A QUALITATIVE STUDY OF THE HEALTHCARE EXPERIENCES OF HISPANIC/LATINO PERSONS OF LIMITED ENGLISH PROFICIENCY IN THE RURAL MIDWEST

Emily Pauli

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A QUALITATIVE STUDY OF THE HEALTHCARE EXPERIENCES OF HISPANIC/LATINO PERSONS OF LIMITED ENGLISH PROFICIENCY IN THE RURAL MIDWEST

by

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Thesis Submitted in Partial Fulfillment Of the Requirements for the University Honors Program

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Introduction

The U.S. population is becoming more diverse, and this diversity calls for adaptations that allow our healthcare system to adequately care for all individuals. The group that is currently growing the most quickly in the United States is Hispanics/Latinos (United States Census Bureau, 2016). This group faces additional challenges when it comes to receiving healthcare services, particularly when it comes to rural settings. For those Hispanics/Latinos with limited English proficiency (LEP) residing in rural settings, it can be quite difficult to access healthcare in Spanish, creating for less-than-ideal healthcare experiences.

In the following pages, we will examine some of the healthcare-related challenges that exist in rural communities, as well as how those challenges impact Hispanics/Latinos. We will observe how Hispanic/Latino demographics are changing in the United States and how a language barrier can affect these individuals in healthcare settings. We will assess the need for interpreters in healthcare settings, as well as examine what type of regulation of training and certification interpreters in South Dakota undergo. Following this introduction and a brief description of methods, we will take a deeper look at the experiences of Hispanics/Latinos of LEP, in a qualitative study performed in rural South Dakota.

Healthcare-Related Challenges of Midwestern Rural Communities

According to the United States Census Bureau, a rural area is a territory comprising of 2,500 or fewer people (United States Census Bureau, 2012). On average, the upper Midwest (including states such as Minnesota, South Dakota, and Wisconsin) has a lower population density than the remainder of the U.S., and consequentially has more areas that are considered to be rural. For example, Minnesota is the most densely populated state in the upper Midwest, having sixty-seven people per square mile (the national average being eighty-eight), while Wyoming comprises a meager seven people per square mile (Stingley & Schultz, 2014). These
rural communities face many challenges when it comes to delivering and receiving healthcare. Some of the major challenges that affect healthcare services in these areas include: a shortage of primary care physicians, population decline, difficult travel conditions, and an aging population. In regard to healthcare, two of the areas of complaint among rural residents include availability and delay of care (Stingley & Schultz, 2014).

One major challenge for rural communities is the shortage of primary care physicians. In an article regarding access to care in rural and frontier areas, Shelley Stingley and Heidi Shultz, Program Director and Program Officer of Helmsey Charitable Trust, address the pronounced shortage that exists in the rural communities. They use Montana as an example, stating, “in 2010 Montana had eleven counties comprising 16,120 people and encompassing 23,787 square miles that did not have a single primary care physician” (Stingley & Schultz, 2014, p. 336-337).

Another challenge that rural communities face is population decline. As people migrate toward bigger cities, a toll is taken on the rural areas left behind. These areas lose economic support, causing businesses to close. The number of medical providers in these areas declines because medical facilities are required to cut back on spending or because these areas are not attracting new, young workers (Stingley & Schultz, 2014). The decreased number of healthcare workers means that the ones who do remain may end up being overworked. In these cases, physician burnout is a concern that may need to be addressed.

Along with a shortage of primary care physicians and a decline in population that results in an increased difficulty of recruiting new physicians, rural communities are also challenged by difficult travel conditions. In some cases, people living in rural areas are forced to travel several hours in order to reach a location that offers the medical services they need (Bergsnev, 2016).
Travel time is only increased by inclement weather conditions. Stingley and Schultz describe additional conditions that make obtaining healthcare services more difficult:

[Rural Midwestern areas] feature mainly agricultural terrain and are accessible primarily by secondary roads with minimal cell phone reception and little traffic. Travel is often affected by extreme cold; blizzard conditions; and slippery, icy roads in the winter and early spring months and by scorching heat and road construction in the summer and fall months. Roadways through hilly and mountainous terrain in parts of Wyoming and Montana can become impassable for weeks at a time in the winter. (Stingley & Schultz, 2014)

Difficult travel conditions can result in a delayed receipt of emergency healthcare services. This can also cause people living in rural areas to refrain from seeking preventative healthcare services, resulting in a delayed detection of serious health concerns.

