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Experiences of Limited English Proficiency (LEP) Patients in Healthcare

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EXPERIENCES OF LIMITED ENGLISH PROFICIENCY (LEP) PATIENTS IN
HEALTHCARE

by

JAVIER CINTRON

A thesis submitted in partial fulfillment of the requirements
for the Honors in the Major Program in Anthropology
in the College of the Sciences
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at the University of Central Florida
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Abstract

As the US becomes increasingly more diverse, the presence of non-English speaking individuals also increases. With healthcare being a vital aspect of most individuals' lives, it is drastically affected by any gap in communication, especially when a language barrier is present. For this investigation, I conducted a research study to examine the experiences of limited English proficiency (LEP) patients in healthcare using anthropological methods. The aim was to understand how having LEP affects patients. The primary form of data collection for this project consisted of Semi-structured interviews with a sample of individuals with LEP. In addition to interviews, I analyzed documents that shed light on the current and future policies as well as the public's perception on this topic. The results indicate that those individuals that a patient speaks with prior to the physician, including nurses and staff, pose an additional barrier to their healthcare. This research contributes to the current body of scholarship on language barriers in healthcare, which have been significantly lacking in patient perspectives. Through interviews, participants had the opportunity to voice their experiences and opinions, which they may have otherwise not been able to do, that could contribute to the development of better policies related to overcoming language barriers in health care. Further, this research could also contribute to better education practices for health practitioners with regards to language and health.

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Chapter 1: Introduction and Background

As the United States (US) becomes increasingly more diverse, the presence of non-English speaking individuals also increases. With healthcare being a vital aspect of every individuals' lives, it is drastically affected by any gap in communication, especially when a language barrier is present between the patient and their healthcare provider. For this investigation, I studied the experience of limited English proficiency (LEP) patients in healthcare using anthropological methods. The aim is to understand how having LEP affects patients. The research question that guides this project is: What are the experiences of LEP patients in healthcare in Florida?

The US population has become increasingly more demographically diverse over the last few decades (Lee et al. 2017). Consequently, there have been several ramifications to those states with increased diversification such as shifting political spectrums or improved educational outcomes for minorities. According to the census bureau, Florida's population alone has seen a 57.4% increase in Hispanics/Latinos between 2000 and 2010 (US Census Bureau 2010). This increase in Hispanics/Latinos comes with an increase in individuals whose primary language is Spanish, and who therefore learn English later in life and achieve various levels of proficiency due to numerous factors, including access to education, the linguistic nature of their daily needs, employment type, and other. Unfortunately, the level of diversity in the US is not reflected in healthcare. There amount of Hispanic/Latino medical practitioners is severely lacking in the US in the categories of dentists, nurses, pharmacists, and physicians (Grumbach and Mendoza 2008). As a result, there is an increased need for programs that reduce accessibility barriers for those patients that do not speak English or have low proficiency.

Title VI of the US Civil Rights Act of 1964 ensures that those who speak a language other than English have access to any programs receiving federal financial assistance (Chen et al. 2007). In 2001 and in 2013 the US Department of Health and Human Services set national standards for culturally and linguistically appropriate services for healthcare organizations. However, even with these standards there are still significant language and cultural barriers in hospitals across the nation that have negative effect on patients (Wilson 2013). It is reasonable to conclude that the same language gap exists for patients who present to other types of medical practices, including community clinics.

An LEP patient is defined as someone who is limited in their ability to read, write, speak, or understand English and they do not speak it as their primary language (Connors 2019). Recent studies show that LEP patients experience diminished healthcare quality due to language barriers that can lead to serious physical or psychological injury or death (Wilson 2013). Translators should help with improving the quality of healthcare that LEP patients receive. One would expect them to advocate for the patient, as they are their voice during a healthcare visit. However, previous anthropological studies suggest that this is not the case (Davidson 2000). Many times, due to time constraints for the physician, the interpreter will selectively interpret in favor of the physician's available time. This is assuming that an interpreter was available. In Davidson's (2000) study, patients would wait for up to an hour in an exam room waiting for their interpreter. In addition to their scarcity, these interpreters were paid hospital employees, yet had no formal training as interpreters. Their training essentially consisted of shadowing another interpreter on their rounds and an assurance that they were bilingual (Davidson 2000). The

interpreters therefore can be seen as another barrier for the patient to go through to achieve quality healthcare.

Furthermore, a previous study done on the interactions of people with disabilities and nurses indicates that nurses project a sense of frustration towards patients that they deem to be more complicated or time consuming (Smeltzer et al 2012). It is important to note that the participants in the study mentioned difficulties with doctors as well as nurses, but nursing staff was most frequently mentioned (a point relevant for results presented later). Many of these patients said that they felt “low priority” and reported that the nurses did not give them the additional time necessary to perform daily tasks, such as asking questions, bathing, eating, etc. The participants felt as though they were a burden because the nurses projected their preference tending to patients that they felt were “sicker” and/or needed more care (Smeltzer et al 2012). From the provider’s perspective, LEP patients take a considerable amount of time to care for compared to non-LEP patients (Michalec et al 2015). Consequently, it is reasonable to make the assumption that these patients feel similar to those participants interviewed by Smeltzer et al (2012). Moreover, nurses spend significantly more time with patients than physicians (Butler et al 2018). As a result, a heavier burden of cultural and structural competency and communication lies with them as opposed to a physician. Many people in the biomedical community understand cultural competency in literal terms. They believe that they must be able to identify and deal with individual cultures and make overarching generalizations of groups of people so that they know what they should do or not do when interacting with those patients. This view is too simplistic and does not take into account many elements that work in tandem with culture. Economics, politics, religion, psychology and biological conditions all interact with culture to form a unique

