lasting 7 months. Additionally, I encountered some difficulty recruiting participants to be interviewed. This is likely due in part to the fact that the Latinx community can be considered a historically marginalized group, and members may be hesitant to discuss sensitive information and experiences, such as those concerning healthcare, with an individual who is not Latinx. This is reinforced by the fact that this investigation originates from Emory University, a prestigious educational institution that, like most educational institutions, has previously been exclusionary and hostile toward people of color, including the Latino/Latinx community. Thus, though I have made every endeavor to make my

interlocutors as comfortable as possible, it is possible that not all my interlocutors felt wholly at ease sharing the details of their experiences with me. Furthermore, the small sample size presents another limitation of this investigation. With a relatively small sample of 12 interlocutors, this study cannot in any way be generalized to the greater Latinx population. It is also crucial to recognize that the Latinx community is not a monolith despite often being treated as one; the umbrella term Latinx comprises a wide range of peoples with varying backgrounds, experiences, and stories. Furthermore, my study participant populations occupies a position of relative privilege, in that they have paperwork, documentation, and legal status within the United States. As a result, they have the ability to leave the United States and seek healthcare elsewhere before safely returning. Since this may not be the case for large swaths of the Latinx population, as well as a multitude of other factors, the experiences my interlocutors share cannot in any way be generalized as universal. As such, this investigation should in no way be considered fully representative or exhaustive of the Latinx community's experiences as a whole. However, this investigation provides the basis for crucial discussions on the impact of linguistic, cultural, and bureaucratic barriers and their effects on patients' experiences of the healthcare system in the United States.

### **Chapter 1: Linguistic Interpretation**

#### **Clinical Language Barriers and their Consequences**

Differences in language of preference or ability between patient and provider is a contributing factor to the (dis)comfort a patient feels in the medical setting (Timmins, 2002; Flores, 2006). As they seek healthcare, already anxious about the state of their health and the unknown, patients can feel even more anxiety and strain in the clinical interaction with difficulty communicating with the provider. A patient who speaks limited English may not feel confident in their ability to communicate effectively and adequately with their provider, especially in matters as important and complex as health. This can greatly impact patient care, as difficulty in communication can mean providers are less aware of their patient's history, and the patient themself less aware of the provider's instructions. It is important to note that these language barriers are not unique to the Latinx patient population; however, the Latinx patient population is a uniquely positioned demographic through which to study this issue. Within the United States, Spanish is the most widely spoken language other than English. This is reflected as well in the rapid growth in Latinx populations; according to US government census data, "Between 2022 and 2023, the Hispanic population accounted for just under 71% of the overall growth of the United States population, driven primarily by Hispanic births"<sup>3</sup>. Additionally, as Spanish is the most widely language other than English spoken in the United States, it has been the primary target for an overwhelming majority of

<sup>&</sup>lt;sup>3</sup> Data taken from the United States Census Bureau, press release number CB24-109 on June 27th, 2024. Source: <u>https://www.census.gov/newsroom/press-releases/2024/population-estimates-characteristics.html</u>

systemic provisions, innovations, and attempts aimed at bridging the language barrier.<sup>4</sup> However, since Spanish is the language for which the most provisions have been made, it is thus all the more useful as a lens through which to analyze the flaws of our current interpretation systems and methods. In this chapter, I explore the contexts surrounding language barriers faced by Latinx patients in the United States as well as various deleterious effects of poorly navigated linguistic barriers and their contributions to the increasingly popular decision to seek healthcare abroad.

The primary and immediate result of a language barrier between patient and provider is difficult and unreliable communication. However, this primary consequence has a wide range of downstream effects on the patient-provider relationship, the patient's comfort, the quality of care, and ultimately, as my thesis focuses on, the patient's decision to seek healthcare outside of the United States. Studies have shown that patients with a poorly managed or unmitigated language barrier are at higher risk for worse health outcomes across a range of metrics; they "are less likely than others to have a usual source of medical care; they receive preventive services at reduced rates; and they have an increased risk of nonadherence to medication" (Flores, 2006). They are also "less likely than others to return for follow-up appointments after visits to the emergency room... and... have higher rates of hospitalization and drug complication" (Flores, 2006). Additionally, these challenges and barriers can damage the patient-partner relationship. As frustrations arise due to difficulty

<sup>&</sup>lt;sup>4</sup> On March 1<sup>st</sup>, 2025, President Trump signed Executive Order 14224, "Designating English as the Official Language of The United States". Previous to this order, the US has never had an official language. This new order poses an immense risk to populations who do not speak or are not comfortable with English, as it removes mandated linguistic accessibility of services. This and other legal context will be further discussed later in this section.

Source: <u>https://www.whitehouse.gov/presidential-actions/2025/03/designating-english-as-the-official-language-of-the-united-states/</u>

communicating on the parts of both the patient and provider, both parties may struggle to reach an understanding of the patient's condition and plan of care (Flores, 2006; Timmins 2002). As a result, patients sometimes express worry that their doctor will give up on communicating to the full extent that they would if the communication barrier were absent. Similarly, doctors express frustration with the amount of time the encounter takes as compared to an English-speaking patient, as well as the patient's potential noncompliance, which they often perceive as the patient being unreasonably difficult or antagonistic, even with regard to their own wellbeing. Luis, an emergency room doctor in Atlanta explains the difficulty of interpretation from the provider's side:

"I think what you'll see most often is that... Finding language interpretation services is a big burden on the healthcare provider because it adds a significant amount of time I think that's the main barrier... it like doubles the time."

Luis is responsible for multiple patients in short time periods, continuously assessing and moving patients through the emergency department to make room available for the next patient. For him, language barriers, even with interpretation, present a time challenge that can become frustrating as he strives to work as efficiently as possible. This mutual misunderstanding and frustration leads to a severe buildup of distrust between the patient and provider, which is then renewed and reinforced on both sides over the course of multiple encounters in a vicious cycle. To mitigate these challenges and deliver higher quality and more efficient patient care in both the short and long term, it is essential to ensure the accessibility of medical care (Flores 2006, Timmins 2002, Chang 1998). As healthcare is so multifaceted and contains a myriad of intricate, interwoven processes, the navigation of this problem requires the cooperation of a multitude of different interpretation and translation

methods—facility signs, pamphlets, patient education, websites, and nurse/pharmacy visits in addition to the interpretation during the physician's clinical visit (Chang, 1998). However, I will focus primarily on the oral/auditory interpretation that occurs in the patient's time with the primary practitioner, most often the physician, both to limit the scope of my thesis and because this is the interpretative context in which most of my patients situated the stories they shared with me.

#### **Analysis of Current Methods of Interpretation**

This issue and its host of consequences reinforce the crucial role of providing comprehensive medical care in the patient's primary language, whether in the intake paperwork, in the clinical encounter, or in the patient's copy of their own medical records. However, linguistically accessible patient care can and often does manifest itself in multiple forms with varying degrees of success. The ideal model is one in which the provider is bilingual and is thus able to communicate fluently and confidently with the patient in their primary language, such that the language barrier is all but limited. This allows for minimized disruption of the clinical encounter and saves valuable time. Despite this, it is clearly not feasible in all or even many settings; while facilities may certainly make an effort, no facility can guarantee that they will be able to provide bilingual healthcare staff providers on shift at all times, even for the most commonly spoken languages other than English. Thus, many facilities strive to offer some form of medical interpretation to their patients, with the most common forms being an in-person employee or volunteer, a virtual interpreter from a contracted company over a device, or an automatic translation software (Gany, 2007; Locatis, 2010). Of these few most common methods, an in-person interpreter is considered the best and most effective for the clinical encounter (Saint-Louis, 2003; Locatis, 2010). An in-person interpreter might also contribute to a more personal, welcoming, and reassuring environment in the clinical setting, which may serve to help ease the already heightened worries of an anxious patient in an unfamiliar physical, emotional, and linguistic environment. Additionally, interpreters are often asked or assumed to take on secondary roles as patient advocates and cultural brokers—someone asked to navigate the differences and serve as a mediator between two cultures—which can be more streamlined in person. Tomás, a Spanish language volunteer interpreter, explains the reason an in-person interpreter is significantly more valuable and beneficial to the patient's experience in comparison to one that is connected via technology:

"[as an in-person interpreter], you can see the body language and you can get all those expressions and connect with the patient compared to you speaking to someone over the phone... Or even I know in some hospitals they put an iPad and through the iPad they have an interpreter through there, which would be kind of similar to like the on the phone interpreter... But there's still not that connection that is forged when you don't have the interpreter expressing the same emotion as the patient or as the provider. Because when we're trained as interpreters, we're not only trained to say exactly what the patient and the provider say, but also to express it in the same way that these both individuals express themselves. So as you can see, if we don't have that interpreter in person or even if we don't have that interpreter at all, it might not reach the patient with the same impact."

As Tomás explains from his experience interpreting for patients in Spanish, the linguistic verbal interpretation is only a fraction of his responsibility; a good interpreter, as he

explains, should also be attuned to both the provider and the patient's mental and emotional states, taking care to deliver the information and communication in not only the same words, but the same tone. Striving for this ideal form of interpretation is more feasible in person than over an electronic device, simply because the interpreter would be able to better understand the tone and atmosphere of the room.

Even with all the benefits of an in-person interpreter, however, it is crucial to note that this situation still has its own set of drawbacks and potential obstacles to care. As a third person in the room alongside the patient and provider, the interpreter may unwittingly disrupt the dynamic between them (Chang, 1998). Patients often discuss sensitive information and experiences with their healthcare providers, whether their family and personal medical history or more serious or stigmatized issues such as houselessness, abuse, rape, or mental health struggles (Chang, 1998). In these situations, patients may be more hesitant to discuss their private struggles in the clinical setting, recognizing that their deepest burdens and sometimes shame will be shared with another person (Chang, 1998). In this way, "interpretation inserts a personal filter, the interpreter, between speaker and listener, patient and provider" (Chang, 1998). Chang's point in describing the interpreter as a personal filter inserted in the exchange is to highlight the fact that interpreters are themselves people informed by their own sets of beliefs, flaws, and cultures. In acknowledging this, it becomes clear that though perfect interpretation is the goal, it is an ideal that can never be attained; the interpretation itself—diction, tone, delivery, and all other components of communication—can never be wholly free of the frequently unconscious influence of the interpreter's own background.

It is crucial to note that this phenomenon is recognized, and interpreters subsequently receive training to mitigate this and other potential risks for misinterpretation or errors. Most interpretation errors can be sorted by categories: omission, addition, substitution, editorialization, or false fluency<sup>5</sup> (Flores, 2012). Though the interpretation guidelines and characterization of these subtle, seemingly unimportant incidences as errors may at first glance appear overly stringent or strict, each of these errors carries potential for misunderstanding and miscommunication. If an interpreter were to summarize the provider or patient's words, for example, the interpreter would have influenced the exchange by inserting their own understanding and rephrasing of one party's words. Formal training and national standardization for medical interpreters seeks to address and prevent such errors.

To become a medical interpreter, a candidate must provide a high school diploma or a GED as well as proof of linguistic proficiency in both English and the foreign language before enrolling in a minimum 40-hour accredited medical interpretation course, equipping the interpreter with tools such as medical terminology knowledge, and emphasizing the importance of certain protocols and a code of ethics. Once the course is completed, the interpreter is then asked to pass a nationally standardized exam from one of two agencies: the Certification Commission for Healthcare Interpreters (CCHI) or the National Board of Certification for Medical Interpreters (NBCMI). The two certification organizations have

<sup>&</sup>lt;sup>5</sup> Omission: "The interpreter did not interpret a word/phrase uttered by the clinician, parent, or child" Addition: "The interpreter added a word/phrase not uttered by the clinician, parent, or child"

Substitution: "The interpreter substituted a word/phrase for a different word/phrase uttered by the clinician, parent, or child"

Editorialization: "The interpreter provided his or her own views as the interpretation of a word/phrase uttered by the clinician, parent, or child"

False Fluency: "The interpreter used a word/phrase that does not exist in that particular language or an incorrect word/ phrase that substantially altered the meaning"

some difference in the languages they offer certification for, but are otherwise largely similar in their requirements, exams, and credibility. After passing both the oral and written exams administered by the organization, the interpreter is considered nationally certified.<sup>6</sup>

Diego, an interpreter from Panama, explains the importance of the methods, principles, and guidelines emphasized in formal medical interpreter certification training:

"And the most important [thing] is that it's the way interpreting works, that it's almost as if I'm not there. I'm just relaying whatever [the provider] say[s]... And sometimes the patients don't understand what the physician says. So like, I just relay whatever the physician says... I just interpret, and then they get like, not upset, but like, 'What are you doing?' I'm just interpreting, man, like, ask a better question, or like, because it's not about, I shouldn't be, if I hear the physician say like, something with a little bit of medical jargon, and I interpret that as is, I cannot simplify it in my own words and tell it to the patient, because that's being dishonest to what the doctor said... because my role is not to be the healthcare provider, my role is to be an interpreter for the healthcare provider."

Diego's description and explanation of interpretation here underscore that, though he has a role to play in the clinical encounter, his responsibility as an interpreter is to facilitate, but not add to, the communication between patient and provider. As such, he must remain honest to what the provider and patient have communicated, refraining from inserting his own thoughts, opinions, or intentions. This is because his role is as a bridge through which

<sup>&</sup>lt;sup>6</sup> Sources for the paragraph: <u>https://cchicertification.org/;</u> <u>https://www.certifiedmedicalinterpreters.org/;</u> <u>https://medicalinterpretingtrainingschool.com/how-to-become-a-certified-medical-interpreter/</u>

the patient and provider can come to understand each other and build their own relationship. Though this is the ideal method of interpretation, Chang's emphasis on the interpreter's own background cannot be dismissed; since interpreters are people informed by their own past and beliefs, they will never be fully neutral and will subsequently influence the interaction between patient and provider to some degree. Regardless of an interpreter's training or experience, they are inherently unable to remove themselves from the contexts they are situated in by virtue of their identities. In this situation, it may be more intimidating to share these experiences when there is an extra person in the room, as compared to an interpreter who is not physically present but rather connected via technology.<sup>7</sup> As a result, though in-person interpreters are often the most successful form of interpretation, there are drawbacks to this scenario as well.

#### Legal Context and Framework of Interpretation

Though many facilities, especially larger, urban, and better-funded ones, strive to provide translation and interpretation services, it is essential to note that there is no official national requirement for standardized, quality interpreting. The federal law under which medical interpretation and linguistic accessibility fall is the Civil Rights Act of 1964 (Chang, 1998; Chen, 2007). Title VI of the Civil Rights Act of 1964 says in Section 601: "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". An overwhelming number of hospitals and other healthcare facilities within the United States fall within the wide range

<sup>&</sup>lt;sup>7</sup> Typically, technological translation and interpretation can either be automated, similar to such softwares as Google Translate, or connect the patient and provider with a live interpreter. Live interpreters can be connected either with only audio over the phone, or over a tablet with capability for both audio and visual.

of programs that this law affects because they accept federal funding through Medicare and Medicaid (Chang, 1998; Chen 2007). However, crucially, there has been no legal precedent or landmark case that has identified language interpretation or lack thereof to be a violation of this law (Chang, 1998). In contrast, *Lau v. Nichols* was a landmark case that created the legal precedent for linguistically accessible schooling and education environments<sup>8</sup>. As no such case or legal precedent exists for the healthcare system, there is significant legal ambiguity surrounding the legal mandate to offer medical interpretation. Another attempt to offer provisions for non-English speaking individuals came in the form of Executive Order 13166, "Improving Access to Services for Persons with Limited English Proficiency", which was signed by President Bill Clinton on August 11<sup>th</sup>, 2000. This executive order mandates that federal agencies and recipients of federal funding offer the same programs, activities, and services in different languages for limited English proficiency persons.<sup>9</sup>

Crucially, however, President Trump signed Executive Order 14224, "Designating English as the Official Language of The United States", on March 1<sup>st</sup>, 2025. Part of this order included the repealing of President Clinton's Executive Order 13166, removing the mandate for linguistically accessible services. President Trump's recent executive order, taken in conjunction with the absence of a landmark case as discussed above, create an increasingly

<sup>&</sup>lt;sup>8</sup> In *Lau vs. Nichols*, schools in San Francisco were faced with large numbers of Chinese students, many of whom did not speak or understand English, after integration. Classes continued being taught in English, and the school system did not offer English supplementary classes to the students not proficient in English. As a result, classes remained linguistically inaccessible to many Chinese students. The US Court of Appeals for the Ninth Circuit ruled in the students' favor, saying this violated Title VI, Section 601 of the Civil Rights Act of 1964 and established a precedent that language barriers in public education settings must be adequately addressed and negotiated. Importantly, no such analogous case exists for the healthcare system, meaning there is no such legal precedent for health settings. Source: https://www.oyez.org/cases/1973/72-6520

<sup>&</sup>lt;sup>9</sup> Source: <u>https://www.federalregister.gov/documents/2000/08/16/00-20938/improving-access-to-services-for-persons-with-limited-english-proficiency</u>

hostile environment for persons who have limited English proficiency. This extends to the healthcare system where, due to the legal ambiguity and lack of strong federal regulation, states and individual facilities largely bear the responsibility of deciding and regulating the extent to which they want to provide linguistic accessibility resources. As a result, there is a paucity of standardized regulations and significant variability across facilities, neighborhoods, cities, and states.