When we take a look at who rural populations are comprised of, all of these challenges become particularly concerning. Rural areas often consist of an aging population, with the elderly population often making up a larger percentage of the residents in rural areas than in more densely populated areas (Stingley & Schultz, 2014). Younger people commonly leave rural areas in pursuit of educational and work opportunities that exist in more urban areas, causing the average age of people in rural areas to rise (Stingley & Schultz, 2014). According to an article on a qualitative study of the opinions of healthcare providers and recipients in a rural Minnesotan community, “health care leaders identified more visits are with patients over the age of 55 and community members identified lack of appropriate services for aging population” (Bergsnev, 2016, p. 95). It is concerning that these rural communities have so many challenges in providing healthcare, because on average this population needs more frequent and acute care.
Some of the main healthcare-related issues that residents of rural communities mention revolve around the availability and delay of provision of care (Bergsnev, 2016). Due to primary physician and specialty care shortages, rural residents have to wait long periods of time or travel large distances to receive healthcare services. In Bergsnev’s study of a rural Minnesotan community, major concerns that participants brought up included being referred to another medical facility or having to wait three to five weeks to see their healthcare provider (Bergsnev, 2016). Bergsnev states that these concerns mirror the results of other studies.

**Hispanic/Latino Demographic Changes**

One group in the rural Midwest that is particularly affected by these healthcare challenges is the rapidly growing Hispanic/Latino population. According to the Latin Business Association’s article, *The Hispanic Population: 2010 Census Briefs*, over half of the U.S. population growth between 2000 and 2010 was attributed to an increase in the Hispanic population (Ennis, Rios-Vargas, & Albert, 2001). The overall population growth in the U.S. during that decade was 27.3 million, with the Hispanic population contributing to 15.2 million (Ennis et al., 2011). The largest growing Hispanic groups included Mexicans, who represented approximately three-fourths of the population increase, followed by Puerto Ricans and Cubans (Ennis et al., 2011).

In South Dakota, Hispanic and Latino populations have grown from comprising of 2.7% of the total population in April 2010 to 3.6% in July 2015 (United States Census Bureau, 2016). This increase in the number of Hispanics and Latinos may call for an increase in language services needed to assist these individuals in their primary language. New Hispanic/Latino immigrants are not always fluent in English and hold on to their native language. For example,
between 2011-2015 it was estimated that approximately 6.5% of people 5 years and older speak a language other than English at home (United States Census Bureau, 2016).

**Language Barrier in Healthcare Settings**

As Hispanic and Latino populations in the U.S. rise, so does the prevalence of language barriers in healthcare settings. Language barriers create a challenge for both patients of LEP and healthcare providers, calling for a need for adaptation. Healthcare systems must find a way to bridge the gap between providers and patients. A couple of possible solutions include training more healthcare professionals in a second language, such as Spanish, or training and hiring more interpreters. Yolanda Partida, National Program Director of Hablamos Juntos, an organization that strives to improve communication between healthcare providers and Hispanic/Latino patients, advocates for this second option. In her article, “Addressing Language Barriers: Building Response Capacity for a Changing Nation,” she states, “the absence of universally available language services is a national healthcare system failure, the burden of which is suffered by patients with limited English proficiency and their healthcare providers” (Partida, 2007, p. 347). Healthcare is one of the most important areas that individuals of LEP need interpretation assistance, because without such assistance, miscommunication can prove to be disastrous. The quality of health and even the lives of these individuals depend on adapting to fill this critical need.

**Interpreters in Healthcare Settings**

When there is a lack of Spanish-speaking healthcare providers in an area, it is important that an interpreter be available to overcome the language barrier between a patient and his/her providers. A simple communication error, such as on how often to take a medication, can result in major consequences, making interpreters an essential part of the healthcare process. However,
using an interpreter to help clear up misunderstandings is not without its own challenges. Professional interpreters are not always readily available, and when they are, doctors and patients do not always agree on whether or not they should be utilized or on how best to do so.

Two studies completed in Sweden by Emina Hadziabic and colleagues examine what it is like to use interpreters in a healthcare setting. Much like the titles suggest, one of these studies, “Healthcare Staff’s Perceptions of Using Interpreters: A Qualitative Study,” (Hadziabic, Albin, & Keikkilä 2010) explores healthcare professionals’ view of this topic, while the second study, “Family Members’ Experiences of the Use of Interpreters in Healthcare” (Hadziabic, Albin, & Keikkilä, 2014) analyzes the family members’ view. Very little qualitative research has been done on the patient’s experience in using an interpreter in a healthcare setting. In looking at these qualitative studies on healthcare providers’ and family members’ points of view (while from a different country, they still focus on relevant issues), and then examining the topic of this paper’s study, the patients’ view, we can gather an idea of the well-rounded picture of the perspectives of most individuals involved in this situation.