experience with each patient (Kleinman and Benson 2006). This is why one must also be structurally competent. Structural competence is the understanding of how socioeconomic and sociocultural structures interact with clinical attitudes, illnesses, or diseases (Metzl and Hansen 2014). To be culturally competent, one must also be structurally competent so that they can maintain a patient's health rather than continuously treat an illness. This should be present in their training. However, the research available does not reflect an acceptance of this responsibility (Smeltzer et al 2012, Michalec et al 2015).

There is significant quantitative research on LEP patients with regards to healthcare. However, the literature is lacking in qualitative data, particularly with regards to the experiences of the LEP patients themselves. The small amount of qualitative data that there is focuses on the perspectives of the healthcare providers (Michalec et al 2015) rather than patients. Qualitative research on this topic can help to inform health policies as well as give health providers insight on how language barriers affect their patients' personal lives.

Florida is a particularly good state in where to examine this issue because of its high proportion of residents whose primary language is Spanish. Currently, Hispanics/Latinos are the largest minority group in Florida at 26.1% of the population. Black or African Americans are the next largest at 16.9% (US Census 2010). According to the 2007 American Community Survey (Shin and Kominski 2007), of the 34.5 million Spanish speakers in the US, 47% are considered LEP, indicating how important it is to have Spanish skills available when working in public services. Furthermore, Florida has several Hispanic-Serving Institutions such as the University of Central

Florida and Florida Atlantic University.¹ These are defined by the US Department of Education as higher learning institutions that have an enrollment of full-time students of at least 25%.² Additionally, according to the Association of American Medical Colleges (AAMC 2019), only 6.5% of 2019-2020 medical school matriculants were of Hispanic/Latino descent. Moreover, being of Hispanic/Latino descent does not necessarily mean that these individuals speak Spanish.

In urban areas, such as Orlando, there are more physicians per patients and therefore more physicians with the ability to speak Spanish. In rural areas, however, there are significantly fewer physicians and hospitals available. As a result, rural areas tend to experience more negative health outcomes overall compared to urban areas (Hung 2017). Those individuals living in rural areas that are also LEP are particularly vulnerable to these problems because they are compounded by having difficulties with English. Additionally, many of those that are rural Hispanics/Latinos are migrant farm workers. The National Center for Farmworker Health (2014) reports that 69% of all agricultural workers were born in Mexico and 27% were from the US and Puerto Rico. Only 31% could speak English “well” or better (NCFH 2014). Undocumented LEP patients would also be particularly vulnerable. According to the Pew Research Center (2016) there are 775,000 undocumented immigrants in Florida. An undocumented person’s lack of papers could result in a delay to seek medical care due to their fear of deportation. Their lack of insurance could also result in a delay to seek medical care. Therefore, the ability of this

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https://www.hacu.net/assnfe/CompanyDirectory.asp?STYLE=2&COMPANY_TYPE=1%2C5#Florida

² <https://www2.ed.gov/print/programs/ideshsi/definition.html>

population to communicate with medical providers is critical since they may experience longer periods without medical care.

This research study will therefore examine the experiences of LEP patients in Florida by using anthropological qualitative methods. In the following sections I will describe my methodological approach and then follow with my findings and analysis divided into three thematic sections. In the concluding chapter, I review the results, explain the significance of this project, and present several recommendations based on my findings. I then consider future research directions that could build on these data.

Chapter 2: Methods

Semi-structured Interviews

The primary form of data collection for this project was Semi-structured interviews. The interviews took place in a quiet area where the participant felt most comfortable. This included the UCF campus, a coffee shop, or a private venue that the participant and me agreed was appropriate for a conversation. Participants who were unable to meet face-to-face due to any number of circumstances were allowed to opt to instead meet over a private Skype call. My interviews followed a semi-structured interview guide, allowing me to ask specific and similar questions for all interviews, while still having the flexibility to inquire and expand on particular responses from the participant. The interview guide is attached as appendix #2. This process has shown great flexibility in addressing both primary topics and nuanced ideas (DeWalt and DeWalt 2011; Fetterman 2010).

Document Analysis

In addition to Interviews, I analyzed documents that shed light on the current and future policies as well as the public's perception on this topic. These included:

- a. Legal Documents: Federal and state policies in place that affect LEP patients in healthcare.
- b. Journal Articles: Reliable news sources that are related to language barriers in health.
- c. Hospital Policies: Comparisons of what a hospital or health clinic says they do to what actually happens.