Unsurprisingly, one of the largest factors in a facility's decision on whether and how to offer linguistically accessible services is finances. Interpretation services, in all their possible forms, require varying amounts of allocated money in the budget.<sup>10</sup> However, finances are proving to be a strain due to shifting dynamics and methodologies of healthcare delivery in the United States. For decades, the healthcare system in the United States has been trending toward large healthcare groups—such as Kaiser Permanente and Sutter Health—that offer comprehensive care for their patients within a centralized system; gradually, healthcare system giants such as these have been consolidating smaller systems, independent clinics, and individual practitioners with the goal of establishing systems that offer all the expertise, tests, operations, and procedures their patients could require<sup>11</sup>

<sup>&</sup>lt;sup>10</sup> Artificial intelligence (AI) is emerging as a potential method of interpretation that minimizes cost. This is certainly an area of current interest, research, and development. Currently, AI and large language models are "currently inadequate for medical interpretation" (Bakdash, 2023). This is due in large part to the fact that these models are most frequently trained on Internet material, meaning the program may perform well primarily with high-resource languages that are prevalent online, but may struggle with low resource languages (Bakdash, 2023; Jiao, 2023). Additionally, other studies have shown "AI has the potential to increase clinician workload" and to "creat[e] more burden through inefficient incorporation into the clinical workflow" (Barwise, 2024).

<sup>&</sup>lt;sup>11</sup> It is important to note that while these systems are expanding across the country, they are doing so unevenly and at different paces in different states. Chang et al. note that "a few states such as California, Massachusetts, and Oregon have several mature markets, primarily in urban areas, while states such as Wyoming and Mississippi have very little managed care statewide" (Chang, 1998). Thus, while this phenomenon is recognized as the future direction of healthcare, it is not occurring uniformly.

(Chang, 1998; Casalino, 2003). Large health groups promote consolidation, arguing that this process makes possible a slew of benefits including "increas[ing] physicians' negotiating leverage with health plans (Haas-Wilson, 1998), operat[ing] more efficiently (Lee, 1990; Newhouse, 1973; Gaynor, 1989), contain[ing] medical care costs (Kralewski, 1999; Kerr, 1995; Kralewski, 2000; Greenfield, 1992), and improv[ing] quality" (Casalino, 2003). In reality, large healthcare groups bring their own sets of negative consequences, some unintended. One of the drawbacks of large health groups most pertinent to this project is the resulting decrease in both insurance premiums and hospital days, especially in areas with developed markets of large healthcare systems (Chang, 1998; Wallack 1992). California shows a dramatic example of this outcome, wherein "hospital days for non-Medicare recipients have dropped from 450 days per 1,000 enrollees nationally to as low as 130 days per 1,000 enrollees" due to the "extremely competitive southern California marketplace" (Chang, 1998). As a result, hospitals are challenged with "concomitant reductions in revenue" which they manage through "reduc[ing] the number of beds" and cutting staff, "particularly lower paid 'ancillary' staff such as aides and interpreters" (Chang, 1998). Chang notes that the first services to be removed as a result of the revenue loss include interpreters, which mostly impacts the patients who struggle with English. As a result, healthcare services are rendered less linguistically accessible, with hospitals and providers struggling to find more cost-effective alternatives.

Thus, due to the lack of standardized, specific, enforced federal guidelines or policies on this issue in conjunction with financial concerns and pressures, many health encounters, especially those taking place in more rural and impoverished areas, occur without professional interpretation. A study exploring the use and efficacy of interpreters within a

public hospital emergency department found that "a total of 22% [of Spanish-speaking patients] said an interpreter was not used but should have been used", with "professional interpreters... used for only 12% of patients" (Baker, 1996). Often, instead of professional, certified interpreters, facilities, providers, and patients have to find workarounds. In some cases, this means simply accepting poor communication and trying their hardest with hand signals and limited vocabulary in each other's languages. This method carries the largest risk of miscommunication and offers the fewest allowances for the patient's needs and comfort. As a result, the patient may feel further too uncomfortable or anxious to share more intimate details or experiences of their lives. If the patient chooses to come forward with such information, they are then faced with the excruciating process of struggling to convey and having to reiterate and rephrase what could be their most traumatic experiences. Crucially, even after this agonizing ordeal, the patient could still nevertheless be misunderstood by the provider, leading to a multitude of potential negative consequences as mentioned previously, including misdiagnosis and incorrectly or inappropriately administered treatments. Thus, these considerations stress the idea that a clinical encounter in which a patient who is not comfortable communicating in the provider's primary language is not offered a method of interpretation is a situation that threatens a host of negative consequences for the patient's care, health, wellbeing, and general healthcare experience.

#### **Ad hoc Interpreters**

Another common method of navigating the language barrier without a professional interpreter is through the interpretation of a family member or another member of the patient's community, both of whom are examples of ad hoc interpreters. Ad hoc interpreters are people who are "untrained, apparently bilingual people" who step into a clinical

exchange to serve as interpreters (Timmins, 2002). This is an extremely common practice and experience, as many children of immigrants, including many of my interlocutors, have vivid memories of interpreting for their parents in clinical settings. Though, at first glance, this method may appear to be a quick, convenient, and comfortable way to negotiate the language barrier, it has undeniable disadvantages and risks upon further analysis. Despite family member interpreters typically being more proficient in the patient's language than the provider, there is no guarantee they are adequately proficient in both languages, as there is no standardization of quality or expertise for ad hoc interpreters, which leads to an increased rate of mistranslations and miscommunications (Paradise, 2019; Timmins, 2002). Medical terminology presents another potential issue, with ad hoc interpreters not having the medical terminology proficiency training that professional interpreters have received and subsequently struggling to understand the practitioner during the exchange (Flores, 2012; Timmins, 2002). Following this trend, other interpretation errors are likely to occur more frequently with an ad hoc interpreter than a professional one (Paradise, 2018; Timmins, 2002; Flores, 2012). Most interpretation errors can be sorted by categories: omission, addition, substitution, editorialization, or false fluency<sup>12</sup> (Flores, 2012). Though family members or other ad hoc interpreters have kind intentions, they are more prone to such mistakes than professionally trained interpreters, as they have not received the same

Omission: "The interpreter did not interpret a word/phrase uttered by the clinician, parent, or child" Addition: "The interpreter added a word/phrase not uttered by the clinician, parent, or child" Substitution: "The interpreter substituted a word/phrase for a different word/phrase uttered by the clinician,

<sup>&</sup>lt;sup>12</sup> Flores, 2012 defines each category as shown below.

parent, or child" Editorialization: "The interpreter provided his or her own views as the interpretation of a word/phrase uttered by the clinician, parent, or child"

False Fluency: "The interpreter used a word/phrase that does not exist in that particular language or an incorrect word/ phrase that substantially altered the meaning"

education in interpretation guidelines. As a result, a family member may see no harm in clarifying what they perceive the doctor's question to mean. Unfortunately, this does not align with the guidelines and standards of medical interpretation as previously described by both Diego and Tomás. Ad hoc interpreters, including family members, have not received professional medical interpreter training and may thus not see the harm in adding to the encounter, believing they are helping but unintentionally skewing the patient and provider's understanding and communication with one another.

These concerns are especially apparent when the interpreter is a child interpreting for their parent. Though this happens often in immigrant families, it is hard to expect a child, especially a young child, to be proficient enough in both languages and comfortable with medical terminology to the extent that is necessary for a medical interpreter. Isabela, a young woman who was born in Mexico but moved to the United States when she was three, shares her memory of interpreting for her parents in clinical settings as a child:

"It was hard because there's things that, you know, as a six, seven-year-old, I didn't really know what they meant. So I, I translated to the best of my ability,

but there was definitely like loss of communicate of like what was being said

between me and my parents and the doctor."

Isabela remembers the stress and anxiety of having to interpret for her parents at a young age despite not being sure of what was being discussed. In hindsight, she notes that her interpretation was in no way perfect because she was a child who just had to do her best despite having limited understanding of the circumstances. Isabela's recollection of having to try her best in interpreting for her parents as a young child highlights the potential detriments to patient care. Similarly, Amy, a Honduran-American born and raised in the

United States remembers one time she had to interpret for her mother in her own clinical encounter:

"I remember, I mean, when I was 15, I had appendicitis. And I had, at first we started at urgent care and then from urgent care, I got sent to the ER at a local hospital. And then from the local hospital, I got sent to Children's here in Atlanta. And throughout the whole process, I was kind of like, I mean, I was in extreme pain, but I was the one kind of keeping everyone up to date and keeping everyone on the same page because there were translators and they would take way too long to get to us. So I just kind of did everything... I was kind of the one facilitating the communication between the doctors and my mom and getting her the information. So I think that was like a really, really significant experience for me... Yeah, it was frustrating. I mean, it's kind of something that I had just gotten used to. You kind of just expect it. But I mean, in the moment, because I was like, you know, not knowing what was going on and not knowing if I needed to have surgery or not, it was a little frustrating being like, I don't want to do this right now. I can barely talk."

Isabela describes a situation in which she was both the patient and the interpreter, since she was a minor and decisions for her care legally belonged to her mother. Though Isabela's health outcomes were thankfully positive, likely in part because she speaks English and Spanish fluently, her experience was generally a negative one. She recalls the distress of an agonizing pain coupled with the pressure and responsibility of ensuring accurate and expedient communication between her doctor and her mother. This dynamic of a legal minor patient who also takes the role of interpreter between provider and parent/guardian is an

admittedly ironic twist on legal provisions which grant the parent/guardian decisionmaking power. In most cases, children under the age of 18 are considered minors and legally unable to make decisions for themselves, a result of the notion that children, especially at younger ages, may be unable to adequately understand a complex situation, weigh potential decisions, and make an informed, rational choice. However, in the situation of the minor holding the dual roles of both patient and interpreter, the information received by the parent/guardian and the decision which subsequently proceeds from it are dependent on the minor. In short, the minor is paradoxically considered unable to understand clinical information or make informed decisions, yet able to reliably transmit the information to their parent/guardian. While Isabela's physical care and outcomes were not impacted by serving as an interpreter in her own clinical encounter, her story here emphasizes that the negative experience nevertheless had a significant impact.

In addition, many of the risks of in-person interpreters previously discussed are exacerbated when family or community members are used as interpreters. Ad hoc interpreters who have a relationship with the patient, such as family members, are even further from the ideal objectivity of an interpreter because they have to negotiate their own biases and beliefs about not only the general world, but about the patient and the patient's condition as well (Chang, 1998). Family members will often have their own opinions about what their loved one should do to remedy a medical issue, and will subsequently influence the interpretation, whether consciously or subconsciously, to align with their agenda. As such, the interpretation between patient and provider will be altered based on the family member's perception of what should be done for their loved one. Similarly, if a patient is already reluctant to discuss sensitive and personal issues—ranging from sex history to drug use, struggles with houselessness to mental health—with a professional interpreter present, they may be even more unwilling to disclose them in the presence of family and friends. Importantly, though family and friends may be well intentioned in stepping into an ad hoc interpreter role, they can never reach the intended neutrality and objectivity of a professional interpreter due to their relationship with the patient and, as a result, will unwittingly further alter or impact the clinical exchange.

#### Linguistic Preference for Bilingual/Fluent English Speakers

Though language can be easily dismissed as a barrier only for recent migrants or migrants with limited English capability, there is, in reality, significant linguistic tension even for migrants who speak English fluently. Julia, who migrated to the United States from Colombia as an infant at one year old, told me that she feels more comfortable seeking healthcare in Colombia, because she feels language and culture act as a barrier to her care here in the United States. I reacted with surprise that she included language as one of her reasons for seeking care outside of the United States, as she migrated at a young age, attended English-speaking schools all her life, and speaks fluent English in her daily life, in her workplace, and in our interview. When I asked, she explained to me:

"Well, as far as language, like I'll still think in like both languages. And it's like, sometimes I'm just like, it's like that Spanglish in my mind... And like, for example, a lot of issues I talk to my parents about and it's in Spanish. And so that's why I guess maybe if I go to Colombia, like I'm more comfortable sharing because I'm already explaining it to them in Spanish. And like, it's ingrained in my brain that, I have all the words in Spanish. And then maybe if I'm already here in the States, like, you know, I'm thinking in Spanish and I'm having to

like think the English version of it. So maybe it's just like the way my mind works that I'm like maybe thinking in Spanish at one moment, thinking in English..."

Julia's account here emphasizes that even when a patient is fluent in English and may be able to conduct the entirety of their daily lives, including healthcare encounters, in English, they may still prefer Spanish. The main reason Julia expresses this preference is simply that she's accustomed to speaking about closer, personal issues in Spanish, most often with her parents. This underscores the notion that the linguistic compatibility that patients tend to seek with their healthcare providers is not simply a reflection of understanding and communication. Furthermore, the healthcare practitioner often assumes a patient's need for a language interpreter based on their personal assessment of the patient. However, this assessment is neither objective nor always accurate and may easily miss the discomfort or preference of someone like Julia or Miguel. Miguel is a professor from Argentina who lives and teaches in Atlanta; he is fluent in English, and our interview was conducted in English. Even so, he recounts a time his friend, a physician in Argentina, told him to seek mental healthcare and remembers an extreme reluctance to do so in the United States due to language:

"And of course, I gave her every excuse under the sun, you know, to not do it because I'm like, no, but that's going to be in English. And in English, I'm not going to feel comfortable. I will not be able to convey exactly what my problems are. And my friend said, you know, even if you have to do this in Japanese, you know, you have to do it."

Surprised, I asked Miguel to explain more about his discomfort with communicating his physical and mental healthcare in English, since he speaks fluently. He continued on to describe how his mind processes the languages he speaks:

"So, yeah, yeah, that's a problem of my own, you know, maybe I speak English fluently, but I do not feel secure, you know, I mean, I feel that I can, you know, sometimes in English, I'm trying to say one thing, and I say something different, because it's easier to say, you know, and I go in that direction... you know, so when you go into things that are so complex as how you feel, you know, and your childhood, and what happened in your life, you know, when

you were a kid, et cetera, et cetera, I was afraid that I was going to mess up."

Miguel's description of the cognitive labor involved in speaking English, exacerbated by the stress, emotion, and high stakes of the clinical setting, emphasizes that linguistic accessibility is not simply a communication issue—it is also one of the patient's ease and comfort during the clinical encounter. Importantly, Miguel makes a clear distinction between his fluency in English and a feeling of security. In this way, he touches on a similar point made by Julia in her explanation of how Spanish offers more familiarity, especially in complex or personal topics. This population of patients who speak English fluently but still feel that the language barrier impacts their confidence should still receive an interpreter, if they wish, because their level of confidence can have an effect on the outcome and experience of their clinical encounter, as explored previously.