In examining the first study, it was found that healthcare staff were in agreement that it is better to use a professional interpreter rather than a family member to translate. They felt that a professional interpreter was more skilled at interpreting accurately and with less bias than a relative of a patient (Hadziabic et al., 2010). It can be more difficult having a family member translate for multiple reasons; the patient may be uncomfortable in divulging all of their medical history and in making all desired inquiries with their family member present, or the family member may be uncomfortable in certain situations such as delivering the news of an unpleasant prognosis. On top of these difficulties, one still runs the risk of having miscommunications if the family member is not well-skilled in both languages. In some cases in the study, healthcare
providers reported that using family members as translators was more time consuming and sometimes resulted in scheduling an additional appointment with a professional translator (Hadziabdic et al., 2010).

While healthcare providers agreed that it is better to use a professional interpreter rather than a family member, they did not always agree on the best mode of interpretation. Some providers preferred having interpreters physically present during a consultation with a patient, while others preferred doing the interpretation via telephone (Hadziabdic et al., 2010). Those who preferred face-to-face interactions argued that interactions were easier when body language, such as pointing at different areas of the body, was more helpful. Those who preferred interpretation via telephone claimed that not having the interpreter present allowed for a better doctor-patient interaction that was not distracted by the third party. One of the study’s participants who advocated for interpretation via telephone stated, “The advantage of using a telephone interpreter is that both the patient and I automatically look at each other when we talk and the interpreter becomes a tool instead of a participant” (qtd. from Hadziabdic et al., 2010, p. 263). Interpretations via phone were also reported as being faster, with less delay in waiting for the arrival of an interpreter.

In examining the second study, it was found that family members of patients had mixed opinions on who would be best to interpret for their loved one. Some participants preferred using professional interpreters as they provided more accurate translations and allowed for more privacy for the patient during a more “intimate/sensitive examination” (Hadziabdic et al., 2014, p. 161). They also preferred using professional translators because accompanying the patient to all appointments sometimes interfered with important events and obligations in their lives. Some participants reported translating for a loved one to be emotionally challenging, and preferred a
professional translator for this reason as well. Other participants preferred to translate themselves instead of using a translator. They felt this way for a couple of different reasons; they did not trust that the professional interpreter would maintain confidentiality, and/or they felt that any bad news would be better delivered by a loved one than by a stranger. When professional translators were used, family members mostly reported a preference for face-to-face translations, allowing body language to be examined.

**Regulation of the Training/Certification of Interpreters**

Because utilizing untrained interpreters in a healthcare setting is neither the most widely preferred nor the safest option, it is necessary for professional interpreters to become trained and certified in a regulated manner. States vary greatly in their interpreter training and certification requirements. South Dakota has particularly lenient regulation requirements for interpreters. For example, the South Dakota Legislation does not require court interpreters to be formally certified (Court Interpreters, 2012). Taking a step toward requiring certification of court interpreters could also lead to more regulation of healthcare interpreters. As there are currently no Masters Programs in Spanish or English-Spanish Translation in South Dakota, implementing such a program could benefit Hispanics and Latinos not only in court rooms, but also in healthcare settings.

**Qualitative Research**

When designing a research project one may choose between taking a qualitative or a quantitative approach. A quantitative research design is appropriate when the research question can best be answered by a large number of responses which can be statistically analyzed. The goal of this approach is to gather data that can be generalized to a larger population. In comparison, a qualitative research design can be defined as “an approach to inquiry that begins with assumptions, an interpretive/theoretical lens, and the study of research problems exploring
the meaning individuals or groups ascribe to a social or human problem” (Creswell, 2013, p. 64-65). A qualitative researcher uses the voices of participants to learn more about such a problem and to create a description of it that quantitative data would not be able to provide.

According to Creswell (2013) there are five different qualitative research approaches; they include: phenomenology, narrative, grounded theory, ethnography, and case study. For this study, we chose to use the phenomenological approach. Following is a brief overview of the five approaches and the justification for why we chose to use the phenomenological approach over the other four.