Sample

In this study, LEP was defined as those individuals whose primary language was Spanish and identified as having difficulties readings writing, speaking or understanding English and/or required an interpreter during healthcare visits. Eligible individuals were people who were 18 years and older and had limited English proficiency. The differences in cultures (Mexican, Puerto Rican, etc.) were not taken into account because only the barrier of language was being considered in this study. I included participants who were adults and consider themselves to have a limited English proficiency and have visited a US medical facility. I excluded individuals under the age of 18 and participants who were not considered to be LEP patients or had never visited a US medical facility. I included participants who were adults and consider themselves to have limited English proficiency and have visited a US medical facility. I intended to recruit 10-15 individuals for this project, with the true number of subjects being determined by the law of diminishing returns (Weiss 1995, 21) (Strauss and Corbin 2008). I recruited 13 individuals: 4 from the UCF campus location, and 9 from Panama City location.

Recruitment

There were two areas that recruitment took place in for this project: UCF campus in Orlando, and Panama City, Florida. To recruit on the UCF campus, flyers were posted in buildings on campus, such as Health and Public Affairs one and two, with the permission of the building liaisons for each building. In addition to this, with the permission of faculty, I made announcements about this project in their classes. I also sought out the Spanish speaking organizations on campus, such as the Puerto Rican Student Organization, and requested permission to make an announcement and recruit during their meetings.

In Panama City, I was in contact with several individuals that are known and respected in the Spanish speaking community as well as the community as a whole. They had access to a significant portion of the Spanish speaking population in Panama City. Therefore, snowball sampling which uses referrals from key community actors was one of my recruitment methods in Panama City. In addition, one of the individuals that I was in contact with has a popular hair salon business with many of the clientele falling within my population of study. With her permission, I posted flyers in her business for recruitment.

Vulnerable Populations

While this study did not target any vulnerable populations, it was possible that undocumented persons might have been interested in participating in this study. I took precautions to protect their rights as research participants. I ensured that consent was properly obtained by thoroughly explaining the research and obtaining informed consent in both Spanish and English as needed. The research for this proposal was of minimal risk to all participants, including undocumented persons. I asked for a verbal (not written) consent only to protect their confidentiality. I did not collect personal identifiers. Instead I assigned a pseudonym to each individual, which I explained to participants.

Data Management and Confidentiality

Once I collected all of my data, I transcribed and coded all interviews. Within the coding process, I identified key themes and perspectives, and analyzed their interaction with the categories created for the semi-structured interviews. Utilizing themes or patterns allows for a

recognition of trends in beliefs or concerns of LEP patients. Labeling and working under themes can synthesize like ideas to showcase similar understandings (DeWalt and DeWalt 2011, 189; Fetterman 2010, 97).

I stored all collected data – interview notes and recordings, and field notes – on my laptop and field notebook. The interviews were recorded on my phone and immediately following the interview were saved onto my computer and then deleted from the phone. When an informant mentioned someone's name during an interview, the transcription from that interview was "de-identified" which means that in addition to using only a pseudonym, any mention of other people was likewise replaced using a pseudonym. All pseudonyms with their associated names were located in a single word document which had its own password protection and was stored on my laptop computer. I utilized the laptop for transcribing interviews, data analysis and write-up. The laptop was protected by security software and was password protected. In addition to requiring a password to have access to the laptop's contents, the relevant research files were encrypted and required an additional password to access. I included in my field notebook observations and interview notes. I concealed all content by using pseudonyms. I did not write any personally identifiable information in its contents. I kept the notebook with me when on location and when not in the field it was stored in my file cabinet for which I am the only one that knows the 6-digit code.

I maintained and stored all data solely throughout the duration of the study. Written notes and transcriptions were stored and will remain stored for three years from the closure of the study. Audio recordings were deleted upon transcription.

Consent Process

The informed consent process took place before data collection through interviews was conducted. Consent took place in a quiet area of the participant's choosing. When I obtained consent from key informants, I described the research and answered any questions they may have had about the research or the interview process. I provided participants with a written description of the study and their role in the interview process. This included guidelines to maintain their confidentiality. I provided this description in an easy to understand language. I informed participants that they may end the interview on their terms at any time if they did not feel comfortable. I only obtained verbal consent to protect the identity of the participants. When participants gave their informed consent, I then documented their agreement through the use of pseudonyms, however, participants did not sign a consent document. I did not collect personal identifiers but instead each individual received a pseudonym that I chose with the individual which I explained to participants.

I provided all written materials in English or Spanish, depending on the participant's preference, and conducted interviews in English or Spanish, depending on the participant's preference. I am fluent in both. To ensure that age appropriate participants were obtained, I asked the birth year of the participants.

IRB

These methods were approved by The UCF IRB (ID: STUDY00001058). Gillian Bernal was the designated reviewer. The IRB approval letter is attached as appendix #1.

Chapter 3: Results – Barriers to Effective Communication in Healthcare for

LEP Patients and Translators

The analysis of my interview narratives yielded several interesting findings. Some of these findings corroborate previous research (Michalec et al. 2015, Smeltzer et al. 2012), however other results contradict common notions in current scholarship of where language barriers begin in the context of healthcare. Throughout the interviews, several common themes arose that fell within three overarching categories. These categories were identified as “Difficulties with Institutional Staff Prior to Visiting a Physician,” “Sources of Anxiety and Comfort in LEP Patients,” and “Cross-Cultural and Semantic Difficulties during Translation.” I divided these common themes into some additional sub-sections as needed and included emblematic quotes from the interviews to exemplify the topics. The sub-sections that fall under “Sources of anxiety and comfort in LEP patients” include “Time constraints resulting in patient anxiety” and “Preference for a physician with a shared language”. The sub-section under “Cross-Cultural and Semantic Difficulties during Translation” includes “Elderly Most at Risk.”