However, this subpopulation—people who have some significant English proficiency if not fluency, yet still identify Spanish as their primary language—is uniquely positioned and has a new potential barrier they must consider. Interpretation, as explored above,

carries its risks and possible detrimental effects on the clinical encounter. Thus, members of this subpopulation are asked to weigh their confidence and comfort with English against the possible risks of asking for linguistically accessible care. Sofia, a professor from Puerto Rico who now teaches in Atlanta, explained that she no longer chooses interpreted Spanish language options, both in healthcare and otherwise, when given a choice between Spanish and English, even though she did when she was younger. In earlier years, she says, she was not as confident in her English as she is now, and had to choose Spanish options in order to understand. Now, however, though her primary and preferred language is still Spanish, she hesitates to express a preference for Spanish because she worries her services will be delayed or otherwise inferior compared to the English services. In short, she and others in this group are asked to balance the lack of comfort of speaking English in the US healthcare system with the anxiety that Spanish-speaking services will mean a disadvantage.

In the examples provided in this section we can see a fascinating phenomenon: how different languages are used for different purposes. In the cases presented, Spanish is the preferred language for personal and intimate conversations, while English is seen as a transactional language. Nevertheless, despite the bilingual status of my informants, the health care systems does not accommodate their linguistic preference, thereby creating linguistic insecurity.

### **Chapter 2: Cultural Translation**

#### **Cultural Barriers in Healthcare**

Cultural dissonance, which I define as an incompatible difference in cultural background, beliefs, or understanding between a patient and provider, has been recognized as a contributing factor to healthcare efficacy for decades. In addition to language, cultural context must be taken into account to accomplish effective communication, especially in healthcare. Even in cases when language is largely shared, cultural beliefs and cultural significances of specific words still greatly impact communication. Incongruous cultural beliefs between patient and provider can significantly impact quality of care, experience, and the patient-provider relationship. If dissonant cultural beliefs are not resolved and an understanding between patient and provider not reached, they quickly become dissonant expectations for the patient's care. As the provider pushes for and proceeds with a care plan informed by their own typically Western medical training, the patient may resist due to unacknowledged or disrespected cultural beliefs. This results in frustration and distress for both patient and provider, as well as increasing distrust and hostility in their relationship. Clara, an immigrant born and raised in Mexico before migrating to the United States and starting her own family, described to me the cultural view of medicine she has, as well as how her upbringing in Mexico has affected her perspective on the body and wellbeing. For example, when I asked Clara how she deals with pain or discomfort, she responded:

"No, en la forma que tú me estás diciendo que te dolía la cabeza y te tomabas una pastilla, no... Mi mamá era la que me daba medicina y era la que me curaba y todo. Ya cuando yo empecé a tomarme mi propia medicina, yo trato lo más de no tomar lo que es pastilla medicina. Porque te vas a curar lo de la migraña,

pero dañando el hígado... por la medicina, la acidez, porque la medicina acido es."<sup>13</sup>

In this quote, Clara expresses a certain hesitancy about taking pills as medicine as opposed to natural teas for which she expressed a preference later in the interview. Her hesitance about pills comes from the belief and worry that even as a pill cures or alleviates one health issue, it raises a myriad of side effects and harms to other systems and organs in the body. It is worth noting that Clara's belief here is grounded in truth; many times, medicines do in reality have side effects that may lead to complications for the patient. However, this reality may be dose- and drug-dependent, rendering the side effects insignificant if the drug is used in the short term or as directed as the medical practitioner. Even so, when Clara's beliefs and the upbringing that they stem from are not addressed and are instead dismissed by her medical provider, Clara understandably feels a sense of distrust toward the provider. Thus, a cycle begins in which Clara's mistrust of her provider prevents her from voicing her opinions, delaying seeking care when she encounters a health issue, or refusing to follow her healthcare provider's advice. Similarly, the provider will likely feel frustration at what they perceive to be Clara's noncompliance and apathetic attitude toward her own health and improvement. In general, Latinx communities are portrayed as "bad biomedical subjects" (Briggs 2007), meaning that they do not pay attention, or abide to western models of good hygiene and follow medical instruction. The example used of Clara's belief is one that is to some degree one with which Western biomedical systems already agree and support; thus, in some ways, this example illustrates a relatively mild case of belief divergence between

<sup>&</sup>lt;sup>13</sup> "My mom was the one who gave me medicine, and healed me, and everything. And once I started to take my own medicine, I tried my best to not take medicine pills. Because they will cure you of the migraine, but hurting the liver... because of the medicine, the acidity, because the medicine is acidic."

patient and provider. Even so, Clara's experience and relationship with her provider are severely compromised when she feels her beliefs are not adequately understood and respected. Thus, it is likely that when cultural beliefs are even more starkly incongruous with the Western biomedical perspective, the negative consequences that arise may be even more dire. This point illustrates the crucial role that understanding and resolving differing cultural beliefs has in facilitating effective communication and, by extension, high-quality and timely healthcare.

Linguistic culture plays a meaningful role as well, as the meanings or contexts in which words are use may vary from person to person. This idea is exemplified in Tomás' experience as a Spanish language interpreter in medical and healthcare contexts. Tomás is a fluent native Spanish speaker, as he was born and raised in Puerto Rico before he moved to the continental United States in his teenage years. One of the programs Tomás has interpreted for is a health program and initiative targeting farmworkers in rural Georgia; however, the majority of these farmworkers are Mexican and thus, have a different cultural background from Tomás' Puerto Rican upbringing. As such, when Tomás interpreted for them during the clinic, he encountered differences in word usage that he had to consider.

"In the farm worker program... most of the individuals [were using] this word called *pomada*<sup>14</sup>. *Pomada* is a cream. I didn't know what it was at all, so I had to, like, ask [the patients] like specifically, 'hey what is a *pomada*?... Everyone keeps requesting this...' and they explained that it was like a cream. And being able to understand that and relay that to the provider and, like, let them know,

<sup>&</sup>lt;sup>14</sup> *Pomada*, the word that Tomás encounters, is typically used to mean a medical ointment or cream. Though it seems to be common terminology for the farmworkers Tomás was interpreting for, this word is not one that he is familiar with in the contexts of his Puerto Rican background.

like, hey most individuals ask for this *pomada* cream... I don't know if they like buy it in the store or something like that. But I'm just gaining awareness of the community you're helping and being able to use that to direct treatment or also to provide them better feedback on anything they're using or any methods of improvement in their practice."

Despite being a native speaker who has spoken Spanish at home all throughout his life, Tomás encounters a word he is not familiar with: *pomada*. The unfamiliarity of this word does not speak to inadequate fluency in the Spanish language on Tomás' part but is instead indicative of the importance of culture in communication, even in situations of linguistic congruence. This is not to imply that linguistic congruence is insignificant—on the contrary, it can be essential to understanding cultural discrepancies. In this scenario, Tomás was able to better bridge the cultural gap between himself and the patient, as well as that between the provider and patient, because he speaks Spanish. Linguistic congruence assists him in forming connections between himself, the patient, and the provider as he determines the relevant information and relays it to the healthcare provider. Tomás' anecdote stresses the point that linguistic congruence, while certainly advantageous and beneficial, by no means guarantees effective communication. This reality, coupled with cultural differences that exist between many providers and patients, presents a significant obstacle to effective clinical care and communication which demands to be addressed (Hsieh, 2021; Leung, 2023; Kreps, 2020).

#### An Analysis of Cultural Competence and Racially-Based Medicine

In response to this cultural dissonance, healthcare and medical education institutions have previously proposed cultural competence and competency education as a method
through which providers can learn about their patients' culture and appropriately modify their treatment plans and communication to effectively help their patients. Through these training programs, providers are encouraged to understand the culture and defining characteristics of different racial, gender, sexual, or other demographic categories. However, a closer look at cultural competence reveals the ways in which it perpetuates the essentializing of patient identities, racially based stereotypes, and healthcare inequities and disparities.

Cultural competence is intended as "a means of attending to the culturally diverse backgrounds of patients, providing person-centered care, and reducing health disparities" (Lekas, 2020). In taking this method of study, however, proponents of cultural competence categorize patients into groups based on a certain identity aspect, utilizing a singular identity to characterize their healthcare experience. In prioritizing one identity as primary or singularly impactful in the patient's experience, cultural competence rejects intersectional readings of identity. Sociologist Brenda L. Beagan further expands on this, noting the emphasis of cultural competence on ethnic cultures, writing that it "circumvents important intersectional analysis, casting health issues as the result of cultural eccentricities, instead of the result of poverty, working conditions, living conditions, stigma, racism-related stress, and so on" (Beagan, 2018). As coined and defined by legal scholar Kimberle Crenshaw, intersectionality serves as "a metaphor for understanding the ways that multiple forms of inequality or disadvantage sometimes compound themselves and create obstacles that often are not understood among conventional ways of thinking" (Crenshaw, 1989). Crenshaw's intersectionality, as applied to healthcare, emphasizes the notion that each patient, situated at the intersection of their identities, experiences a unique set of challenges and

disadvantages to their health, as well as within the healthcare system. The methods of cultural competence involve sorting people into categories based on an identified "primary" identity—gender identity, sexuality, socioeconomic status, or, most often, race. This assumption that one identity status takes precedence over a patient's health experience is inherently problematic, as it seeks to distill the complexity of a layered identity into a single aspect.

Race has historically been utilized as a singular aspect that affects a patient's health issues and healthcare experience. Medical anthropologist and physician Paul Farmer cautions against this tendency, noting that "abuses of cultural concepts are particularly insidious in discussions of suffering in general... cultural difference is one of several forms of essentialism used to explain away assaults on dignity and suffering in general" (Farmer, 1996). Though Farmer speaks more to an international context, his larger point and its principles are applicable to discussions of the medical healthcare system within the United States as well. A clear example of Farmer's point can be seen in the practice of race-based medicine, such as race adjustments in calculated medical scores. Standard medical practice uses symptoms-based scores to calculate risks for complications in certain situations, such as having a vaginal birth after caesarean section (VBAC). These online, publicly available calculators provide a standardized and objective metric for risk that healthcare providers can quote; however, oftentimes these calculators, including the original VBAC calculator<sup>15</sup>,

<sup>&</sup>lt;sup>15</sup> The VBAC calculator was originally created in 2007 by the Maternal-Fetal Medicine Units Network (MFMU) under the National Institute of Child Health and Human Development. When it was originally created, it took race into account, adjusting the score to be lower (meaning a lower chance of successful vaginal birth after C-section) for Black and Hispanic patients. Race was later removed as a factor of the calculator in June of 2021 as part of an update from MFMU. However, many other health calculators continue to consider race as a factor in calculating risk for patients (Edwards, 2023).

take race into account as a factor, increasing the risk most often for Black/African American and Hispanic patients. Initially, race was taken into account because un-refutable data showed that certain racial groups had worse health outcomes. However, these health discrepancies are not a direct result of race and racial differences; instead, they speak to a myriad of confounding factors which, taken together, comprise the experience of inequity which in turn negatively impacts the patient's health. Thus, race is utilized as a shortcut metric, encompassing many influencing factors and inequities under one label. In continuing to attribute the poorer health outcomes to race as a proxy for the effects of racism and disadvantaged circumstances rather than addressing the underlying injustices, race-based medicine contributes to inequity. Doing this fails to clarify the racist, historically weaponized, and biologically false notion that racial differences have inherent scientific basis for different healthcare experiences and treatment (Vyas, 2020). Furthermore, through calculators that include race adjustments, there is significant danger that by "systematiz[ing] these existing disparities by building race/ethnicity subtraction factors into a predictive tool... [it ensures] that these trends will simply continue" (Vyas, 2019). This acceptance of race as a proxy for racism and inequity is the outcome that Farmer condemns, as unequal health outcomes become simply accepted as a factual aspect inherent to that race. In short, in assuming that a patient's healthcare experience is singularly impacted by one identity aspect, especially race, over all others, cultural competence fails to recognize and adequately address the complexity of the individual's experience and contributes to the perpetuation of racial health disparities.

When the categorizing identity is a racial one, as it often is, cultural competence and the assumptions it brings can often further perpetuate the racism and subsequent racial

inequity that it seeks to prevent. This comes from the structure of cultural competence education and training as it pushes healthcare providers to consider identities, cultures, and experiences as static and factual—knowledge to be chronicled, studied, and learned as objective—instead of recognizing them as inherently dynamic, fluid, and variable. The rigidity of this approach is seen even in the name and terminology of the practice, cultural competence, as "the claim that one can become competent in any culture suggests that there is a core set of beliefs and values that remain unchanged and that are shared by all members of a specific group" (Lekas, 2020). This perspective of fixed cultures leads to generalized and racialized stereotypes which are then forced onto patients in the form of clinical assumptions. The negative social and physical health consequences that patients suffer as a result subsequently perpetuate racial inequity and health disparities.

Amy described an experience her father had with a doctor in the American healthcare system, in which he suffered because of the racial assumptions and stereotypes made by the healthcare provider.

"My dad had an encounter with a doctor here when he had insurance and he was having some issues with his triglycerides. And the doctor was like, oh, just stop drinking. And my dad was like, I don't drink. And the doctor was like, oh, what are you working? And my dad was like construction. He was like, then stop lying to me. You drink. And my dad was like, 'I don't drink. What do you mean?'... [The doctor] was just like, 'just stop doing it. Like, you don't have to lie to me. Let's be serious.' And [the doctor] was like, 'you have to cut down on tortillas.' And like my family is Honduran and we do eat a lot of tortillas in Honduras, but we don't really eat them here. We're just not used to eating them here. We don't like them... as often. And he was like, 'yeah, just cut down on tortillas and stop drinking beer and you'll be fine.' Turns out my dad had something completely different. He needed a different way to get his medication changed."

Here, Amy shares a dramatically egregious example in which her father is not believed by the practitioner. The medical provider in this anecdote made incorrect assumptions based on the patient's Latinx identity, relying on some combination of stereotypes and previous encounters to make and reinforce his own judgments despite the patient's objections; even as the patient responded that he did not drink alcohol or eat tortillas, the provider insisted the patient was lying. The provider held a rigid, unchangeable view of the patient, Amy's father, who is portrayed as a poor biomedical subject, and assumed that answers that differed from his expectations must mean the patient was unwilling to cooperate or participate in his own care.

Though it is not clear whether this provider has had or was adequately following cultural competence training, Amy's story emphasizes the consequences of generalized stereotypes. Amy's father suffered disrespect in the provider's office, and his personhood and individuality were overlooked in favor of generalized racial stereotypes. The provider likely left the exchange with reinforced racial stereotypes of Latinx people, assuming in the future not only that they consume unhealthy amounts of alcohol and refined carbohydrates, but also that they will lie to the contrary. As a result of this interaction, Amy's father justifiably felt unheard and misunderstood, and the trust between provider and patient was degraded. Furthermore, Amy's father experienced delayed care since he left the interaction without having found a satisfactory answer to his triglycerides problem and had to further

seek the medical advice of another medical professional. While he ultimately suffered no lasting or serious medical consequences, the delayed care that can result from medical providers following racialized stereotypes and assumptions over listening to their patients as individuals can have dire repercussions in more urgent or emergent cases. Unfortunately, this provider's perspective is inaccessible and, as a result, it is impossible to determine whether he was practicing or educated in cultural competence. However, as cultural competence involves categorizing people based on certain identities and defining these categories and their cultures by fixed traits, the experience Amy's father had can be taken as a cautionary tale of the dangers of cultural competence and the stereotypes it can promote when taken to an extreme.

Finally, cultural competence perpetuates historic ideas of normativity and "otherness" which prove harmful through the exclusionary world constructed by such language use. The systems of cultural competence emphasize that the student is being asked to study and learn more about the "other" (Beagan, 2018). By having the provider study different cultures as the "other"—that is, something foreign and unusual that must be understood—cultural competence education reaffirms the white male practitioner as the normative, excluding any variance or difference as outside the normal. This establishes a cultural hierarchy through the implicit characterization of the white male cultural backdrop as more objective and natural in contrast to any beliefs, customs, or perspectives that fall outside the bounds of the "norm", which are subsequently considered less rational; in short, the provider is portrayed as the logical, intelligent, and objective clinician who then must lower their expectations and descend to the illogical and inferior patient (Beagan, 2018; Kirmayer 2012). This attitude, in addition to being overtly racist, white-centric, and

problematically hierarchical, influences the provider's approach to the patient as well, with patients often feeling condescended to or worried their doctor will not tell them everything. As a result, cultural competence education reinforces the implicit hierarchy of the white male as neutral and objective: scientifically factual and unbiased as medicine is often advertised. Medical anthropologist Janelle S. Taylor coins this phenomenon a "culture of no culture", in which healthcare providers' training, knowledge, and perspectives are portrayed and come to be accepted as objective, neutral, and universal (Taylor, 2003). This falsified objectivity further cements the white male practitioner as the norm, simultaneously casting any differences in cultural beliefs or customs as less valid, acceptable, or correct. The characterization of the white male provider of biomedical care as an objective, unbiased, and unequivocally factual personage is placed in direct contrast with the beliefs and perspectives of my interview participants, who view the healthcare provider's knowledge as one method among many, each of which has their advantages and drawbacks.