Phenomenology is the study of experience. The goal of a phenomenological study is to gather information from individuals who have all experienced the same phenomenon and to use that information to create a general description of that phenomenon. In order to create this description, the researcher must look for common themes that prevail throughout the data. This method of research can vary in its number of participants from 3 to 15 individuals (Creswell, 2013). A researcher will use more or fewer participants depending on how long it takes for saturation to be met. Saturation is met when no new ideas are surfacing from the data collection from additional participants. The data that is collected is used to describe the essence of the phenomenon and can be used to better “understand these common experiences in order to develop practices or policies, or to develop a deeper understanding about the features of the phenomenon” (Creswell, 2013, p. 81). We chose to use phenomenology because one of the main goals of this research project is to contribute to the research of and bettering of the healthcare experiences of Hispanics/Latinos with LEP in the rural Midwest. By studying the experiences of participants and creating an understanding of their general essence, we hope that this research may serve as an educational tool for future and current healthcare providers, lawmakers, and all
other individuals interested in this topic. The following research methods would not be quite as effective at accomplishing this goal.

Narrative research focuses on collecting stories from individuals, ordering events chronologically, and using these stories and events to learn how individuals identify themselves. This type of research method is best for “capturing the detailed stories or life experiences of a single individual or the lives of a small number of individuals” (Creswell, 2013, p. 73-74). Such research sheds light on what that individual’s life experiences have been like. It may provide insight on how time, place, and the individual’s culture or other characteristics may have affected these experiences. This approach was not chosen because the focus of this study did not include long-term chronological events.

Unlike narrative research and phenomenology, the goal of a grounded theory study is to “move beyond description and to generate or discover a theory […] for a process or action” (Creswell, 2013, p. 83). In other words, a grounded theory study is similar to narrative research and phenomenology in that participants are still asked to describe their experiences, but unlike these two methods of research, a grounded theory study takes collected data a step further and uses it to generate a theory. Rather than doing a grounded theory study and generating a theory, we chose to use the phenomenology approach allowing readers to create their own interpretations from the data gathered.

Ethnography differs from the previously described research approaches in that it focuses on studying an entire group or community of people who share the same culture. In order to do an ethnographic study, we would need more than 20 or so participants all from the same culture-sharing group (Creswell, 2013). While we are interested in looking at one particular group of people in this study (Hispanics/Latinos with LEP living in rural South Dakota), these individuals
have diversity in their cultural backgrounds, coming not only from different cities, but also, in some cases, from different countries. Culture does play a role in this study, as we are interested in knowing how it affects patients' experiences, but our interest is not in studying culture itself.

While phenomenology, narrative, grounded theory, and ethnography research studies can in some cases be completed relatively quickly, case studies differ in that they require the researcher to study the subject over a long period of time. The subject or subjects of the case(s) are studied in-depth and a case description and case themes are recorded. Because this approach requires a significant amount of time and because it is not necessary to study individuals' experiences so well in-depth for this project, a case study was not a practical choice.

**Purpose of this Study**

The purpose of this study is to gain a better understanding of what it is like to obtain healthcare services as a Hispanic/Latino person of LEP in rural South Dakota. The results of this study will hopefully shed light on what such an experience is like and may provide insight on how best to go about improving such an experience.

**Research Question**

**Grand tour question.** The grand tour question, the question that conveys this study’s subject of interest is, “What is the essence of the phenomenon of seeking and obtaining healthcare as a Hispanic/Latino individual with limited English proficiency in rural South Dakota?” While participants were not asked this question directly during interviews, the questions that were asked all centered around this general idea. The interviews specifically focused on the role that language and communication play in people’s healthcare experience, and as interviews proceeded, culture’s influence became of special interest as well. In Appendix C, a list of interview questions can be found in both their English and Spanish forms.
Methods

Participants

The participants in this study were residents of a rural town in South Dakota. To be eligible to participate in this study, individuals had to be 18 years or older and identify as Hispanic or Latino. They also had to have received healthcare services in South Dakota or elsewhere in the Midwest, and had to self-rate as having limited English speaking abilities.

Initially, participants were found through the help of a community partner. This community partner invited me to a social gathering of individuals who were good candidates for the study. At the social gathering, she introduced me to everyone present and allowed me to explain my research project. Fliers containing general information regarding the study were distributed. A copy of the flier can be found in Appendix A. Those who were interested in participating arranged a time and place in which I could meet with them. Through the help of these initial participants I was able to recruit more individuals as a snowball effect took place and initial participants introduced me to more individuals.

My goal for this study was to recruit somewhere between six to ten individuals. In total, seven people participated. Saturation of the study was met with interviews of these seven people, as many people had similar responses to questions and no new ideas were surfacing. Eligibility was met in all cases, with the exclusion of one individual who rated his/her English-speaking abilities to be at about sixty percent. Because this individual qualified in all other aspects for participation, and because sixty percent can still be considered somewhat limited, we allowed this individual to participate.

Role of the Researcher

As a researcher for this study, my role included preparing interview questions, conducting interviews, and analyzing all data collected. While I did my best to remain neutral
and not allow my personal biases to affect any part of this study, it is important that I disclose all personal biases and motives for research.