Difficulties with Institutional Staff Prior to Visiting the Physician

The most significant finding of this investigation was how consistently participants described having difficulties with the staff of the healthcare institutions that they visited prior to seeing a physician. In particular, every participant described having several negative encounters with nurses. Several of the participants were individuals with LEP that spoke English well enough to functionally translate for their family members. These individuals described the nurses that they encountered as being dismissive and disinterested with their family members for whom they were translating. During interactions requiring translations, the nurses would acknowledge only

those that spoke English. One of my participants, Maria, is a young college student who frequently translated for her elderly grandfather throughout her teen years. She learned English at a relatively young age but primarily speaks Spanish in her household. As a result, she has a slight but noticeable accent. Her grandfather spoke no English. Consequently, Maria was left with the burden of all communication between her grandfather and the medical staff. The following is her description of their frequent healthcare visits.

They [the nurses] weren't going the extra mile... There was just some that they wouldn't even look at my grandfather. They talk to me, then I'd talk to him. They didn't address him directly... he didn't want to be there. Like he didn't care that much to be in the hospital. (Interview with Maria)

Maria was always anxious when she went to translate. She was placed in an uncomfortable position of authority that superseded her grandfather's. The body language of healthcare providers is important, because how they project themselves is reflected in the patient. The patient can sense through body language alone the attitude and degree of interest and care of the provider toward them. In the case of Maria's grandfather, he knew that his power and locus of control was taken away from him because he had no method of communication. As a result, he was not fond of going to his healthcare appointments. This sense of anxiety and loss of power was a frequent topic during my discussions with research participants. While many individuals did not explicitly state that they did not go to clinics because of a language barrier and mistreatment from staff, they mentioned that their friends refused to go to healthcare appointments for these reasons. What was interesting about this was that some of these participants knew each other and referenced each other when describing those that avoided

clinics. This might suggest that delaying or refusing to go to healthcare appointments may be perceived as problematic or embarrassing, and therefore it is easier to discuss as something that “happens to others” but not to oneself.

A majority of the participants described the nurses that they encountered as agitated or frustrated. Carla is an engineer from Puerto Rico. She speaks fluent English but has a noticeable Spanish accent. Carla had a situation where her father needed a hip replacement, but they were having difficulties with the nurse. She described the nurse as dismissive of her concerns and projecting constant agitation. These difficulties were exacerbated by the physician rarely seeing them and Carla requiring the nurse’s approval before an in-person visit by the physician. These difficulties eventually led to Carla’s father having complications from the delay in treatment and having to be hospitalized. She eventually decided to use another physician. The following is Carla’s response when asked whether or not they felt any prejudice due to language barriers when they spoke to healthcare workers.

I think there's always something like that, well, not always, but that you at some point... you will experience something like that, you know. And sometimes it's, you know, the perception on my part or maybe it's the perception of the person who is trying to explain things to us. For example, especially when you have the... especially when you have, before you see the doctor, you have the nurses that come and ask all kinds of questions of you. So, depending on how they feel, they might feel that we're wasting their time more because they can't speak it and

then she has to wait until I translate and stuff like that, you know. So, there might be... you might see some aggravation. (Interview with Carla)

Some of my participants were involved in the medical community, either as a medical scribe or as a translator, and described nurses' agitation towards LEP patients as they saw it from within the clinic.

I would see the back end of the situation where they will roll their eyes and complain (Interview with a bilingual medical scribe)

An additional problem that arises when communication is not possible is how readily medical staff make assumptions based on physical appearances. While this reaction is not ideal, it is not surprising given that appearance is something that can give context in a conversation. Dirty, worn clothes and boots can point towards a working-class individual while a button up shirt and slacks can indicate someone in the middle or upper class. These observations give hints towards the amount of resources or education an individual has. A couple that I interviewed, Doña Luz and Don Carlos, discussed with me their observations in clinic waiting areas.

The way in which one presents themselves is among the most influential, because there are humble people that don't get treated the same... well I've observed it.

There are those people that don't have dirty clothes or don't speak any English and have darker skin. I've seen how those people are treated unfortunately.

(Interview with Doña Luz)

Doña Luz is saying that, there is racism and classism towards those with darker skin and rougher looks, which is emphasized when communication is removed during interactions.

Nursing is a noble profession with many stressors. However, nurses are essentially the frontline to most clinics and hospitals. They are frequently the first and last person that the patient sees.

The frequency of patient contact is likely the reason that many of my participants have had negative experiences with nurses and positive experiences with physicians. Yet, this frequency of patient contact is the reason that nurses should be held to a high standard with regards to cultural competency and patience. The difficulty of a language barrier alone can make going to a healthcare facility a dreadful and anxiety inducing experience. Difficulties with the clinical staff that are supposed to be there to help them can prevent LEP patients from returning or seeking medical attention in the future.