Since each of my interlocutors lives and exists within their own cultural context, this casting of the white male provider as neutral and objective presents a problem. As my interlocutors (and other patients) step into a clinical space that validates the white male biomedical views as normative, they encounter a cultural clash in which their perspectives are discarded as inferior. Faced with this tension, especially in the context of the unequal authority that characterizes a patient-provider relationship, patients may instead opt to seek care from their own communities, motivated by distrust of biomedical institutions.

## Cultural autoatención (self-attention)

People utilizing support and knowledge from their social networks, communities, and cultures as their first resort in coping with illnesses is a common phenomenon that

anthropologist Eduardo Menéndez (1984) coins "autoatención" (self-attention). Menéndez defines autoatención as "una estructura permanente que los microgrupos generan en toda sociedad para atender sus padecimientos, que se caracteriza por un proceso constante de cambio, al igual que las otras formas de atención, incluida la denominada medicina tradicional" (Menéndez, 1984; Menéndez, 2003; Menéndez, 2018)<sup>16</sup>. Menéndez's autoatención comprises a multitude of different forms of community, family, and individual care—such as herbal remedies and tradition-based notions of the body and health—which fall outside the limits of Western biomedical training and research. Though this form of care is often disregarded or dismissed by providers in the biomedical system as illogical, Menéndez argues for its acceptance alongside clinical medicine. Menéndez notes that through autoatención, people and patients reclaim autonomy and agency in their own health and wellbeing, often utilizing a mixture of home or cultural remedies alongside institutional or biomedical ones. Carlos and his family shared with me how autoatención plays a role in his life and his family's response to illness:

"Or like, for example, if I'm sick, [my grand-aunt] gives us this weird-ass jarabe of mint. I don't, it's like a mint syrup. I don't know, she cooked it up too. I did not question her. I did not question the medicine. You just sit there and drink it. Yeah, that's basically it, you know? Yeah, it's just like I never questioned that. Yeah. I don't know, I don't remember the efficacy of it. I think I do remember just getting like, yeah, like actually healing."

<sup>&</sup>lt;sup>16</sup> A permanent structure that microgroups generate in every society to treat their illnesses, which is characterized by a constant process of change, the same as other forms of care, including so-called traditional medicine.

Here, Carlos describes depending on the knowledge of his family and his community as a response to illness; he and his family often use local herbs and herbal medicines as their first response to injuries or sicknesses, based on the knowledge passed down from his family. Often, it is his grandmother and grand-aunts who know which plants to use for which issues, as well as how to use them. Crucially, Carlos emphasizes that he trusts his family's remedies, even going so far as to say he never questions what his grand-aunt gives him. This absolute trust is characteristic of Menéndez's autoatención, as this form of care is rooted primarily in the relationships that constitute the microgroups he describes. This stands in stark contrast to the distrust and wariness that Carlos expresses with regard to biomedical healthcare practitioners. When asked about if and how he brings his family's knowledge of plants, herbs, and alternative medicine into the biomedical clinic, Carlos explains that he prefers not to mention it to avoid the practitioner's judgment:

"So it's not like it's incredibly, like most of the time, it's not even brought up because we mostly assume they're going to think we're loonies, you know? So it's like, OK, you know your field, and we know our methods. So it's like we kind of sometimes keep, at least my experience, some people will be, I don't know, some people will be more vocal about it and will tell a doctor they don't know shit about anything."

Carlos expresses anxiety and reluctance to share his methods and remedies with his healthcare professional, due to feeling condescended to or dismissed as ignorant, alluding to previous experiences in which they have shared, only for the provider to dismiss them as irrational and the patient and their family as "loonies". What results is the perception of mutual exclusivity wherein the patient's cultural and historical remedial knowledge is pitted

against the provider's biomedical training. Carlos notes that though he avoids mentioning any herbal or alternative medicine use, some members of the community actively argue with the practitioner. With this tension, the patient-provider trust and relationship also subsequently suffers; the patient, as Carlos expresses, feels as though there is little point in even sharing their beliefs and attempting to work with the provider. Though the ideal of cultural competence is to provide sufficient understanding of the patient's culture to facilitate the partnership between the practitioner and patient—as well as of their cultural beliefs and behaviors—the reality falls far short of the intention, as seen in the anecdotes of Carlos and his family. This tendency of providers to write off alternative and cultural medicine as less logical or valid could be a result of the unintentional "Othering" in cultural competence, in which Carlos' and his family's inclination toward alternative medicine is portrayed as a barrier the provider must navigate. However, it is important to note that it is impossible to tell for certain, since there is no access to the perspectives of the providers that Carlos speaks of in his anecdote.

Additionally, cultural competence tends to assume the physician's cultural background as a white man, without engaging with or recognizing the specific set of biases and beliefs that result. Though this is a crucial dynamic documented in the literature, I have not been able to find a clear interview example of this. This results from the discomfort that would arise in asking my interlocutors to share how they experience the medical "culture of nonculture" or how they experience their provider's whiteness in the encounter. Thus, the casting of the white male provider as neutral and objective is a tension that remains unresolved, and a potential frontier for further exploration and understanding through interviews with both Latinx patients and medical practitioners themselves.

# **Chapter 3: Symptomatic Translation** Failure of Symptomatic Translation

A recurring theme I encountered in my interviews was that my interlocutors felt as though medical practitioners in the United States simply failed to sufficiently address their complaints. Often, they feel they have suffered unnecessarily for long periods of time before getting their symptoms explained and treated. This stands in stark contrast to their perception of the healthcare they receive in Latin America, which they describe as more expedient and efficient—and much less frustrating. As a result, they express a preference for seeking healthcare in theirs and their family's home countries, believing that those healthcare systems can succeed where this one has failed them. I describe this as a failure of "symptomatic translation", which I define as the systemic processes that occur to propel a patient with a set of symptoms through the healthcare system until they reach the completion of a diagnosis or, ideally, a treatment. In this section, I explore the ways in which failure of symptomatic translation, which I argue is a manifestation of conflicting expectations between the patient and provider (or, in other words, a difference in the medical cultures of Latin America and the United States, of the patient and the provider), factor into my interlocutors' decisions to seek healthcare outside of the United States.

One of the primary reasons my interlocutors gave me for their decision to leave the United States healthcare system behind in favor of Latin American systems from their home countries was the feeling that their concerns were recognized, heard, and addressed more professionally and expediently abroad. Many of my interlocutors have expressed frustration at the amount of time and the seemingly arbitrary barriers and hurdles that they have had to navigate to receive the care they need, from the start of the first clinical encounter with a primary care physician to their final step of at last receiving the care they need. Amy explains how she sees this frustration and the way her mother taught her to navigate it:

"I guess one thing that my mom always told me from when I was younger, because like when you go to the doctor, act sick, like, be dramatic... They're not going to believe you. So I think that's something that's still in the back of my

mind... These are my concerns, but I have to be really dramatic about them."

Amy expresses a doubt, ingrained by her mother and informed by both her own and her mother's experiences, that the healthcare provider will truly believe her and give serious consideration to her complaints. This advice, given to her by her mother, speaks volumes about the lack of trust their family has in the healthcare system to adequately understand and treat their ailments. Amy mentioned on the side that this is a common practice and piece of advice she has noticed repeated by her friends and peers. Thus, Amy and her family, amongst others in their community, have identified a failure—or, at the very least, a perceived failure-of symptomatic translation within the healthcare system; from their perspective, the system they have encountered has been unable or unwilling to see the severity their complaints, and are subsequently unable to respond sufficiently. In response to this observed phenomenon, Amy and her community have found a solution in simply dramatizing and exaggerating their complaint, such that the provider is more likely to give them the care they require. What ensues is a clinical chess match between patient and provider, in which both parties view one another through a lens of suspicion and maneuver to force the desired reaction from the other party. This reality is reflected in the strategy Amy and her community employ to act dramatic, but also in the anecdote Amy shared about her father's healthcare in an earlier section, in which the provider accused his patient of lying

and insisted his health issues could be solved through management of alcohol and tortilla consumption. Ultimately, this fosters dangerous distrust in the patient-provider relationship, leading to a vicious cycle in which both patient and provider see each other as the primary barrier to effective healthcare.

Though Amy's tactic of acting more dramatically in her clinical encounters is designed to help her overcome the barrier of the provider's doubt, other interlocutors expressed frustration with other obstacles in navigating their way toward a resolution for their complaint. Isabela is a young woman who was born in Mexico and moved to the United States with her parents when she was three. Currently, she works within the healthcare system as an occupational therapist, receiving benefits and health insurance from her job. However, even as a member of the healthcare system, Isabela tells a story of a health problem she experienced and expresses her frustration with the system's seeming inability and inefficacy at translating her symptoms and complaints into a diagnosis and, eventually, cure:

"One time I showed up and I had this lump on my neck and I was like you know it's kind of worrying 'cause I was like it's a lump. So anyway I go, I get it checked out, and the lady's like, 'oh it's probably just your lymph node, like it's swollen you know.' Which, you know, probably was, but she had me put it off for, like, another month and a half, and then she was like if it doesn't go away within a month with antibiotics, like, come back and we'll do, like, a ultrasound... which to me, like, I don't know. A lump is concerning to where I feel like the ultrasound should have been done there and then because it was, like, a chronic thing by then. But yeah so she made me wait, like, another month. I eventually got the ultrasound and everything, but yeah. I don't know, it's just kind of like she made me wait a little longer than she probably should have, you know."

Isabela explains to me her frustration as, from her perspective, the healthcare system and provider seem to delay her care unnecessarily, despite her significant worry. She feels the provider's response was insufficient given her complaint, and she should have received a scan immediately to understand the nature of the lump; in short, from Isabela's perspective, the healthcare system and providers in the United States failed to translate the issue and symptoms she brought—in the form of her lump—into a resolution. This is reflective of a discrepancy in the expectations—or the medical cultures—of Isabela and her provider. While her provider might be anxious about unnecessary interventions, Isabela feels her provider should be able to quickly resolve her symptoms and assuage her worries. Dissatisfied with the care she received in the United States, Isabela mentions that she ultimately sought care for this problem in Mexico, and explains the impression the experience left on her:

"Here, they told me it was nothing. So I went to Mexico because, you know, it continued to stay there. So I went to Mexico, and they did an ultrasound, prescribed me, like, a whole, like, treatment because he thought it was, like, some sort of infection. And I mean it cleared up within a week and you know that the lady here gave me, you know, a month's worth of, like, medication and you know that still couldn't get solved. So I just feel like they're more effective in Mexico."

Here, Isabela describes efficiency as the primary difference between the United States and Mexican healthcare systems. In the United States, Isabela felt as though her care was

unnecessarily delayed and the system and people she encountered were unwilling or unable to help her reach an efficient diagnosis and treatment. In stark contrast, when Isabela returned to Mexico, the system she finds there is one that immediately scanned her lump and provided her with the appropriate medication, translating her symptom into a medicine and a resolved issue within a week. This marked difference between her experiences in two different healthcare systems and how they respond to an identical problem laid the foundation for Isabela's conclusion that the US healthcare system is simply inefficient, and places too many obstacles that the patient must navigate—such as trying out a medicine only to find it does not resolve the problem—before finally reaching the care they need. I argue that this is a result of bureaucratic systems and explore the ways in which this bureaucratization of health and healthcare systems leads to inaccessibility, driving many of my Latinx interlocutors to seek healthcare outside of the United States. Notably, Isabela's story is not unique; in the following subsections, I analyze other interlocutors' anecdotes and situate them within the lens of efficiency as characterized by the intersection of Max Weber's bureaucracy and the healthcare system.

### **Overview of Bureaucracy and Bureaucracy in Healthcare**

Though bureaucracy is a word and concept that may elicit resentment and bring to mind endless forms and red tape, its basis is in formal rationality, which prioritizes systematized efficiency, the very virtue Isabela complained was deficient in the US healthcare system. Formal rationality, coined by German sociologist Max Weber, is defined as "the purposeful calculation of the most efficient means and procedures to realize goals" (Cockerham, 2015; Weber, 1922). This type of rationality, which Weber identifies as the dominant method of thinking in Western society, focuses on achieving objectives and goals with maximized efficiency.<sup>17</sup> According to Weber, formal rationality has played a significant role in the rise of capitalism and modern social norms through the bureaucratic organization of labor. Weber conceptualizes the bureaucracy as "a rational and impersonal division of labour characterised by the principles of office hierarchy and levels of graded authority... as well as by fixed and official areas of jurisdiction governed by laws or administrative regulations" (Cockerham, 2015). Weber's ideal bureaucracy is an organization in which strict, impersonal, and systematized policies are enforced uniformly by layers of specialized employees. The ideal resulting effect is a finely honed organization which has specifically defined goals and protocols to efficiently reach them. As such, the bureaucracy was created not as a hindrance, but as a structure to achieve maximum efficiency.

Weber's notion of ideal bureaucracy, in the context of healthcare, drives the specialization of healthcare practitioners and both the consolidation and systematization of resources and resource access, in the form of large healthcare groups, called managed care groups. As discussed previously in the linguistic interpretation chapter, these groups were formed, as bureaucratic systems, under the premise that further consolidating and systematizing healthcare could improve health outcomes and cost efficiency. At its peak, bureaucracy in the healthcare system can achieve some of these goals, maximizing efficiency and expediting all processes of seeking care, from finding a trusted doctor to navigating the system to obtain the necessary care. Sofia explains this as she talks about her experience as

<sup>&</sup>lt;sup>17</sup> This emphasis in formal rationality stands in contrast to what Weber identifies as substantive rationality, which is more dominant in Eastern and Asian thought. Substantive rationality, in contrast to the practicality and individuality formal rationality emphasizes, places importance on values and ideals along with social harmony, traditions, and notions of social honor. Of course, formal and substantive rationality are not found exclusively in the West and East; however, Weber noted that formal rationality dominated in the West while substantive rationality was more common in the East (Cockerham, 2015).

a graduate student and their system of care<sup>18</sup>. At her graduate school, Sofia and other graduate students were mandatorily enrolled into the graduate student health insurance provided by the university, which then enabled them to seek healthcare from the school's centralized health clinic. Anytime Sofia needed anything, she would book appointments through the university's health system. Sofia notes that, though she feels she did not adequately appreciate it then, she now recognizes how convenient it was to have all the providers she needed within her university's healthcare suite. Additionally, she emphasized that the centralized system allowed referrals, prescriptions, and appointment reminders to be sent and received with ease, expediting any care she needed. Sofia's assessment of the efficiency of this system was largely a positive one; she recognizes that because of the consolidation and organization of healthcare and health resources within the system, she had the full, comprehensive care she needed at her fingertips. As such, Sofia's description of the healthcare she received as a graduate student underscores the ideal effects of bureaucracy on a systemic level: efficiency, convenience, and regulated, systematized processes.