There were two big factors that played into my decision to do this research project – my academic interests and a personal experience that I once had. My academic interests include psychology, Spanish, and healthcare. This study was perfect for me because it allowed me to combine all my interests. I am a psychology major with a Spanish minor and plan on continuing my education in the University of South Dakota’s Physician Assistant Studies Program in the Fall. Besides Spanish classes, my exposure to Hispanic/Latino cultures in the past includes a semester abroad in Sevilla, Spain, a few weeklong trips to Mexico, time spent with Hispanic/Latino friends, and a recent weeklong trip to Guatemala.

Along with my academic interests, a personal experience aided in initiating my desire to do this type of research. This experience occurred during my junior year of college when I went to visit a nursing home located in South Dakota. At the nursing home resided an individual who spoke Spanish, but little English. I listened as the individual and a healthcare worker made an unsuccessful attempt to communicate with each other as neither one could understand the language of the other. This made me wonder what it would be like to be in this individual’s position. I thought that it must be difficult to rely on someone for your healthcare needs when even a simple conversation is a challenge.

My hope for this research project was to gain some insight on what it is like to be a Hispanic/Latino individual with LEP seeking and obtaining healthcare in the rural Midwest, and to use this information to deduct some methods or approaches that would improve these individuals’ healthcare experiences. Another hope was that results from this study would help me
to become a more culturally competent Physician Assistant in the future, and would help other future or current healthcare providers as well.

**Procedures**

In October, 2016 I arranged to meet my community contact at a small social gathering to begin looking for potential participants for my research. As previously stated, my community contact introduced me to everyone present and I was given the opportunity to explain my research project and distribute fliers. A majority of those present were interested in the project and willing to participate. Those who were interested set up a date and time to meet with me. They also chose between meeting to interview at the local high school or at their homes.

Originally I had planned on interviewing all subjects in a classroom at the local high school. We had been granted permission by the principal of the school to use a classroom on weekends for interviews. However, before meeting with potential participants at the social gathering, my community partner informed me that people may be more comfortable interviewing in their own homes. Many of those who would be at the gathering had young children to care for and it would be more convenient for them to stay at home rather than making a trip to the high school. Before beginning the search for participants, I contacted the IRB and an amendment to the study was made allowing interviews to take place at participants’ homes should they prefer that over the high school. This proved to be a beneficial amendment as all participants chose to be interviewed at home.

After setting up preferred dates and locations, I began meeting with participants to interview them. They graciously welcomed me into their homes and were very kind to me. First I explained more about the study and gave them each a consent form and plenty of time to read it over. In some cases, I read the consent form aloud to help participants who were not quite
understanding something. Participants were then given the chance to ask any questions that they had about the study. Those who understood everything and had no further questions signed the consent form and were given a copy for their records. There was one participant who I struggled to communicate with, so I had her wait to sign the consent form until she was able to speak with Dr. Helmer about her concerns. Participants then chose a pseudonym to which their responses in the interview would be linked with in place of their actual names. Some participants made up a name while others chose one from a list of random names that I had created.

After consent forms were signed and pseudonyms chosen, Dr. Helmer was called via Skype and participants were greeted and given an additional opportunity to ask questions. Dr. Helmer was able to clear up any confusion, as she is much more fluent in Spanish than I. When everyone was ready, we used the QuickVoice application on my phone to start a voice recording of the interview and began asking questions. We began the interviews by asking “Preliminary questions” followed by “Main questions” and “Probing questions,” all of which can be found in both their English and Spanish versions in Appendix C. I asked participants these questions, and both Dr. Helmer and I also asked some supplemental questions when necessary. At the conclusion of each interview the voice recording was stopped and the participant was thanked for their participation and time. Participants were asked if they would like a copy of the interview transcript to review and make changes to should they wish. One participant affirmed that he would like a copy while the other six participants declined and stated that they were confident in their responses. More thanks were given, goodbyes were said, and I left the participants’ homes.

Following interviews, I played back the voice recordings and wrote out transcripts. This was a very long and tedious process because Spanish is not my first language and some parts of the recordings were difficult to hear and understand. There was quite a bit of distracting
background noise as many of the participants had young children nearby playing with the television volume, fans, bathtub faucets, etc. When I had transcribed all that I was able to understand, Dr. Helmer listened to the recordings (which I had sent her via email) and edited my transcriptions, fixing words I had misinterpreted and adding in words I had missed. Between the two of us it took many, many hours to complete the transcriptions. The participant who wanted to review his transcript, Rubén (pseudonym), was given a copy to review. Following review, Rubén informed me that he did not wish to make any changes.