Sources of Anxiety and Comfort in LEP Patients

Time constraints resulting in patient anxiety

As shown previously, healthcare workers constantly feel a constraint on time. They do their best to refrain from projecting this onto the patient (Michalec et al 2015). However, most of the participants expressed that they felt rushed during their healthcare visits and that the nurses that they encountered were short with them as well as agitated. With these individuals being LEP patients, their visits inherently take longer and require more care on the side of the medical provider. By portraying agitation and a sense of urgency, the LEP patient then does their best to avoid asking for what they feel is unnecessary, such as a translator, when in reality they may desperately need it for optimal provision of care. The following individual is Maria, discussed

earlier. She was describing why, when she accompanied her grandfather to the doctor, they never asked for translators, even though she had trouble properly translating.

Usually they were in a mood or they're busy... seems like we have enough family. (Interview with Maria)

Another research participant who brought up this problem was Sarah. She was a bilingual college student that volunteers as a medical scribe. She was describing her observations and why she believed that the nurses felt as though they needed to rush the LEP patients.

So, for them, it's just like, Okay, I'm spending 15 minutes with the patient who I'm helping translate through a machine while I can be seeing more patients with that time. So, for them, I guess it's more annoying for that. (Interview with Sarah)

The machine that Sarah was describing was an iPad that the clinic would use to access translators on video chat. I have translated in a similar clinic myself and have seen how they use them. This connection does take time to set up, so the nurses avoid using it as much as possible. They rely instead on the nearest person available that can translate, regardless of whether they can only translate at an intermediate level or a more advanced one, which makes the quality of translation inconsistent.

When an LEP patient or translator feels rushed, they inevitably feel anxious. This causes them to forget what simple words mean, resulting in further delays or omission of symptoms. There is also the danger that when patients feel rushed, they may be more selective in what they tell the

doctor or nurse, thereby increasing the risk that their condition may be misunderstood by the healthcare providers. Previous research shows that Latino patients tend to have more mistrust toward physicians, especially regarding providers' interpersonal competence, than white patients (Sewell 2015). However, my findings additionally suggest that the experience of being rushed as a patient can also create or accentuate an already existing sense of marginalization by healthcare providers and may further mistrust.

Many patients do not understand what is accessible to them and what is not. This issue is more apparent with LEP patients who feel as though they should not waste the time of the doctor and who may be less familiar with the US healthcare system than the average American. The following is the response from Carla when asked whether or not she was offered a translator for any of her family members when she or her children went to translate.

I mean I'm sure if we'd looked, they would find one [translator] but they didn't offer one. We also never asked. (Interview with Carla)

Preference for a physician with a shared language

Most of my participants had a preference for a bilingual physician that spoke Spanish. Don Carlos and Doña Luz insisted on only seeing a Spanish speaking physician.

I won't see doctor... I speak a little bit of English, but even so, I won't see a doctor unless they also speak Spanish. (Interview with Don Carlos)

Don Carlos and Doña Luz had this option because they live in an area with a large population of Spanish speakers. This is not the case in many parts of the US. Many LEP patients barely have access to a translator. Going to a healthcare facility can be an uncomfortable experience. The patient is placing their trust in their medical provider to ensure that they remain healthy. When there is a language barrier that trust is strained because the patient has less in common with their medical provider. While in college, I was fortunate enough to translate for a free clinic in central Florida which provided primary care. Most of the patients that visited the facility only spoke Spanish. I will never forget this one patient that I translated for. She was a refugee from Venezuela who did not speak or understand English. The patient had a gynecology appointment. Her situation was already a sensitive and uncomfortable one because the physician was male and had a heavy Bulgarian accent, resulting in what was essentially two language barriers. His English was difficult for her to understand and she could not communicate in English to him. Nonetheless, he was an excellent physician and was compassionate with his patients. Yet, she was understandably uncomfortable. The situation was not improved when I, a male, came into the room to translate. However, once she realized that I spoke Spanish, her demeanor immediately brightened and she visibly relaxed. She began expressing more of what she felt and even told me some of her life story after she was finished. Sharing a language does more than simply open a line of communication as needed for effective medical care. It also makes the patient feel comfortable and accepted. They share more information with the medical provider, allowing for a higher quality of healthcare.

Cross-Cultural and Semantic Difficulties during Translation

Difficulties with context arise even when speaking a similar language. One can easily misinterpret the meaning of a phrase, depending on their cultural background (Fadiman 1997). When a language barrier is present, people are having difficulties understanding what the involved parties are saying, resulting in the problem of understanding their meaning being exponentially exacerbated. In medicine this issue can result in deadly consequences. The patient may not understand the proper dosage that a physician is recommending that they take. A physician may not understand what kind of pain that a patient feels or may underestimate the amount of pain that they may be in. Being able to adapt to an individual rather than just having a general understanding of their overall culture is an important aspect of cultural competence (Kleinman and Benson 2006, Metzl and Hansen 2013). The majority of participants in this study, whether they interpreted for family members or spoke no English themselves, mentioned difficulties in context. Many had trouble with the medical terminology and confessed that they oversimplified what the physician was saying when they translated for a family member. Those that I spoke to that did not speak English had to rely on the family members that accompanied them. The following individual, Josephina, was a college aged LEP patient that learned English during her middle school year in Honduras. Here she explains the difficulties she observed in conveying meaning:

...for the dosage of how much I mean. I would sometimes say una cucharada.