### **Minimization of Interventions**

The intersection of Weber's bureaucracy and healthcare systems brings forth the question of what metrics of efficiency and success are utilized. These metrics are conceptualized in the form of ideals and guiding principles that direct healthcare, occasionally in ways that bring dissonance or dissatisfaction with the patient. One such principle is minimizing the number of medical interventions performed on a patient,

<sup>&</sup>lt;sup>18</sup> No direct quotes are available, as Sofia requested that I take notes on the points she made rather than directly record the audio of our interview.

simultaneously one of the ideals of Western medicine and a significant point of frustration for my interlocutors. Notably, there is significant range between preferences for the degree and extensivity of medical interventions and services they would like to receive; this categorization of interventions as necessary or not is unique to each individual's preferences and beliefs, along with the clinical circumstances and context in which the intervention is proposed (Scherer, 2016; Scherer, 2020). Recognizing the significant variance between individuals in what is considered an adequate level of care, psychologist Dr. Laura Scherer developed the 10-item Medical Maximizer-Minimizer Scale (MMS-10) as a tool to help patients identify where on the spectrum they fall (Scherer, 2016). Scherer classifies the two ends of the spectrum as medical maximizers, or individuals "who prefer active and aggressive medical treatments and being proactive about their health", and medical minimizers, or individuals "who prefer to avoid medical intervention unless it is necessary", often opting to "watch and wait" (Scherer, 2016). Naturally, there are risks to both extremes. Medical minimizers risk rejecting necessary and beneficial interventions, increasing the possibility and danger of complications or other medical conditions. Conversely, medical maximizers may undertake minimally beneficial interventions, exposing themselves to the unnecessary harmful side effects of an intervention whose cost outweighs the potential benefits in a given circumstance. Another metric of efficiency is financial efficiency, minimizing the resources necessary for a certain outcome to be achieved, such that excess resources can be invested elsewhere. More invasive procedures and scans cost more than a simple doctor's visit in which the physician provides a general, standard assessment. This is especially of greater concern in the United States, where the healthcare system, like any

other capitalist corporation, is responsible for its profit margin. As such is the case, the healthcare system as a whole is incentivized to minimize patient interventions.

My interlocutors have expressed significant frustration at the perceived tendency of the US healthcare system to prefer medical minimizing. Daniel, a FedEx courier who was born and raised in the United States to Mexican parents, recounts a time that he injured his knee. When he saw his primary care physician, he was told he had Runner's Knee, a common condition in which the kneecap rubs against the thighbone, causing knee pain during movement. However, Daniel feels that the providers did not give his concerns adequate attention, instead generalizing his complaint:

"They just generalize things. And when I went in, they kind of, like, asking questions. They kind of took a look at it. They just kind of, like, generalize it as like runner's knee. And, you know, when I did some more research and asked more people at my occupation at the time, they were like, 'yeah, I got the same thing.' So I think they were just blaming everybody's — if you had a bad knee, it was Runner's Knee. So, yeah, that was one time where I felt like they weren't really listening to what I was trying to tell them. And they just kind of, like, you know, categorize it as that... I definitely feel like it should have been, like, at least some type of, like, MRI or, like, a x-ray done; I think it was just such a common injury in my last occupation that it was kind of just, you know, very common for a doctor to see somebody with knee or back pain, so yeah, I wish they would have done, like, something more- more of a, like, an x-ray like I said or, like, some type of- some type of scan. I think it would have made me feel more comfortable with, like, their decision."

Daniel's story emphasizes the idea that medical minimizing, especially when inadequately communicated to the patient, can lead to the patient feeling as though the provider is generalizing or dismissing their concerns—simply refusing to thoroughly address them. In this anecdote, Daniel expresses dissatisfaction with the providers because he feels they did not examine him or collect data about his condition thoroughly enough to reach the diagnosis. As a result, Daniel left the clinical encounter with the impression that the physicians, lacking the information necessary to make an accurate judgment, gave him a generalized, nonspecific diagnosis. In short, Daniel's anecdote highlights a potential failing of medical minimization: the insufficiency, whether perceived or genuine, of knowledge and data for an accurate diagnosis and subsequent resolution of the condition.

Most often, my interlocutors' frustration stemmed from being asked to wait beforehand instead of directly receiving a scan or test to diagnose their complaint, seeing this as an unnecessary delay in their care and the resolution of their problem. This can lead to increased anxiety as their complaints are seemingly dismissed in favor of more "watching and waiting". Miguel, a professor from Argentina recounts a time he was suffering from frequent acid reflux as a graduate student:

"Well, basically, I was experiencing acid reflux at night. And I had no clue why I was having that. I was a little bit overweight, but that was the only clue... And I went to the Student Health Center and a doctor used a stethoscope to evaluate my breathing. And that was it. And he gave me a pill, and I used the pill, and the pill didn't work. I went back and the second time he didn't examine me and gave me a different pill. And so that pill didn't work. So I went back, you know, this time a different doctor saw me. And again, stethoscope

breathing, reflexes, you know, like a little hammer, you know. And I explained that I was having acid reflux. And I said, 'well, maybe we should do an endoscopy or something.' And he said, 'no, that's not necessary. You know, I think that if you take this other pill, you know, it's going to be helpful.' You know, so I was between three pills."

Miguel continued to explain that, since he had a trip back home to Argentina scheduled for other academic reasons, he decided he would see an Argentinian doctor's opinion, since it could only be beneficial. There, he had a vastly different experience:

"I went to the public system in Argentina and saw a doctor. And this female doctor examined me more thoroughly. And at some point, she did something here. She touched me here under the sternum. And she said, 'you know what, I think you have a hiatal hernia. But in order to make sure, why don't you go around, you know, I'm giving you this order for an endoscopy. Go around and come back.' You know, so I got out of the building. Did like one block around... You know, so it was, I say, 30 seconds. I mean, it was 30 seconds. So he confirmed the hiatal hernia and wrote something and gave me a picture. So he printed out something, an image. I went back to the doctor. The doctor looked at the image and said, 'yeah, you have hiatal hernia. Usually these things are either because you're gaining too much weight, which she said, I don't think it's your case. You probably have a birth defect, you know, and it's probably genetic'... So I talked to my dad and my dad said, yeah, I have hiatal hernia. You know, so I also have this problem."

Miguel's two vastly different experiences emphasize the divergence in medical culture between the United States and Latin America. While in the United States, Miguel's doctors sought to avoid scans and interventions, likely choosing instead to try out medicines for acid reflux instead of further probing for the cause behind it. Unfortunately, this was not able to resolve Miguel's problem, since his acid reflux originated from a genetic condition. One of the most significant differences between Miguel's experience in Argentina and the United States is the willingness or reluctance of the primary care provider to order an endoscopy. This was understandably a point of significant frustration for Miguel, as he wondered why his American doctors refused to simply scan and understand what was happening rather than suggesting what appeared to be a trial and error of pills. While, of course, it is impossible to understand his physicians' exact motivations, as they are not part of my interview population, it is possible that they were adhering to the ideal of minimizing interventional risk; it is common practice to start with the least invasive interventions before gradually, if necessary, moving toward more invasive ones to minimize both any possible risks and costs of invasive methods. Even so, this was not communicated to Miguel, and he was left wondering why he seemed to be experimenting with medication rather than understanding and treating the issue. Consequently, Miguel's impression after these clinical experiences was that the US healthcare system unnecessarily delays the translation of his symptoms and concerns into a diagnosis, treatment, and, eventually, a resolution. Miguel cites this experience as one of the most impactful in his health journey, influencing his future perspective on the healthcare system in the United States:

"But, I mean, after that, I kind of lost, you know, a lot of confidence in the American system, you know, because it was my first experience with something

about health, you know, and every time I had to see a doctor, you know, I had to second guess, you know, the protocols they were following... But I think that sometimes American doctors abuse, I mean, not in a bad sense, you know, but that they abuse of the 'wait-and-see', you know. The 'wait-and-see' in American doctors, I see that it's much larger, you know, in scope than the 'wait-and-see' in Argentina. In Argentina, doctors generally don't wait and see much, you know. They say, 'let's see what's wrong,' you know. Or maybe that's the way I feel it because it's pretty much my experience, you know. It's not that I was going to Argentina because of the cost or, you know, because it was cheaper or because it was free."

Miguel's experience led to his questioning of future clinical providers and encounters in the United States, because he was no longer sure that they were as efficient as he wanted and thought they should be. As a result of his vastly different experiences in the United States and Argentina, he was left with the conclusion that the system and providers in the United States encourage delays in interventions through the "wait and see" perspective; in short, he feels that the healthcare system he has encountered in Argentina is more efficient in resolving his symptoms and concerns.

The principles of minimizing interventions and "wait and see" affect preventative care efforts as well, since the need for preventive measures is tempered with the hesitation of minimizing interventions. As a result, the United States healthcare system tends to minimize early care, especially scans and other interventions that include possible risks, leading to a less robust infrastructure of preventative care. Mateo, a professor who was born and raised in Brazil, noticed the lack of preventative care in the United States as compared

to Brazil through both his genetic heart problems and, as discussed later, his bulging disc and subsequent leg numbness. Though he attended school in the United States, Mateo maintained access to his parents' private insurance in Brazil. As a result, he often chose to return to Brazil for most non-emergent care, including preventative measures and regular health check-ins:

"So anything that was not emergency, that referred to, let's say, long-term health care, I did in Brazil, when I traveled, we're talking about my particular case, yearly appointments with a cardiologist, my family has a very bad history with heart problems in particularly men... whenever I went to Brazil, we do like, you know, yearly checkup, those kinds of like preventative health care that I always found a little bit easier."

Mateo explains that, as a graduate student with access to both Brazilian and American healthcare, he chose to return to Brazil for most issues, especially for preventative care. He continued on to emphasize that in Brazil, more tools and scans are available for preventative care:

"If you have any problem, like they will do a battery of exams. If the problem persists, right, persists. If it's not something that can be easily medicated, like a pain or inflammation or something. So in order to get that kind of like, let's say a more, a deeper comprehension of preventative health care that you would get from echocardiograms, MRIs, x-rays, endoscopies, like for example, I have, I had like acid reflux for like the longest time of my life, and I wouldn't have discovered it without an endoscopy."

Mateo's assessment of one of the differences between the US and Brazilian healthcare systems is the availability and emphasis placed on preventative care. In Brazil, he was offered and utilized a slew of scans for preventative care, leading to the discovery of his acid reflux that he otherwise would not have known about for years to come. In contrast, Mateo notes that the United States tends to require more justification for imaging. This is similar to Miguel's perspective on the US healthcare system's tendency to "wait and see", opting for imaging only when other things have failed. As explained earlier, this tendency is emblematic of the celebrated efficiency of Weber's bureaucracy, both with the metric of cost and patient intervention. By requiring more justification for imaging techniques, the US system prevents waste of medical resources and protects the patient from unnecessary interventions. A single X-ray costs hundreds of dollars due to the specialized equipment, the high amounts of energy it requires, and the labor of a specially trained technician. Additionally, the scan includes exposure to ionizing radiation with a range of approximate effective radiation doses.<sup>19</sup> Though some of these doses are only the equivalent of 3 hours' worth of background radiation, others are larger doses, equivalent to more, such as 10 days' worth for a chest xray, or even years' worth in higher-radiation scans like computer tomography (CT). As such, frequent use of these imaging techniques can add up to a significant increase in a patient's radiation exposure and subsequent risk of radiation-caused conditions, such as cancer. Acknowledging this potential danger of further harm, providers in the United States respond

<sup>&</sup>lt;sup>19</sup> Approximate effective radiation is a measurement, often in millisievert (mSv) of the radiation that is absorbed and the risk that it poses to the whole body during a scan. It is dependent on the amount of radiation that the body is exposed to as well as the sensitivity of the scanned tissues or organs to radiation. As such, the same scan in a more sensitive part of the body could yield a higher approximate effective radiation as compared to a less sensitive part of the body. (https://www.radiologyinfo.org/en/info/safety-xray)

with a reluctance to utilize scans unless necessary, opting for lower-risk interventions first. It is important to note that this tendency is not only a healthcare culture within the United States—it is federal law. Title 10, Section 20.1003 of the Code of Federal Regulations introduces the concept of ALARA, an acronym that stands for "as low as is reasonably achievable", with regard to radiation exposure across all pertinent fields, including in healthcare.<sup>20</sup> Ironically, it is this prioritization of systemic efficiency and the subsequent reluctance for imaging that is principally the point of frustration for my interlocutors, who understandably feel dissatisfaction with a system that has failed to resolve their complaints. This paradox emphasizes that the failure of symptomatic translation arises from differences in expectations between the system and the patient of the specific goals of healthcare, as well as what constitutes efficiency in the clinical setting.

Ultimately, these differing expectations emphasize the reality of insufficient communication between the patient and provider. While the provider in many cases has very understandable reasons for withholding certain procedures, tests, or imaging, these are not always adequately communicated to the patient, as seen in my interlocutors' experiences. Mateo, frustrated with not receiving the care he needs, frustratedly emphasized that he would understand if certain interventions were withheld or denied, if only the reason were explained to him:

"It always felt a little like a little bit, I don't know, they were doubting. And I had a concern because a lot of it were interactions about my back pain. I thought that they were concerned about, like, I don't know, someone trying to

<sup>&</sup>lt;sup>20</sup> Acronym definition and summary taken from the U.S. Nuclear Regulatory Commission webpage: <u>https://www.nrc.gov/reading-rm/basic-ref/glossary/alara.html</u>

go for pain meds. I don't know to what extent that was a concern that was never articulated to me... But it had, like, barriers to put, like, probably also concerns for like people asking for too many meds and not having, you know, genuine consent. Now, none of those were articulated to me, and I would be very sympathetic if someone tells me like, 'you know, I would like to wait a little bit more. Because we do have a lot of histories of people going for pain meds when they don't need them.' I would have been a very, as a patient, I'm usually all ears to doctors. I'm not skeptical of doctors. I'm like, well, if you tell me what you're thinking, like, at least I can understand why you are concerned, right?"

Mateo speculates that he was stonewalled in his interactions with primary acre because they had concerns, perhaps about pain medications, that they were not sharing with him. While it is not possible to know for certain if his hypothesis was true, Mateo's sentiment of simply wishing providers would explain to him their reasoning for withholding certain treatments or interventions is nevertheless a powerful one, and one shared by many of my interlocutors. Like many of my other interlocutors, Mateo does not truly understand why the care and interventions he was seeking were denied—and the providers did not seem to explain, at least to an adequate degree. Thus, Mateo's perspective here underscores the point that these differences in expectations of healthcare and efficiency within the system are, in reality, in large part a communication barrier. This, in turn, reemphasizes the crucial point of a previous section: language barriers in the clinical setting are not simply a matter of speaking differing languages, but of the efficacy of communication between the patient and provider during the interaction.

In this case, Mateo, the patient, is eager to accommodate and understand the provider's reasoning for withholding medical healthcare he requests; even without an explanation provided by the physician, Mateo has voiced understanding that certain interventions may be withheld due to potential risks or liabilities. His frustration with the system, then, arises not as a result of the care plan itself, but rather from the paucity of justification and explanation communicated to him. Thus, in some ways, Mateo's emphasis here of his willingness to understand and follow the rationale behind his provider's decision presents the bureaucratic barrier as a culmination of the linguistic and cultural ones. Though Mateo speaks fluent English, there is still a failure of effective communication between him and his provider—hence his confusion about why interventions he requests are being withheld. The reasoning for this is a difference in medical cultures held by Mateo (and the healthcare system he has previously experienced in Brazil) and by his physician in the United States; while Mateo's anecdote characterizes the Brazilian healthcare system as a medicalmaximizing one, in which more interventions are used with greater frequency as diagnostic tools, the United States medical culture, and subsequently his physician, takes a more conservative approach, favoring the "watch and wait" model as described above. Thus, the bureaucratic challenge of navigating the minimization of interventions can itself be analyzed as a failure of linguistic and cultural translation transcending the typical definitions.

### **Primary Care and Referrals to Specialists**

Similar themes are seen in the role of primary care and specialized physicians in the United States as compared to Latin American health systems, as minimizing referrals in the US is similarly a metric of efficiency in the bureaucratic system of healthcare. In the United States, a patient typically must see their primary care physician and receive a referral from the primary physician in order to see a specialist. However, in contrast, in Latin America, it is much more common for patients to directly see a specialist without a referring order, as seen in Mateo's experiences. In Brazil, Mateo was able to regularly visit the cardiologist for frequent check-ups on his heart without first having a visit with his primary care provider each time. This system allows for more patient autonomy since the patient can obtain a specialist's opinion if they wish. This stands in stark contrast to the system in the United States, where a specialist consultation almost always requires the primary physician—and often the insurance company—to agree that the patient's condition necessitates it. The US healthcare system highlights this as a method by which excess waste is eliminated, following the rationale that if the patient does not require a specialist consultation or intervention, it would be wasteful to provide it. As sociologist Dr. William Cockerham notes, "specialist care is usually more costly," so "the primary care physician serves as a gatekeeper to the use of specialists and is usually rewarded by keeping referrals to a minimum" (Cockerham, 135). In this way, primary care physicians serve an integral role in maintaining low levels of resource and economic waste within the healthcare system, ensuring that only patients who need specialist attention and intervention receive it.