After transcription and review were completed, all transcripts were then translated from Spanish to English. This process was not quite as difficult as transcription, but it still took many hours. After I went through and did my translations of the transcripts, I met with Dr. Helmer and we went through the documents together. She edited my translations and taught me the meaning of many words and phrases that I was unfamiliar with. While both the transcription and translation processes were quite educational, I enjoyed the translation process much more than transcription because I felt like it had taught me a lot.

During the entire process of transcription and translation, data was kept safely on password protected devices, as well as kept anonymous, linked only to the pseudonyms that participants chose. Signed consent forms were locked away in Dr. Quevillon’s office following interviews. Transcripts and recordings will be destroyed at the conclusion of the study.

Data Analysis

Following translation, transcripts were thoroughly reviewed several times and common themes within them were found. Quotes that were linked with these themes were selected and sorted through, and during this process subthemes beneath major themes were developed. These themes and subthemes are meant to create a description of what it is like to receive healthcare services as a Hispanic/Latino with LEP in rural South Dakota. I was surprised by how prevalent
the themes were throughout the data. Many participants had the same or similar things to say about their healthcare experiences.

**Verification and Ethical Considerations**

**Verifications procedures.** In order to preserve the integrity of this study, the following verification procedures were employed:

1. A native Spanish speaker and one of the study’s committee members, Dr. Helmer, verified and corrected the Spanish used in this study. She reviewed the flier, consent form, and questions used for the study, cleared up any misunderstandings that occurred during interviews, and advised me in the revisions of both the transcriptions and translations of interviews.

2. Participants were interviewed until saturation was met, meaning no new ideas were surfacing with additional interviews.

3. I gave participants the option to review and revise a copy of their transcripts. One transcript was reviewed but no revisions were requested. Had there been any revisions made, the transcripts would have been amended.

4. After I identified a theme and subthemes in the data, the director of the committee reviewed the interviews and agreed with the themes I had chosen. Dr. Helmer was able to help verify the chosen themes as well as she was quite familiar with the interview content, having been present during the interviews themselves and having assisted with transcription and translation processes.
Ethical considerations. In order to preserve the integrity of this study, the following ethical considerations were taken into account:

1. All procedures were done according to IRB guidelines. Before commencement of the study, approval of both the study and one additional amendment was given.

2. Participants were informed that they could drop out of the study at any time, with no consequence to them. They were informed that their participation was voluntary.

3. Participants were informed of the risks and benefits of this study. They were told they would not receive compensation for their participation.

4. Participants were informed of their right to ask questions, and all questions were answered.

5. The actual names of participants were not linked to interview data. Participants were allowed to choose code names for themselves. These names are the only names connected to the data.

6. All names of towns have been omitted to further protect the identity of participants.

7. Consent forms were signed by participants and stored in a secure location in my thesis director’s research space.

8. All data collected from individuals was kept confidential. Interview recordings and typed transcripts were kept on secured devices.

9. Interview recordings and transcripts will be destroyed following the conclusion of this study.
Results and Discussion

Participants

Seven individuals participated in this study. Of the seven, six were female and one was male. All participants were over the age of 18. They all self-identified their primary language to be Spanish. Five of the participants rated their English-speaking ability as “little,” “none,” or “low.” The other two used percentages to describe their ability, with one rating their ability at fifty percent and the other at sixty percent. These two individuals acknowledged that their ability has not always been at this level, but has improved with time and experience. All seven individuals had received healthcare services in rural South Dakota in the past.

Themes

A total of four major themes, each with two subthemes, arose from the study’s data. The major themes include: (1) inadequate communication (subthemes: desire to understand more – information lost in translation and desire to say more – hindered by inability and discomfort), (2) inconvenience (subthemes: traveling and waiting), (3) vulnerability (subthemes: depending on others and trusting others), and (4) quality of care and service (subthemes: respecting culture and patient care satisfaction). Figure 1 exhibits a diagram of these themes and subthemes. These themes will be further discussed using interview quotes as illustration. These quotes will be presented in both their English and Spanish versions.
Figure 1: Themes and subthemes of the healthcare experiences of Hispanics/Latinos with LEP in rural South Dakota.
Theme 1. Inadequate communication. One common theme that persisted throughout the interview data was inadequate communication between the study’s participants, medical personnel, and translators. While it is expected that an individual with LEP would have difficulties communicating with nurses and doctors who only speak English, there are many other challenges that may not be quite so evident. Some of the challenges that surfaced from the interview data include: communicating in the absence of a translator, communicating with a poor translator, and hindrance of communication due not only to a participants’ inability, but also to their discomfort. These challenges will be discussed below.