How do you say that in English? Like what is it? Is it a cup? I don't know

(Interview with Josephina)

Josephina was describing how when she was younger, her mother would always give her “una cucharada,” or one spoon full, of medicine. She went on to explain her difficulties in understanding the dosages that physicians were recommending her because the physicians were describing them in proper units. An issue like this is one of linguistic and cultural context. I myself grew up with “la cucharada” and explicitly remember that it was essentially a spoon full of the first spoon available that was in the kitchen. When that is all you know, relating measurements to a particular unit, in particular one in a different language, can be a challenge.

Jose is an engineer from Puerto Rico. He moved to the US after he joined the air force. He speaks English fluently but has a noticeable accent. In the following statement, he describes a time that he took his wife to the hospital when she had chicken pox.

I had to take my wife to the hospital because she had broken out in chicken pox. I think it was chicken pox... yeah it was chicken pox. And we walk in the hospital and we had no idea how to say chicken pox because they don't know what the name of the condition is in English. So, you sit there and, chicken pox is easy to identify, because a person's broken out in hives and stuff. And I just pointed at the nurse and then at her face and they were like, "Oh, she's got chicken pox." Yeah that!" (Interview with Jose)

The chicken pox vaccine was not developed until well into Jose’s adult life, so it is likely that he had experienced it and was familiar with the symptoms. Jose knew what his wife had but could not express it because he could not remember the English word. Fortunately, there was no

substantial impact to the delay in care. However, small delays like these could lead to significant harm in more serious conditions.

The elderly most at risk

I noticed, while conducting my interviews, how vulnerable elderly LEP patients were. The issue was not discussed at length, but it was apparent to me that, without the constant help of family members, that these individuals would likely not be able to receive any form of decent health care. I spoke to one participant, Doña Celia, who was from Puerto Rico. She spoke no English, had difficulties understanding it, and had difficulties reading it. She had moved to the US recently to be with her daughter and grandchildren. Fortunately, they were bilingual and were able to help Doña Celia in the clinics, but without them she would have not been able to receive adequate healthcare. She told me a story about a time when she was having problems getting medicine from the pharmacy. She needed her medication. While there, she explained to me that the pharmacist began heckling her and giving her difficulties because she did not speak English. She could not defend herself and eventually became so frustrated that she left to get her granddaughter so that she could help her. Doña Celia eventually received her medication, but not without her granddaughter helping and having to defend her. This story exemplifies the difficulties that can be experienced by older individuals that must rely on others. Additionally, it shows that barriers are made by other medical providers that are not nurses or physicians. Doña Celia is fortunate that she lives with her family, but for those that do not, going to a clinic can be a momentous task, even without barriers to movement and transportation.

Policies

Based on my interviews and literature review, it is reasonable to conclude that the policies and legislation put in place to reduce barriers for LEP patients are not always followed. My participants frequently were required to bring their own translators or were not offered one during appointments in hospitals and clinics that received government funding. Furthermore, even when these translators are offered, there is no minimum standard requirement for their language skills and therefore no quality control.

Chapter 4: Conclusions

The interview narratives in this study demonstrate that many LEP patients have difficulties with staff prior to actually seeing a physician. Nurses in particular were the most common medical staff that patients had difficulties with. They also show that many LEP patients feel anxious when they visit clinics because they feel as though they are taking up too much of the medical practitioner's time – this sense is mainly produced by the agitation expressed by nurses and them projecting their desire to move on to patients that they feel are more worth their time. Data also showed that there are significant cross-cultural and semantic difficulties during translation in a medical setting. This means that physicians and nurses are having trouble communicating with LEP patients, even if the patient speaks English. The patient associates certain terms in context with their language and culture, while the physician assumes that they understood what they meant because they speak English. This issue also occurs with translators as many times family members are used to translate for the physicians. These translators have the same issue of not properly understanding exactly what the physician meant and, instead of a direct translation, they translate within the context of their culture.

This study additionally found that elderly LEP patients are more vulnerable to negative health outcomes due to many of the previous issues being exacerbated by the physical barriers presented by age.

These findings are important because the US is an incredibly diverse country, where Spanish is rapidly becoming one of the most important languages but furthermore with many other languages spoken, including those that are spoken by indigenous populations. This study only

examines the Spanish language, but these difficulties can be found across the linguistic spectrum (Fadiman 1997) and remain a serious challenge for patients' abilities to receive quality care.

Healthcare is not only for those that speak English but should be an equal right across all linguistic categories. Injuries and illnesses affect people indiscriminately, so why should those that speak English receive better care than those that do not? While the language barrier between the healthcare provider and their patient has been identified as a concern in the current research, effective ways of overcoming language barriers are yet to be established.