However, this becomes a source of tension when the primary care physician and the patient disagree on what is necessary, as was often the case in the anecdotes my interlocutors shared. Crucially, as Julia's story emphasizes, primary care physicians can sometimes refuse to write referrals despite the patient's significant anxiety about their condition or, in Julia's case, direct evidence that they should be referred. Julia shares a story about a time when, as a child, she had repeated urinary tract infections. She notes that the doctors in the United States were unable to explain the reason for her frequent infections, so

her parents took her to physicians in Colombia. There, the practitioners identified a kidney issue, which she describes as the kidney "refiltering itself" such that the urine was going back through the same loops, as the cause. Upon returning to the United States, her mother took her to see her primary care physician, brought the results from Colombia, and requested a referral so Julia could receive the necessary treatment. Instead, Julia remembers her mother telling her, the primary physician dismissed the findings and refused to write the referral:

"My parents did take me to Colombia. And, you know, I got examined over there and stuff where that's when they finally were able to figure out the cause of my, my infections... And my parents, once we came back... like, told them of these results at that time... But at that time I had an Indian doctor and she, she just, she was just like, for her, she thought it was just like a normal infection that I was having... It so happened that my mom was asking for a referral for a specialist to, you know, so that I could have a treatment here. And my, what my mom tells me is like the doctor, this Indian doctor, she did not want to give the referral. And my mom stayed until in the office, in her office or in the clinic, like she was just not going to leave without a referral. And what my mom says is that the doctor just came, like had the referral and like threw it at my mom, like, 'here, take her referral.'"

Julia's story of her childhood sickness underscores the potential dangers of the primary physician as the gatekeeper to the specialists. Though the premise of the system—requiring a medical professional to verify that there is a need for specialist intervention before providing it—makes sense, this system also has the potential to bring significant risk and harm, as Julia's anecdote illustrates. In her case, the primary physician refused to entertain

the possibility of her own mistaken conclusion and insisted that a referral was not necessary. However, because specialist care in the US healthcare system necessitates a referral in most cases, the primary physician's refusal could have led to significant harmful outcomes for Julia. Thankfully, in this case, Julia's mother was stubborn enough, refusing to leave until she received the referral she needed for her daughter's treatment. Of course, it must be recognized that the physician and her behavior in this anecdote are an extreme case, and the majority of primary care physicians do not behave in such an egregiously unprofessional and disrespectful manner. Even so, Julia's anecdote serves as an illustration of the frustrations that can underlie a patient's interaction with their primary care provider. Furthermore, Julia's experience exemplifies the unequal authority in the patient-provider partnership; though the patient may express their opinion, it is ultimately the physician who decides on a referral. As a result, experiences and anecdotes such as this erode the trust and confidence between patient and provider, and the primary physician becomes increasingly an obstacle that must be cleared in order to reach the specialist who will ultimately offer relief.

This outcome is, of course, damaging to the relationship between the patient and the primary care provider, as patients increasingly begin to see specialists as the solution in the United States. Mateo speaks to this perspective through his experience with care in the United States and Brazil for a bulging L5 disc in his lumbar spine and the subsequent leg numbness. Since this issue arose during the years of the pandemic, Mateo could not travel back to Brazil to receive healthcare, and instead found himself struggling to work his way through the United States healthcare system for treatment:

"So I saw a PCP at the health center, student health center, and several times from my back, my back was getting progressively worse, I was feeling

numbness in my leg. And I would always get like, you know, 9 out of 10 cases, the inflammation just recedes. So keep doing what you're doing, do some exercises. And it was progressively worse and I would go back, I was like, it's not getting better. So it took me about six months for me to be referred to a specialist, which was the precondition of that system, right?... Only after I said, 'you know, I've been going to the Student Healthcare Center for about six months. And I don't believe I've been given the care that I needed. My leg is getting worse. And I have not seen a specialist yet. So I don't want to go back, refer me to a specialist now.' And they said, 'I'm very sorry. Here's like the referral'... Then when I saw a specialist, there was an immediate epidural. Like the specialist just did some imaging, like sent me to an imaging, saw the imaging, said you need an epidural, let's see if with the epidural it would recede."

Mateo expressed that he considers this experience with the primary care providers in the Student Healthcare Center his worst healthcare experience due to a system that seemed to stonewall him instead of addressing his severe pain and condition. However, this changed drastically when he saw a specialist:

"Then I was referred to the specialist. The specialist immediately sent me to an MRI, saw the MRI, gave me an epidural, and said, 'two weeks, we convene again. If you're feeling in pain again, we have to think about surgery,' right?... As soon as I hit the surgeon, like it was just like, he looked at the things, he did like a questionnaire, like to evaluate, and that was like quite close to a strike by hospital folks. So he said like, you know, it was a meeting on Friday, he said,

how is your schedule on Monday? So it was like that, the turnaround was so quick in comparison to the six months that I spent seeing [primary care providers]"

The point Mateo emphasizes here is the vast difference in care he experienced between the primary care provider and the specialist. During the six months he was seeing the primary care physicians, he felt as though he did not receive care. He voiced frustration at repeatedly waiting on the primary care system in the Student Healthcare Center, even as his leg rapidly deteriorated. Eventually, he managed to get the attention he needed, but only through demanding a referral. Thus, in Mateo's experience, the primary care providers acted, arguably far too effectively, as the "gatekeeper" to the specialists, as noted by Cockerham. Ultimately, Mateo's experience was one in which he experienced primary care as a delay and an obstacle to overcome before reaching the care he needed. However, Mateo emphasizes that the experience he had with the specialist was drastically different. The specialist immediately sent him for imaging and, after looking at the results, scheduled him for emergency surgery within days. For Mateo, similarly to Julia, the barrier and hindrance in the US healthcare system is simply the primary care provider and the challenge of obtaining the needed referral. When I asked how this was different from his experiences in the Brazilian healthcare system, Mateo explained that the specialists in the United States offered excellent care, like in Brazil, but American primary care providers did not seem to have the same level of care, especially preventative care:

"I think as soon as you hit specialist, basically to sum up, as soon as you hit specialist here, with a good health insurance, I feel like the treatment that you're giving is really good for a specific problem. But the preventative stuff

that I was very used to, that would sometimes enable me, I never had to be on the surgery table for my back problem for 15 years. And I think that largely because of the preventative health care that I had access to. Every time that I would have like my disc, my L5 disc would be bulging, I would start physical therapy and etc. And having access to x-ray and MRIs as preventative measures was something that made the experience with the Brazilian private health insurance quite positive."

Mateo notes that in Brazil, he had access to a wider range of preventative interventions offered by his primary care providers, which he believes played an instrumental role in keeping him from needing surgery before. In contrast, the primary care available in the United States seemed ineffectual to him, asking him to return repeatedly for several visits with little to no intervention, and no referral to a specialist. As such, Mateo had to advocate for his own care in the United States, demanding a referral like Julia's mother did, in order to get the attention his condition required. Thus, the anecdotes Julia and Mateo shared emphasize the frustration and even negative health outcomes that can be caused by minimizing referrals, as well as the difference between primary care efficacy in the United States and Latin American health systems.

## **Neoliberalism and Patient Satisfaction in Health**

Another metric of success and efficiency privileged in the intersection of Max Weber's bureaucracy and healthcare is patient satisfaction. Increasingly, patient satisfaction, measured through a slew of surveys, feedback forms, and questionnaires, has grown as a marker of success. Though this new trend seems to have emerged as a helpful tool for the consistent betterment of hospitals and healthcare facilities, crucially, there is limited evidence that high patient satisfaction scores are linked to better health outcomes (Al-Abri, 2014; Tevis, 2015). Even so, they continue to be utilized throughout many health systems, with patient satisfaction scores even becoming increasingly tied to federal funding.<sup>21</sup> In this section, I analyze the emergence of measuring patient satisfaction scores and their effects on the healthcare field.

Liberalism, the political and moral philosophy that predominates in the modern Western world, naturally exerts its influence and principles over all spheres of life, including healthcare, in the United States. As such, it is necessary to adequately understand the central principles of liberalism and their evolution. Liberalism and its founding ideas were first proposed "in Western Europe in opposition to feudal society with the aim of redefining the limits of political authority" (Schiller, 2015). Thus, liberalism and its subsequent moral, political, and economic frameworks are predicated on the principle of freedom and autonomy of the rational individual; taking the rational individual as the basic unit of society, liberalism prioritizes the rights and autonomy of the individual to make free decisions for their own benefit. As a result, the governments "must be powerful enough to secure individual liberty but limited enough that it cannot impose restraints on individuals" (Schiller, 2015). In the context of the economy, this meant an emphasis on a laissez-faire market with limited restrictions, such that the government's regulations would not influence or restrict the economy, but rather provide the basis for it to flourish. Neoliberalism arose in the late 1970s and early 1980s as a reactionary response to classical liberalism and its

<sup>&</sup>lt;sup>21</sup> The Centers for Medicare and Medicaid Services developed the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) in 2002. Starting in 2012, however, HCAHPS scores have been factored into value-based incentive payments through the Hospital Value-Based Purchasing program. <u>https://www.cms.gov/medicare/quality/initiatives/hospital-quality-initiative/hcahps-patients-</u> <u>perspectives-care-survey</u>

gradual decline in popularity. Neoliberalism introduced new ideas, especially with regard to the economy, positing that the market cannot flourish when left alone; rather, it is the responsibility of the government to ensure through policy the ideals of "competition, free trade, and rational economic action on the part of every member and institution of society" (Brown, 2003). Neoliberalism also puts forth a normative claim that all aspects of society ought to be "submitted to economic rationality"; simply put, all spheres of existence and society are evaluated through a lens of the market and profitability (Brown, 2003). This shift in a societal framework leads to a gradual erosion of community values as each individual is expected to make decisions based on rational profitability for themself. Similarly, in following the neoliberal principle of market rationality in all aspects of society, toward the commodification of services such as healthcare.

With neoliberalism and its principles permeating all spheres of life, clinical systems and encounters are reshaped to accommodate the neoliberal model of rational economic action. As such, healthcare is increasingly treated as a good to be purchased by the consumerpatient. This new perspective is reflected in the prevalence of surveys, questionnaires, and sampling techniques designed to measure patient satisfaction scores. As mentioned above, these scores have a wide-ranging impact on the facilities that collect them, from funding to facility reputations and standing with the federal government. Importantly, however, multiple studies have found that the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) used by the federal government are not consistently correlated with favorable health outcomes. One study exploring the correlation between high HCAHPS patient satisfaction and surgical outcomes found "very little correlation between 'traditional' surgical outcomes and patient satisfaction", noting that "the only factors that correlated with
enhanced patient satisfaction were high hospital and surgical volume and low risk-adjusted mortality" (Tevis, 2015). Aside from high hospital and surgical volume and low risk-adjusted mortality, other metrics such as rate of surgical complications and readmissions were not correlated (Tevis, 2015). This data suggests that, at best, patient satisfaction is weakly predictive of some health outcomes. Consistently, similar findings were replicated across different studies and in different settings, emphasizing the overarching theme that patient satisfaction is influenced by a wide range of factors, including those that are outside the control of the facility, and as such, cannot be taken as a strong predictor of health outcomes, or as a metric of the facility's performance (Chen, 2019; Cohen, 2017; Tevis, 2015). Given this consensus, it becomes increasingly clear that utilizing patient satisfaction scores as a metric encourages providers and systems not to improve their quality of care, but to better market to and appease the consumer-patient; in short, providers are asked to take on the additional consideration of how their decisions and actions will affect the patient's view of them.

In some cases, this pressure could lead to positive changes; as seen in many previous anecdotes shared by my interlocutors, there are multiple instances of providers behaving disrespectfully toward patients, or acting without regard for the patient's desires. However, this pressure can also set a dangerous precedent, encouraging physicians and providers to prioritize the patient's opinions, and subsequently withhold concerns to preserve favorable impressions from the patient (Cohen, 2017). Miguel noted the possibility of encountering this himself when he spoke with me about his mental health, voicing confusion as to why no provider in the US identified what in hindsight seems like a clear struggle with anxiety: "And anyone, anyone would have noticed that I was having anxiety problems. I mean, and I had this doctor at Emory that was a very good doctor. In hindsight, what I see that she didn't do and I think that anyone would have probably done is that she never insinuated that maybe I had to see a psychologist, you know, or a psychiatrist. But I tell you, I was a mental case. I was crying in the, you know, in the doctor's office. You know, I didn't know why I was crying, you know. But nobody ever said anything, you know. And I also had a trip scheduled to Argentina, you know. And I saw my friend, you know, in her office, you know. And my friend said, 'man, you need mental health medication. So, you need to start seeing a psychologist and a psychiatrist.'"

In this quote, Miguel emphasizes the contrast between seeing a primary care physician in the United States and Argentina, specifically concerning his mental healthcare. In the United States, Miguel heard nothing about mental healthcare despite noting that he had experienced breakdowns, even in the physician's office. In contrast, when he arrived at his friend and physician's office in Argentina, she immediately pointed out that he had a condition that needed to be assessed and medicated by a professional, even pointing out that neglecting this issue would impact not only him, but his family as well. When I asked why he thought his primary care provider in the United States seemed to miss what, in hindsight, seems so obvious, Miguel offered his hypothesis:

"And my primary care physician never mentioned it. And I don't know how anyone can miss something like that. Or maybe she didn't miss it, but there are regulations that she could have gotten in trouble for mentioning something

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like that. Maybe mental health issues are very sensitive. Frankly, up to today, it's a mystery to me how the primary care physician doesn't say, 'hey, have you considered seeing a therapist?' You know, and I wouldn't have considered such a comment as insulting, you know. Or, you know, maybe some people think, 'oh, my God, she thinks I'm crazy,' you know."

Miguel considers it possible, albeit somewhat inexplicable, that the primary care physician in the US was concerned about offending him by referring him to mental healthcare. Another possibility, similar to Miguel's theory, is that the provider simply did not consider his mental health within her authority due to the US cultural tendency to divorce the physical and mental realms. Of course, there are numerous unknown variables in this exchange, from the physician's perspective to the influence of mental health stigma within the United States; there are any number of alternative explanations, such as that the physician simply didn't feel his behavior warranted a mental health referral. Additionally, her perspective is likely a nuanced one, comprising a multitude of factors together. Even so, Miguel's wondering of whether the physician withheld this concern out of consideration for his reaction and potential offense is justified, especially within the context of healthcare systems leaning increasingly on patient satisfaction metrics. Miguel's anecdote then serves as a warning of the types of conditions and concerns that could go unvoiced due to this type of pressure on the provider, and the provider's need to comply with a system that places the desires of the consumer-patient above all else.

Miguel's concern reflects the possibility of the evolution of the patient-provider relationship into a consumer-market one. In hesitating to voice potential concerns, Miguel's provider reinforced the neoliberal analysis of all spheres of life through the lens of

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profitability. On her part, it would likely not be profitable to raise concerns of mental health issues at the risk of angering or offending her consumer-patient. As such, Miguel's interaction with his provider reemphasizes the influence of neoliberalism, market rationality, and bureaucracy in healthcare, as there is increased pressure for clinical encounters to be tailored to the individual consumer-patient's wishes, even at the cost of high-quality healthcare.

## Conclusion

Healthcare is widely recognized in the United States as a broken system, with widespread dissatisfaction. In this study, I focus on some members of the Latinx community and how they interact with and experience the healthcare system, as they are the largest community of immigrants in the United States. Though there is no shortage of literature documenting poorer health outcomes for people of color, including for the Latinx community, I encountered an interesting phenomenon in my interviews that lacked significant presence in academic literature: almost all of my interlocutors regularly sought healthcare outside of the United States.