Desire to understand more – information lost in translation. Participants described a desire to understand more during medical appointments. They revealed that they were uncomfortable going to the doctor without having a translator, but when they did have a translator, other complications arose, namely the translations were inaccurate or incomplete. Lucía spoke on what it is like for her to visit the doctor without a translator, stating, “I have felt nervous because I do not know if she understands me and she does not know if I understand her.”¹ Lucía was put in a situation in which her health and wellness were at risk and it caused her to feel nervous. It also brought out other emotions as well; Lucía stated, “The only problems that I have had have been when I go [to the doctor] alone because I have to. But one is afraid to because we do not know exactly what s/he is saying to you, only the little that one understands.”² Visiting and accepting treatment from a doctor whom one cannot understand would be a terrifying situation, especially in a more serious or delicate medical case. In such a case, it would

¹ Me he sentido intranquila porque no sé si ella me entiende ni ella sabe si yo le entiendo.

² Los únicos problemas que yo he tenido han sido cuando voy yo sola [al doctor] porque tengo que. [...] Pero si con miedo lo hace uno porque no sabemos exactamente lo que te está diciendo no más lo poquito que entiende uno.
be reasonable to assume that having a translator would be very beneficial. However, after speaking with participants it became apparent that having a translator creates new challenges.

Translators run into a couple of different difficulties while interpreting. These struggles affect the translation itself. Zoe spoke on one of the downfalls of translation; she stated, “The bad part is that one loses information when there is a translator in the middle. The information is not complete.” Information can be lost due to multiple reasons. One possibility is that the information is being spoken at a rate too quickly for the interpreter to translate. Another reason is that there may not be a direct translation for some words or phrases spoken. María touches on an additional reason in the following example.

When asked what she thought about her experience using a hospital-provided translator, María stated:

Well, I thought over it carefully. But, at the same time I did not understand him much when he translated into Spanish. I did not understand much because the person who translated for me through the phone almost did not give me the information well. That is to say s/he speaks more perfectly in English, I think, than in Spanish. It is common that bilingual people will speak one language better than the other, like María noticed of her translator. This is where it becomes important that a translator has received enough education to communicate effectively in both languages. In fact, in order to avoid as many miscommunications as possible, it is best that a translator receives training to become a professional translator. During her interview, Kimberly stated that the people hired as medical

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1 Lo malo es que es una pierde información cuando hay un traductor en medio. La información no se da completa.

4 Pues, lo pensé muy bien. Pero, al mismo tiempo no mucho le entendí al que me traducía en español. No mucho lo entendía bien porque la persona que me traducía a través del teléfono casi no me daba bien la información. O sea, habla más perfectamente el inglés creo que el español.
translators are not necessarily professional translators, and that in some cases these translators do not always explain everything that is spoken during a medical visit, causing her to not fully understand the doctor. Unlike other states, South Dakota has no law requiring translators to have professional training and education. This absence of translator standards is a danger that could lead to many problems not only in the medical field, but also in many other fields such as law and business.

*Desire to say more – hindered by inability or discomfort.* A desire to understand more is coupled with a desire to say more. Participants described how their expression of thoughts during medical appointments is hindered by discomfort or by an inability to communicate. For some, both of these obstacles apply.

In Rubén’s case, language is the biggest issue. Rubén, who described his English proficiency to be around sixty percent, feels comfortable enough to visit the doctor without a translator. However, he does so with some difficulties; he stated, “Sometimes one would like to say more, but one reaches the limit on what one can say, that is, the language.” María and Gabriella also commented on the challenges that the language barrier creates. They both stated that if they were to visit the doctor without a translator, they would neither have the ability to explain their symptoms to the doctor nor understand the doctor’s responses.

While communication is hindered by the language barrier, it is further hindered by the discomfort that arises in having a translator privy to one’s personal information. When the interpreter is a relative or a friend, the participants said that they were sometimes uncomfortable sharing some things with them. Kimberly, who has accompanied friends to doctor’s appointments in the past, shares why this can be a problem:

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5 Quisiera uno a veces decir más, pero que ya no le alcanza el recurso a uno, o sea, el idioma.
It is a problem because sometimes [the person I’m accompanying] does not feel one hundred percent comfortable saying all that they want to say to the doctors. Because she knows me and it embarrasses her when I’m there. So, as a result of that sometimes they do not explain to the doctor what they really feel or what the problem is.\textsuperscript{6}

Participants voiced some medical issues to be more difficult to discuss than others. For example, some of the women interviewed expressed discomfort in having a translator present while discussing women-specific medical issues with the doctor. Gabriella, for example, stated that she would say things differently or would ask the doctor more questions pertaining to “women things”\textsuperscript{7} as she referred to them, if her husband was not present translating for her. Rather than feeling discomfort herself, she said that she refrained from talking about such topics with the doctor because she “would feel bad making her husband uncomfortable.”\textsuperscript{8} She stated that having a nonfamilial translator would not make her feel at ease either; she would prefer to go alone. Unfortunately, that leaves her in a conundrum because her current level of English would not allow her to effectively communicate with a doctor, leaving her with few options.