Several recommendations arise from the findings of this study. First, there should be a greater emphasis on cultural experiences for nursing staff during their training. In public discourse, the physician is the one that is expected to be culturally and structurally competent because of a common top down perspective in healthcare delivery. They are viewed as the top of the medical hierarchy, leading to the belief that they should be the ones responsible for difficulties with communication with patients. In reality, however, nurses spend the most time with the patients and their training should reflect as such. This emphasis could be incorporated during training after their formal nursing education is completed. Ensuring that nurses have diverse clinical experiences during their formal education is also necessary to ensure their understanding of this. Second, there needs to be increased cultural education within nursing programs. For example, a review of Bachelor of Nursing programs at the University of Central Florida, University of Florida, Florida State University, and Florida Atlantic University showed no evidence of required coursework dedicated to health disparities, cultural competence, or structural

competence.³⁴⁵⁶ Moreover, I also recommend classes dedicated to LEP patients specifically, as this was lacking as well in the curriculums that I reviewed, even though LEP patients are frequently encountered in healthcare settings, especially in Florida. Third, there needs to be an understanding that language barriers result in anxiety, as well as the consequences of this anxiety. Patient anxiety is further exacerbated by interpersonal barriers such as agitation, shortness, etc., presented by medical staff. This anxiety can result in omission of symptoms, lack of requests for translators, lack of questions about their condition, and increased difficulties in communication. This issue can result in decreased quality of care for the patient as well as negative health outcomes. A medical provider's responsibility is not to increase anxiety, but to set the patient at ease so that any issues can be comfortably discussed. Fourth, there should be an additional language requirement during the formal education of health professionals (medical, PA, nursing school). Florida only requires the completion of two sequential foreign language credits in high school and allows the universities and colleges to determine their own minimum language requirements.⁷ By including this requirement in health professional schools, medical providers will have a greater understanding and awareness of the difficulties that LEP patients experience in healthcare settings. The language requirement in high school is too far removed for students to properly understand its importance in health professions. I would argue that the minimum university requirement is too far removed as well, since these basic language classes

³ https://nursing.ucf.edu/wp-content/uploads/2019/03/UG-POS_TraditionalBSN.pdf

⁴ <https://nursing.ufl.edu/programs/bachelor-of-science-bsn/traditional-bsn/traditional-bsn-curriculum-plan/>

⁵ <https://nursing.fsu.edu/sites/g/files/upcbnu411/files/pdf-files/BSN/BSN%20Program%20Academic%20Map.pdf>

⁶ <https://health.usf.edu/nursing/undergraduate/programs/upper-division>

⁷ http://www.leg.state.fl.us/statutes/index.cfm?App_mode=Display_Statute&URL=1000-1099/1007/Sections/1007.262.html

not career focused. My own university, the University of Central Florida, exempts students in the field of science, technology, engineering and mathematics from taking any language credits. Ironically, the students make up a significant portion of majors that go into health professions. Fifth, I believe that funding dedicated to trained translators, as well as a universally standardized medical translators certification program, would alleviate some of the difficulties that LEP patients experience. This is because expansion of funding is needed to increase the numbers of translators present in healthcare facilities, especially in public community clinics. Likewise, a standardized translator certification program is vital to address the mixed quality of translators' skills currently available.

An important aspect of medical anthropology is understanding the health disparities among different populations. Unfortunately, the anthropological literature on the LEP patient population is scarce. This project expands our understanding of the difficulties that language barriers pose and provides a better understanding of the patient's perspective towards these barriers. By learning and understanding the anthropological and theoretical perspectives of cultural and structural competency, medical providers can have better interactions with LEP patients that result in more positive health outcomes.

Chapter 5: Future Research

The results of this study encourage more research in this important area of scholarship in the future. One of the topics that was briefly discussed by my research participants during my interviews was that there was an assumption that those from Spanish speaking countries automatically spoke Spanish as their first language. I was informed that many people from these

countries actually speak indigenous languages rather than Spanish. Future studies should therefore focus on examining these indigenous languages and how they impact the healthcare system. Studies could be designed with patients who speak indigenous languages to understand their experience with healthcare, given that they are mistaken for Spanish speaking individuals and would likely have difficulties finding a translator that speaks their language. Future studies should also work to expand on this investigation in other areas of the country as well as for different languages so that we have a broader perspective from LEP patients.

Appendix I: IRB Approval Letter



UNIVERSITY OF CENTRAL FLORIDA

Institutional Review Board

FWA00000351

IRB00001138

Office of Research

12201 Research Parkway Orlando, FL 32826-3246

EXEMPTION DETERMINATION

November 14, 2019

Dear Joanna Mishtal:

On 11/14/2019, the IRB determined the following submission to be human subjects research that is exempt from regulation:

Type of Review:	Initial Study, Category
Title:	The experiences of Limited English Proficiency (LEP) Patients in Healthcare.
Investigator:	Joanna Mishtal
IRB ID:	STUDY00001058
Funding:	None
Grant ID:	None

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made, and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request so that IRB records will be accurate.

If you have any questions, please contact the UCF IRB at 407-823-2901 or irb@ucf.edu. Please include your project title and IRB number in all correspondence with this office.

Sincerely,

Gillian Bernal
Designated Reviewer

Appendix II: English Interview Guide

Interview Guide

Project Title: Experiences of LEP Patients in Healthcare

(After Informed Consent)

Thank you for agreeing to talk with me today. I'm Javier Cintron, and I'm an anthropologist based at the University of Central Florida. In this interview I'm interested in understanding your experiences in healthcare. All of the information you give me will be confidential – I will not ask you for your name or any information that could identify you. The interview is voluntary, and it will take 20-40 minutes. Can I audio record our interview, or would you prefer that I didn't? Would you like to start now?