Through this study, I've explored the dissatisfactions of my interlocutors with the US healthcare system, comparing their experiences in the US with Latin America to highlight the stark differences between the healthcare systems of the United States and Latin America. In this comparison, I've highlighted some key differences in my interlocutors' experiences. Overall, my interlocutors felt more at ease seeking healthcare in the countries they and their families are from due to a variety of reasons, which I have categorized into linguistic and cultural comfort as well as ease in navigating the bureaucratic system. In both linguistic and cultural terms, my interlocutors, immigrants and children of immigrants alike, explained that they felt more easily understood in their home countries. While this was unsurprising for immigrants who were accustomed to the culture of their home countries and mostly spoke Spanish, the consistent preference even among children of immigrants who were born and raised in the United States was an unexpected finding. This surprising result indicated, as explained by my interlocutors, that bilingual patients fluent in English sometimes still preferred Spanish as a matter of comfort and ease in a more familial and close language,

especially when discussing health matters. My interlocutors also emphasized the importance in differences between the bureaucratic systems of healthcare in the United States as compared to Latin America. Through their evaluations of the US healthcare system's inefficiency, I saw the US healthcare system and its goals contextualized within the influences of Max Weber's bureaucracy and neoliberal economics. As a result, my interlocutors encounter significant barriers in the US healthcare system and opt instead for healthcare from Latin America, citing efficiency in reaching a resolution or cure for their conditions as a driving factor.

Importantly, this study is not intended to portray the systems of the United States as inferior or otherwise lacking in comparison to its Latin American counterparts. Instead, this investigation takes the perspective that understanding the differences between the two systems as well as the views of people who have experienced both could be an interesting lens through which to analyze and identify potential areas of improvement within the US healthcare system. Of course, Latin American health systems and institutions are by no means flawless, and this is not the central claim of this investigation. Rather, through analysis of my interlocutors' experiences, this investigation presented an examination of barriers that create distrust between patient and provider, ultimately informing their decisions to seek healthcare abroad. Additionally, though many of my interlocutors expressed largely negative and, at times, frustrating experiences in the United States, but favorable ones in Latin America, it is important to acknowledge that this is not a universal perspective. Latin American systems of health can be overburdened and unjust, facing problems similar to those in the United States. Thus, my interlocutors' positive experiences with healthcare in Latin America may not necessarily be shared by people who live in those countries. Instead,

there are a variety of nuanced factors that likely contribute to my interlocutors' positive experiences in Latin America, including but not limited to their social status and their economic class. This is a crucial point to recognize, as many of my interlocutors occupy a position of relative privilege, even in having the documented legal status required to leave the United States to seek healthcare abroad and return. Furthermore, my interlocutors may hold certain privileges within their own countries which grant them increased access to better or more efficient healthcare and systems than other individuals and residents in the country.

Finally, it is essential to recognize the limitations of this study. Due to a small sample size of 12 interlocutors, as well as due to the critical point that the Latinx community is not homogenous, this study is not meant to be generalized to the larger community. Though my interlocutors came from a wide variety of backgrounds and contexts, they and their experiences cannot in any way be considered representative of the larger Hispanic/Latin/Latino/Latinx community; to do so would be to contribute to erasure of other perspectives and voices, including those of undocumented people and people of indigenous descent, for example. As such, one future direction for this project would include expanding it to a larger and more diverse sample population, as well as a longer duration, such that its results may have more investigative credibility. Other future directions include deeper comparisons between the healthcare systems in the United States and Latin America, and a comparison of private vs. public healthcare in the two contexts, especially in an examination on the differences between bureaucratic frameworks. Furthermore, a deeper exploration of the intersections of linguistic, cultural, and bureaucratic barriers could yield further significant results. However, even given these limitations, this study has provided

valuable insight into the issues of communication, linguistic and cultural differences, and bureaucratic hurdles interact to foster distrust and hostility toward the US healthcare system. Ideally, these preliminary observations will lay the groundwork for future investigations into and possible solutions regarding these barriers.

# Appendices

## Appendix I: Semi-structured Interview Guide and Questionnaire General Background

- 1) Where were you born? How long have you lived in the United States?
- 2) What do you do for a living?
- 3) When was the last time you visited a clinic or saw a doctor? About how often do you go?
- 4) How do you decide when to go to the doctor?
- 5) Have you experienced a recurring injury or sickness? Can you describe it?

## **Experience in Healthcare Systems**

- 6) Have you felt disrespected by healthcare professionals and healthcare settings before?
- 7) What were some frustrating experiences with healthcare professionals?
  - a) What questions were you asked, and what about them frustrated you?
  - b) What did the healthcare professionals do, and what about it frustrated you?
- 8) What questions would you like to be asked in healthcare settings?
- 9) What can healthcare professionals do to make you feel more comfortable?
- 10) What do you take as a sign that your healthcare professional is listening to you and values what you say?
- 11) Was there a time you hoped or expected your healthcare professional to do something that they didn't do? Why do you think they didn't do it?

## Healthcare Experiences Abroad

- 12) Have you ever sought healthcare outside of the United States? Have you ever traveled specifically for healthcare?
- 13) What made you decide to seek healthcare outside of the United States?
- 14) How do you think doctors in the US and doctors in your/your family's home country are different? Did they treat you differently?
- 15) Why do you think your experiences in the US and abroad are so different? What does each system do well or not well?

## Language Barriers

- 16) Does language factor into your choice to seek healthcare outside of the United States? Why does this matter to you? (especially if interlocutor is fluent in English)
- 17) Have you ever encountered a healthcare provider who doesn't speak your preferred language? Did you feel comfortable? How did you navigate this?
  - a) Did someone interpret for you? If so, who?
  - b) Did you feel like that person did a good job?
- 18) Have you ever had to interpret for another person in a clinical encounter, such as a family member or otherwise? How old were you? How was that experience?

## **Cultural Barriers**

19) Have you ever felt like the doctor doesn't understand your culture?

- 20) Has there ever been a time you've felt like the provider has made assumptions about you based on what they think your culture is?
- 21) Does your culture contribute to your decision to seek healthcare abroad?
- 22) Do you use cultural/home/traditional remedies? Do you prefer this over biomedical medicine, or use them together?
- 23) Do you think biomedical medicine is reliable and good for you? Why or why not?

## Appendix II: Sample Interview Transcript

#### Ме

Great, so we are recording now and then just because I have to for IRB with every study, do you consent to participate in this study?

## Julia

Yes.

## Ме

Okay, wonderful. Then we can get started. Can we just start off by like tell me a little bit about you and like what you do and things like that?

### Julia

Sure, so I'm [NAME REDACTED]. I recently, last year, I earned my doctorate in occupational therapy and just in December, I started working with [UNIVERSITY] at the [REDACTED] Lab, and a lot of my work is going to be working with Spanish-speaking families and trying to do, you know, adapt, help adapt their studies so that we can, you know, have more participants, diversify.

But I usually, I beforehand, I worked with Babies Can't Wait, Georgia's early intervention program. So my life has always centered around birth to three and that's what the population I enjoy the most. And so, yeah, I'm just now getting more situated and, you know, my OT career and I have a big passion for, you know, helping the Hispanic community, Spanish-speaking families.

So yeah, I've been blessed to be bilingual. I'm Colombian. I came to the United States when I was a year old, but I usually traveled every summer back home. And I've always just been one to, my parents really instilled in us to keep in touch with our roots and our culture, the language.

We didn't speak English at home. It was strictly Spanish. And I really am grateful and thankful that they saw the importance in that. So yeah, that's a little snippet of my life.

## Ме

That's awesome. And so do your parents speak English or did they choose to have a Spanishonly home?

#### Julia

No, my father, when he was younger, he came to the States to study English, strictly English. And then once it was, they decided to finally come to the States, my dad was, you know, English speaker as well, but my mom wasn't really. But throughout the years, it's been almost 30 years that we've been here, she's learned the language.

And again, as an older person, it has been more difficult for her. And, you know, she still has her accent and there's still like difficult things to understand. But, you know, for the most part, she is an interpreter. She can defend herself and help others. So. I have an older sister who came when she was 10 to the States and, you know, she was younger, so she was able to adapt to the language much, much easier. And then, of course, I came at a very young age. So, yeah, you obviously learned the English quick as you do when you go to a strictly English-speaking education.

But yeah, it was my parents' choice to just make sure we were still learning the language and keeping that true to us.

### Ме

That's good. Yeah, that's really important. And so, what is your work with the lab that you mentioned? What are you what's the project you're working on?

#### Julia

So we're working on a project with babies with cerebral palsy. And in many of their cases, they have usually like a weaker side. And so we have this kind of intervention going where we're trying to do intervention to get that weaker arm moving. So just doing certain therapy strategies.

And a big part of it also is, you know, parent education, because, you know, they're the they're the main ones. They're the one of the most important part of the team for their child. So, so, yeah, we we it's kind of a two part thing. And then, again, my big part is that they did get a diversity supplement.

So that's what we're trying to kind of adapt this English study to a Spanish-only study and working on first doing like more focus groups and like we have an advisory board and kind of like you interviewing so we can make sure we, you know, culturally adapt this study so that I can benefit these other families.

#### Ме

Yeah. And what are some of those linguistic, I mean, linguistically, obviously, English to Spanish, but culturally, what are some of the differences you see in some of the adaptations that you have had or you anticipate having to make?

#### Julia

Well, definitely like the language, just passing it over to a Spanish only study and just really taking into account, you know, some of maybe that health literacy, maybe some of that, you know, that Latino stigma or cultural stigma and like maybe values.

And as of now, for sure, just like language is the biggest barrier. And probably like trying to instill that trust in parents so that they can trust us as providers that we know, you know, these diagnoses, these conditions, and that we were prepared to teach them along the way and help their child progress and their development.

So, you know, it's like still a work in progress to see what, you know, how to better help these families. But overall, that's kind of the biggest ones.

#### Ме

Awesome. Yeah. And what are some of the things that you think go into building that trust, either from your experience, just like as an OT or from your experience personally with the healthcare system?

### Julia

I think a lot of times as Hispanics, we can tend to be more reserved. And my experience is like sometimes you kind of have to pull teeth to like get parents to really share and communicate. And so, you know, it goes as far as like the basics of like not really asking, of asking, you know, more open-ended questions.

And again, like sometimes going that extra mile as a provider to like really know the work so that you're more prepared to ask better questions in the midst. So sometimes it's, you know, you could probably have a script, you could have, you could probably have like questions set, but kind of have to think on your feet or in the moment where you're, you, maybe the family isn't as engaged.

So kind of keeps you on your toes to like really have like that active listening so that your parents or your families are more willing to participate. And I think, again, just building that rapport is going to go slowly, because sometimes it's not just so quick to build that trust. But in those, that first impression, you can, where you can, yeah, where you can just kind of show that compassion and understanding and that makes them more willing to open up and trust you more. So yeah, that's kind of been my experience.

#### Ме

Yeah, that makes a lot of sense. And so, what do you think, because you mentioned like good questions and bad questions, like what do you think, what do you think is one of the differences between those?

#### Julia

You know, like just a very simple question is just like, does your child sleep? I mean, that can be like, yes or no, but so you gotta be like, okay, what's their sleeping routine? Like, 'what do you do before you go to sleep?' Or, 'what do you do?' You know, 'what's the routine leading up?' Or, you know, that's just very vague, but yeah, I don't know. There's so much in a child's development that you can ask. So you just want to strive away from like them just responding yes or no.

You know, 'does your child like to play?' You know, that could be like, 'yes or no,' but it's like, 'okay, well, what are their favorite toys?

Or, you know, 'what's in their favorite part of their routine?' Or, you know, 'what are the things that they dislike?' And that just gives you a better picture.

#### Ме

Okay, that makes sense. So more open-ended questions. And like you were saying, openended questions instead of like, 'yes, no.'

#### Julia

Yeah, for sure.

#### Me

I see. And then so shifting into like your personal experiences, only if you want to talk about it, of course, what have your personal experiences with the healthcare system been? Have they been like largely positive, negative? So-so?

#### Julia

I would say maybe so-so. When I was younger, I had like a bad kidney issue. One of my kidneys like was like kind of refiltering itself and that was causing me to have infections. And I was obviously here at a young age, but doctors here weren't really giving my parents answers to what was going on.

And it wasn't until I did go, my parents did take me to Colombia. And, you know, I got examined over there and stuff where that's when they finally were able to figure out the cause of my, my infections. And again, it was just like, you have one of your, I'm drawing a blank now that you're asking me this, but again, it's like the urine was like going back to the same, you know, loop or whatever.

So it was just kept giving me infections. And my parents, once we came back, you know, that, that's, that was just a short trip over there. We got answers, but we came back here and my parents like told them of these results at that time. And this could be like a stereotype of, you know, different ethnicities, like not having trust in other ones.

But at that time I had an Indian doctor and she, she just, she was just like, for her, she thought it was just like a normal infection that I was having. And she's just like totally dismissed like what the doctors found in Colombia. And it was kind of like, you know, 'over there, they don't know anything,' you know?

So that's just kind of, it's definitely like disheartening, like when people are kind of bashing your own, your own culture and stuff. So, but, and it so happened that my mom was asking for a referral for a specialist to, you know, so that I could have a treatment here.

And my, what my mom tells me is like the doctor, this Indian doctor, she did not want to give the referral. And my mom stayed until in the office, in her office or in the clinic, like she was just not going to leave without a referral. And what my mom says is that the doctor just came, like had the referral and like threw it at my mom, like, here, take her referral. So, you know, it was just no compassion or like trying to understand or maybe a pride thing, like that someone else figured out in another country, who knows what went through their minds. But, you know, that's not what you would, that's not what you hope to expect, especially when it's your child's health.

So, so yeah, that was, you know, after that, getting the referral, I needed all that. I did my treatment and I was fine and luckily never had issues again with that. But yeah, I mean, I would go to Colombia usually every summer with my parents and they would just also take advantage of going to the doctor, getting tests done, you know, whatever problems were arising in that moment.

And I would do the, you know, I would tag along and do the same. You know, also I had as a teen, a late teen, I was having some hormonal issues and in Colombia, that's where they tested me and like found that, yeah, my hormones are a bit out of, not too well.

And they did put me on birth control with like a low dosage of the hormones that I needed to balance them. And for a long, a couple of years, I, you know, I was purchasing those pills in Colombia because they didn't have anything similar here in the States.

And like this, I really liked it because it wasn't something that gave me like heavy symptoms, like you would think. So again, I was very low dosage, but it managed to do the work. And so, but again, after, you know, it does become a hassle, like if maybe, you know, I'm not going as often and I'm running out and things like that.

So, and yeah, a lot of times my mom also suffers from migraines and like, sometimes they had medications from Colombia that seemed to work better. So again, she was having to

purchase, you know, out of pocket medic, you know, and necessary, and it was more so, you know, less expensive in Colombia.

So she was getting her medication for her migraines for a good while over there. Actually, my mom does get Botox for her migraines because they're so severe and it wasn't in Colombia was where they were able to first give her the Botox because here for a long time, it was an issue with insurance and the, the expense of it.

It's, you know, sometimes it's not, again, covered all the way. And then recently she just got approved about last year, two years ago. And here they have like very specific points to where they need to go. they can apply the Botox. But my mom, like again, very severe. She needs some Botox like on her jaw because that's where a lot of the pain gets concentrated. But unfortunately here they don't, the insurance doesn't cover that to put it on the jaws. So it's just like, okay, she's getting, yeah, it's just like the migraine just kind of radiates to her jaw and stuff.

So that's like the biggest part where she needs it, but insurance won't pay for it. Part of what the protocol for the Botox is not doing it like on the mandible. It's just like certain parts of the head, the neck, the back, so anyway.

### Ме

So, other places it would be okay, insurance would cover it?

#### Julia

No, I think like this, well, I'm not sure. It just recently, we recently were able to get with an insurance that does it. So I don't know about the other ones. But in Colombia, she would just put, again, medical with the licensed doctor. And there wasn't that issue of like, restricted of where I can put it or not.

So little things like that that just are different. And I don't know the logistics or like the indepth of why or why not. So, and yeah, I mean, I would say I'm lucky that I come from a country where medicine has been pretty good and well and trusted.

And even last year, I always felt like I was having a thyroid issues, like hence my hormone situation. And it wasn't until last year, I went back to Colombia and getting tests done. Like, and again, you can easily just make appointments, not necessarily needing many referrals and all that.

And yeah, they did find a, they ordered a ultrasound on my thyroid, which here like they had never done. And yeah, they found like an abnormal node. And I did, and I even got a biopsy and everything over there. And luckily like it was benign. So it's just something I need to monitor.

But again, it's like, it also takes an effort to go to your country and all that stuff. And all this time that I'm 29. And so all this time, like that wasn't pop, that wasn't expressed or like that wasn't an option of like, hey, let's like look further into it.

Let's do an ultrasound. So yeah, it can be hard, but luckily, I'm able to get answers over there. Yeah.

#### Ме

Interesting, thank you for sharing so much. I really appreciate it. So do you still, it sounds like you still also go to Colombia for healthcare? Like you wait until you're going back and then you get things done there?

## Julia

Yeah, I mean, more so, especially last year, I didn't have health insurance for a good while. So again, just, it would have been so much more out of pocket here trying to do tests or just go to the doctor. And so it just worked out better if I had, going to Colombia and just getting all my tests done.

So, yeah.

#### Ме

So yeah, I mean, that makes a lot of sense. So do you go to Colombia like for healthcare or are you going there to visit family and then you also get healthcare while you're there?

#### Julia

Both, like usually vacation. I just go for vacation usually for me the summertime and yeah, vacation, family. And then I'm already there to, might as well do my medical stuff if needed. So it's not always, but if something comes up here, I'm like, let me just get it checked out over there and see what they say.

So yeah.

#### Ме

And do you think your parents started doing this after what happened when you were really young or were they doing it before that too?

#### Julia

Well, I mean, we moved here when I was young. So I don't, they didn't live here beforehand. So I don't know if like, they would have, I mean, maybe, I'm sure like they would have still, maybe the language too. Like my mom wasn't necessarily at that moment when she moved here.

She wasn't fluent in English. So I'm sure she would have just preferred a Spanish speaking provider. So, but yeah, I mean, even like I had LASIK surgery when I was in my early twenties and I got it in Colombia. We had like a family doctor who had done the procedure to like a lot of my family members and it was just a trusted doctor.

And so by the time I was ready to have LASIK, you know, it was better to get it over there. And, you know, my parents have had a lot of dentists. I mean, dentists here is kind of definitely expensive and, you know, it's a separate insurance here. So, you know, my parents have done a lot of like dentist appointments to Colombia.

Like that, even I got my, I went to the dentist back when, last summer and got a cleaning and all that. So it's just like, if you're not, it's just like, if you're able, then you're, you know, privileged to kind of get all that stuff done and you just might as well take advantage.

#### Ме

Yeah. That makes sense. Cool. Do you know how old you were when that story happened where you had like the kidney and it was going a little bit backwards?

#### Julia

I was about four.

## Ме

Do you remember anything about it?

## Julia

I remember, so, like being hospitalized over there and I always complained of like back pain. It seemed odd for a little girl to complain of back pain. And, yeah, it just got to the point where I just, you know, the doctors told them like, there was like, if you had waited longer, like in Colombia, when they finally tested me, they shared that if I had, if my parents had waited any longer, there was a chance that I was going to lose that kidney.

Yeah. So that was a shock because, you know, my parents did try here and they were just kind of turned away and they weren't taken serious. So, yeah.

I think also like the persistence of a mother or a parent and maybe like sometimes that motherly intuition. And I think, but I think as part of like the Latino culture, I think we can be very more upfront also. So, and persistent and like finding ways to like get answers and, you know, finding ways to like get answers.

So just how my mom just stayed in that office until she, you know, got her the referral. So, yeah.

#### Ме

I see. And I know, so, you know, you were four, you don't necessarily like remember everything, but now like listening back to your parents, telling that story of what happened when you were four and also similarly like taking into account when you were a little bit older and you were talking about your hormone problem and how like doctors here like didn't really listen to you and didn't really do the scan.

Like they didn't do the ultrasound of your thyroid like they did back in Colombia. I'm just curious, why do you think they like wouldn't do it? Why do you think they wouldn't just scan you and see what the problem is?

#### Julia

Um, I mean, I wouldn't really know why. I mean, if, you know, it might be like a, I could only guess like if it's just like overwhelming with a bunch of patients maybe or just not thinking it's necessary or, you know, not really weighing all the options or, you know, maybe the easy way out.

Or, you know, again, like luckily like I haven't, from my hormone situation wasn't like something so severe.

#### Ме

Right.

## Julia

So maybe it was just like, you know, it'll balance out, you know, your late twenties. So I don't really know, you know. I, I mean, I think for the first incident of my kidney situation, like I think that was just, you know, not very, again, like a compassionate, like holistic doctor to, you know, kind of disregard a family and like where they come from.

I'm just kind of putting a stereotype of like, you know, a Hispanic culture that they don't know anything. And, you know, that's definitely not true. Like all cultures have things to offer.

## Ме

So, yeah. Okay. Yeah, that makes sense. I just asked because yesterday I gave a work-inprogress presentation, like to the Spanish department, and all the professors were there and everyone has, like, everyone has an opinion on the healthcare system and, like, why, why we have what we have.

So I was just wondering if you had one too, like if you had an opinion of like why you think like you encountered, you know, like the issues that you have and like, it's easier in Colombia to get health problems resolved. But if not, it's okay.

#### Julia

Yeah. I mean, I think in your own country, there's like just more comfortability. You know, you're speaking your language and, you know, you know, maybe those cultural values are more considered. And I mean, I think that's something big on the U.S. that they have to, as providers, like being more like culturally, having more like cultural humility. You know, at the end of the day, the U.S. is a big melting pot and, you know, it's not just learning the perspective of Hispanics, but a lot of other cultures as well. So, you know, there, it might be, there's definitely more on a plate, I would say of a provider here in the States where in Colombia, you know, you're more probably just seeing Colombian patients. So that might be a factor. I don't know if it's like major or minimal, but perhaps.

#### Me

No, that makes sense. That's, that is something that, yeah, that makes sense. I forgot my next question. So, oh yes, I remember now. So you mentioned like language and culture and comfort. And so you came to the United States when you were really young and you speak fluent English.

I'm curious though, because it sounds like language and culture still play a significant role. I mean, of course you are still Colombian and like your first language was still Spanish, but I'm kind of curious if you could explain to me further how language and culture play a role in your healthcare experience, considering you're not like, you're not someone who doesn't speak English at all, for example, or who has just crossed into the United States and is just learning the culture.

I'm a little bit curious if you don't mind.

#### Julia

Well, as far as language, like I'll still think in like both languages. And it's like, sometimes I'm just like, it's like that Spanglish in my mind.

Ме

Yeah.

Julia

And like, for example, a lot of issues I talk to my parents about and it's in Spanish. And so that's why I guess maybe if I go to Colombia, like I'm more comfortable sharing because I'm already explaining it to them in Spanish. And like, it's ingrained in my brain that, I have all the words in Spanish.

And then maybe if I'm already here in the States, like, you know, I'm thinking in Spanish and I'm having to like think the English version of it. So maybe it's just like the way my mind works that I'm like maybe thinking in Spanish at one moment, thinking in English or like, even for example, we had a focus group the other day and it was in Spanish, but we were taking notes.

Like us providers were taking notes of what was being said. And we agreed that we would write the responses in Spanish. But in the moment, like I was writing a lot of times, like I was thinking like the English word and not the Spanish word. So yeah, I think it's just like a more personal thing or just like thinking both languages.

But personally for me, like the language hasn't, again, been like such a big barrier. Cause again, I can explain what I have or, you know, my concerns in English easily here, but luckily I can also do the same in Spanish. So, yeah.

### Ме

Okay. That makes sense.

### Julia

And I mean, I will say, like, as a Spanish, a Spanish-speaking person, in my case, who learned it so young and also English so young, but because I'm here living in an English-speaking country, you know, there are times I felt like my Spanish has lacked, or like, oh my gosh, I already forgot, like, I knew how to say these words, and then, like, I forgot, or, you know, because it's not all the time you're speaking your language, so.

#### Ме

No, I definitely get that.

#### Julia

Yeah, so it also takes, like, an effort for me to, like, still keep up with my language, and, you know, like, I've seen the value in it, so, like, I don't want to lose it either, so.

#### Ме

Yeah.

#### Julia

So I don't know if it would have been different, like, you know, someone growing up in a Hispanic country and, like, also knowing English, like, maybe their English isn't as used compared to Spanish, so.

#### Ме

Yeah. Yeah, that makes a lot of sense. And so do you mind if I ask, like, when you go back to Colombia and you seek out health care, is it, like, public health care or is it private health care? I'm not really familiar with how the system works.

## Julia

I mean, we, it's just kind of like, I don't necessarily know if it's, like, private or public. I mean, I guess it's a public of, like, just finding a doctor and, like, calling them and, like, hey, I want to, you know, see you or I need to set up an appointment.

I, like, because I was born in Colombia, like, I have, I still have a Colombian citizenship, so I have, like, my ID number, like, that's big in our country where we have, like, our, your memorized ID-for-life number. So, you know, making an appointment, like, that's all I need. It's just easier. I don't know if, like, someone who's not. Well, my younger sister was born here. You know, maybe it wouldn't be so hard as long as you have an ID or something. And, I mean, I would say maybe there's, like, a preference for, like, Americans.

Like, they know a lot of Americans go to, like, these countries to get procedures done. And, I mean, you might know, like, Colombia is a big, you know, plastic surgery country. So maybe that's not really that big of an issue. But, yeah, like, all the times it's just, like, if you found someone or, like, family that knows someone and you just make the appointment and, like, that's kind of it.

The one thing that was kind of stressful the last summer that I went, I guess a lot in our, in the Spanish-speaking country, in these Latin American countries, they use the WhatsApp a lot.

#### Ме

Yeah.

## Julia

Which I don't necessarily use that here. I mean, I just, I think you and I both agree we just do text messages and whatnot. But not, we're not, like, avid, at least I'm not an avid, like, WhatsApp. Yeah. And so a lot of, like, the communication or, like, registering things was done through the WhatsApp.

So that was just a weird experience for me. It wasn't really like, oh, go to this website or create, like, this portal. Like, the communication was just more like, and a lot of times it was just kind of difficult because they had, you know, you would try to call, call their numbers, whatever.

But then they direct you to, like, use the WhatsApp. And they had, like, kind of, like, automated messages and, like, that got you through the steps. So, like, that was kind of, that was a little bit annoying for me in my experience. Because, like, I just call, you know, I call an office and I want to make the appointment and they're like, sure.

Or again, it could be easy to, like, have a general portal. So, again, the WhatsApp was just too much for me. Like, it just felt like a mix of, like, personal, you know. Yeah. Personal contacts, like, messages and then, like, all these, like, medical messages and things like that. So.

## Ме

It feels a little weird. Yeah.

## Julia

And also, like, I'm just thinking of this right now, like, getting, like, test results in my experience, like, pretty, pretty quick. Not, not really something of long extent, but that's just been my experience. I don't know.

#### Ме

Yeah. Like, getting results faster. Yeah. Interesting. And I was actually going to ask something kind of related to that. Like, do you feel like it's easier to get an appointment in Colombia than it is to get an appointment here in the U.S.?

#### 00:38:26 - Julia

Um, I mean, perhaps because, like, I would travel in the summer, you know, maybe two months, you know, more so when I was younger. And then, you know, already being over there, just calling to make the appointment and something would be available and like, you know.

#### Ме

Right. So, I mean, like, in terms of scheduling, like, like, are they more available?

#### Julia

I mean. Yeah, more so. I mean, here, like, I just, you know, a few weeks ago, I made my I try to make my appointment for a physical. Hence, like, I'm a new employee and all that. So I would need a new physical and like, I don't have that appointment until June.

Because there was available. So, you know, I guess everybody's everybody. A lot of people are just doing their, you know, their annual appointments, you know, start of the new year, new insurance or like insurance kicks in. So, but I mean, for the most part, it's never been really an issue scheduling.

You know, I don't really remember any times of like, dang, I couldn't see the specialist or this doctor because they weren't available unless, you know, they were out of the country or, you know, on vacation. And I just didn't coordinate with my schedule of being in Colombia, you know, having to leave again.

So, yeah, that never really was a big issue.

#### Ме

Yeah, no, it makes sense. OK. I think that's really all I have. Yeah. Do you have anything else you want to add? If not, that's OK, too.

#### Julia

Let me think.

#### Me

I guess. Well, I have. I just thought of another question, if you don't mind. I'm sorry. So it seems like between like like you were saying, you're scheduling and you the appointment you got is in June, which is kind of crazy.

That's like six months away. I mean, five at least. And and like you were saying, in Colombia, you get test results back much faster. And so my guess and you can correct me if you think

I'm wrong, of course. But my guess would be that's because there's just so much more like the health care system here is just so much more overwhelmed.

And I'm wondering, like, why do you think that is? Do you think there are just like fewer doctors here compared to people who need health care or like? And I don't know the answer, so if you don't either, that's fine. I'm just curious your opinion.

## Julia

You know, like I worked in the sector of early intervention, and this is an area that just doesn't have a lot of providers. Like there's always been a lack of not enough providers. And a lot of factors are that as providers, like applying for insurances is not easy.

There's not a special guide. There's many insurances. You know, sometimes the pay isn't the pay, the pay can be a factor. It's not necessarily something that's like you're receiving bonuses and things like that. And early intervention is a very much like a contractor work. So you're just working for basically the early intervention agency and and, you know, you're you're only seeing patients, you know, when they when they're scheduled and you see them. So if there's cancellations like that's, you know, you don't earn money.

So that from my perspective, that's just what I know. And, you know, there's pros of it because it's a it's an area where you're you can be flexible. You create your own schedule. So like, you know, it's ideal for like if you're a mother and, you know, you can work out your schedule, create your own schedule where you, you know, works these certain days or certain hours.

And then, you know, you have the free will of like scheduling the rest of whatever time for your children. So but as like a doctor, you know, there's definitely more demand and the hours and all that stuff. And and, yeah, the insurances. I mean, right now it seems, you know, as you know, the there's a lot of insurance.

There's a lot of, you know, uncertainty, like Medicaid and all that stuff.

And so I do want to say, you know, I. I travel to I guess my experience getting medical care in Colombia is just maybe easier because for one, like I am paying out of pocket, like if you're paying out of pocket, like it's just done and go and you just pay.

You know, I know Colombia has had its issues with their insurance agencies and things like that. So like as a actual citizen, like I can't I don't have that perspective, like I don't have an insurance over there. And, you know, I'm not having to deal with Colombian insurances and applying or like am I going to get covered for this or that?

Like that's not a worry for me because in Colombia I just pay out of pocket for whatever I need. So it's like easier if you're just paying and that's it. You know, so I don't have to worry.

## Ме

Sorry. How how does Colombian insurance work? I don't I don't think I am familiar.

#### Julia

Well, that's why that's why that's what I'm saying. Like, I don't know. I've never had insurance over there. And so, again, I'm just going and I'm paying out of pocket. So, again, I don't have to go through loops and holes of like I have to apply somewhere or like I have to wait for the government to, you know, pay my, you know, medical needs over there.

Because, again, I'm paying there up front. So that might be just something easier for, you know, a doctor to have like, oh, they're just going to pay up front. Like, OK, I can get you in and out. Maybe. I don't know. So.

## Ме

OK, I understand what you're saying.

### Julia

We don't have to worry about that insurance aspect in Colombia. And like, I don't know that experience. My only experience is like I'm paying up front, you know, whatever the test cost. OK, I'll pay it. But perhaps a family who doesn't have that privilege, you know, has their insurance.

And if there's issues with insurance in Colombia and, you know, maybe similar to the problems here, you know, that's the hurdle they have to go through. But like and again, if I wanted to do a test here and just pay up front, like that's easy. Just if I have the money, just pay and like it's done.

Move on. So.

#### Ме

OK, that makes sense. Yeah, I think that's that's pretty much all the questions I had. Do you have anything else you want to add?

#### Julia

No, not that I can think of anything right now, but. Yeah, the experiences are very unique and really depend on.

Again, my experience was coming, being here in the States as, you know, as a one year old, and I'm sure that might be different for someone who comes later in life. And so my perspective is like not really the best of both worlds.

#### Ме

No, your perspective is is great. And I really appreciate you taking time out of your day to talk to me and to share these anecdotes with me. I really appreciate it.

#### Julia

Yeah, of course. And again, congrats on your last year. And I have to see the end results because I think it's something a very interesting topic. And yeah, if it comes out, let me know.

#### Ме

I will. I will definitely send it to you once I'm done working on it.

#### Julia

Awesome. Well, best of luck. And you're almost at the finish line.

#### Ме

And thank you so much again. And I hope you have a good weekend.

**Julia** Thanks, Frances. Take care.

## Me

You too. Bye. Take care, you too. Have a good weekend.

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