Research Site: _____

Date: _____ Time: _____

Background Knowledge

1. Would you prefer English or Spanish for this interview?
2. How well do you speak English?
3. What is your primary language? [probes: family, home,]
4. How did you learn how to speak English? [probes: when, where]

Healthcare Seeking

1. Have you been to a clinic for emergency [non emergency]?
2. How often is language an issue during health care appointments?
3. Do you take an interpreter with you to healthcare appointments? [If yes, who?]
4. How often do you have a healthcare appointment?

Experiences with Healthcare

5. Have you ever felt prejudice from a medical provider due to a language barrier in healthcare? Would you share the experience?

6. Have you ever had a healthcare appointment with a provider that speaks the same language as you? [if yes, how did they compare to a provider that only spoke English; probes: anything different aside from language?]
7. Did a healthcare setting ever make you feel uncomfortable? [Please explain]
8. How has a language barrier in healthcare affected health at home? [your health - following home instructions for taking medications, your family's health]

Would you like to add anything that I didn't ask you?

Thank you for your time. Please contact me if there's anything else that you would like to add that you have not had a chance to say during this interview. Here's my contact information: Javier Cintron, Email: javiercintron50@knights.ucf.edu.

Appendix III: Spanish Interview Guide

Borrador de la Guía de Entrevistas

Título del proyecto: Experiencias de pacientes con LEP en el cuidado de la salud

(Después del consentimiento informado)

Gracias por aceptar hablar conmigo hoy. Soy Javier Cintron, y soy un antropólogo de la Universidad de Florida Central. En esta entrevista estoy interesado en entender sus experiencias en cuidado de la salud. Toda la información que me proporcione será confidencial – no le pediré su nombre o cualquier información que pueda identificarlo. La entrevista es voluntaria, y tomará 20-40 minutos. ¿Puedo grabar nuestra entrevista, o prefieres que no? ¿Te gustaría empezar ahora?

Sitio de investigación: _____

Fecha: _____ Hora: _____

Conocimiento de antecedentes

9. ¿Prefieres inglés o español para esta entrevista?
10. ¿Qué tan bien hablas inglés?
11. ¿Cuál es su idioma principal? [sondas: familia, hogar,]
12. ¿Cómo aprendiste a hablar inglés? [cuándo, dónde]

Búsqueda de atención médica

13. ¿Ha estado en una clínica para emergencias[no-emergencia]?
14. ¿Con qué frecuencia es un problema el lenguaje durante las citas de atención médica?
15. ¿Lleva a un intérprete con usted a las citas médicas? [En caso afirmativo, ¿quién?]
16. ¿Con qué frecuencia tiene una cita médica?

Experiencias con la atención médica

17. ¿Alguna vez ha sentido prejuicios de un proveedor médico debido a una barrera del idioma en la atención médica? ¿Compartirías la experiencia?

18. ¿Alguna vez ha tenido una cita de atención médica con un proveedor que habla el mismo idioma que usted? [Si es así, ¿cómo se compararon con un proveedor que sólo hablaba inglés; algo diferente aparte del idioma?]
19. ¿Alguna vez un entorno de atención médica te hizo sentir incómodo? [Por favor, explique]
20. ¿Cómo ha afectado una barrera del idioma en la salud a la salud en el hogar? [su salud - siguiendo las instrucciones caseras para tomar medicamentos, la salud de su familia]

¿Quieres añadir algo que no te haya preguntado?

Gracias por su tiempo. Por favor, comuníquese conmigo si hay algo más que le gustaría agregar que usted no ha tenido la oportunidad de decir durante esta entrevista. Aquí está mi información de contacto: Javier Cintron, Correo electrónico: javiercintron50knights.ucf.edu.

Appendix IV: English Flyer

Volunteers Needed for Research Study on Language Barriers in Health

My name is **Javier Cintron** and I am an undergraduate student at the University of Central Florida. I am conducting approved research about language

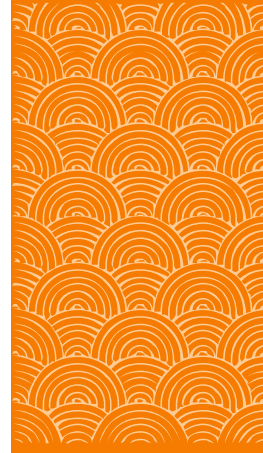


barriers in health and I would like the opportunity to speak to you **confidentially** about your experiences with healthcare. Please let me know if you are interested.

- Research **approved** by the University of Central Florida, USA
- All research is **confidential**
- Language being studied: **Spanish**

001-850-814-9249

Javiercintron50@knights.ucf.edu



Appendix V: Spanish Flyer

Voluntarios necesarios para el estudio de investigación sobre las barreras del lenguaje en la salud

Mi nombre es **Javier Cintron** y soy un estudiante de pregrado en la Universidad de Florida Central. Estoy llevando a cabo investigaciones



aprobadas sobre las barreras del lenguaje en la salud y me gustaría tener la oportunidad de hablar con usted **confidencialmente** sobre sus experiencias con la atención médica. Por favor, déjame saber si usted está interesado.

- Investigación **aprobada** por la Universidad de Florida Central, USA.
- Toda la investigación es **confidencial**
- Las entrevistas durarán entre 20 y 60 minutos
- Idioma que se está estudiando: **Español**

001-850-814-9249

Javiercintron50@knights.ucf.edu

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