Gabriella’s conundrum would be solved if a Spanish-speaking doctor or professional translator were hired in the area. Kimberly proposes another possible solution when she stated, “We have to learn the language, and although we can’t speak it much, sometimes we feel safer [visiting the doctor] alone than when someone else goes.”\textsuperscript{9} Rubén is an advocate for this option

\textsuperscript{6} Es problema porque a veces esa persona no se siente cien por ciento cómoda de decirle todo lo que quiere decirle al doctor. Porque me conoce y le da pena conmigo. Entonces, eso le ocasiona. Le ocasiona que a veces no le explica todo al doctor lo que realmente tiene.
\textsuperscript{7} Cosas de mujeres
\textsuperscript{8} Me da pena con mi esposo
\textsuperscript{9} Tenemos que aprender el idioma y aunque no lo podamos hablar mucho, a veces nos sentimos más seguros [visítando al doctor] solos que cuando va alguien más.
as well. He explains that one is not all alone in trying to understand. He stated that, "[the doctor and nurses] understand that I do not speak much English and they try to help me."\(^{10}\)

**Theme 2. Inconvenience.** A second common theme that persisted throughout the interview data was inconvenience. Not having readily available medical assistance in one's own language can be very inconvenient. The entire process can take up a lot of time. First, one has to find assistance in making a medical appointment. Second, one must drive to a town where one's language barrier can be accommodated, which can either be somewhere where a doctor speaks Spanish or somewhere where an interpreter is provided. Third, in the case where an interpreter is being used, one must wait for said interpreter to be available. This slow process is quite inconvenient, and when a circumstance calls for immediate medical attention, it can quickly turn from bothersome to lethal.

\(^{10}\) [El doctor y las enfermeras] entienden que no hablo mucho inglés e intentan ayudarme
Traveling.

Just as people’s actual names are not used in this study, the names of towns are not used either as a safety measure to help protect participants’ identities.

Figure 2. Illustration of distances participants travelled to obtain medical assistance in Spanish.
The town in which interviews were conducted does not have Spanish-friendly medical services available. Zoe stated that there are no translator services in the hospital or clinic in this town (her town of residence), so she had to travel to Town B, located roughly an hour away, in order to receive translator services. When she has gone to the doctor in her town of residence, she said she has to bring her cell phone with in order to use a Google Translate app to help interpret. Google Translate provides rough and sometimes inaccurate translations and is not a very safe option to use for medical appointments. Zoe stated that if she has no internet, then she is unable to use her app and cannot communicate.

Luna and Kimberly confirmed Zoe’s statement about the lack of translators provided in the town, and stated that they had to travel to Town B to go to the doctor as well. Lucía confirmed this statement as well, but said that she travels to Town C, located about two hours away, to go to her family doctor who speaks Spanish. “It is more convenient for us,”11 she said. She reported that her family makes a trip to visit their doctor there once or twice a year. Lucía also revealed that the Sanford clinics in Town B, C, and D always offer a phone interpreter as well.

Like Lucía, María mentioned that she has also traveled two hours to visit a doctor who speaks Spanish. She visited Town A to receive these services. When possible, for those who are exceptionally limited in their English proficiency, it seems that visiting a doctor who speaks Spanish is preferred over utilizing a translator service, and that visiting the doctor alone is a last resort option utilized only during emergencies. This means that these individuals will be traveling approximately 2-4 hours roundtrip every time they wish to visit the doctor. If weather conditions are unfavorable for travel, which is not uncommon in a South Dakotan winter, travel

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11 Es más cómodo para nosotros
time can be increased or travel can be impossible altogether, delaying an appointment even further.

**Subtheme 2. Waiting.** After travelling to a location where a translator is available for a medical appointment, participants noted that even more time is taken up waiting for the translator. Zoe spoke on the inconvenience of waiting, “Many times I have to, to wait. To wait for the translator to come or to be online, or wait many minutes for her to translate through the phone.”\(^{12}\) On her last visit, she said she had to wait half an hour. After the translator is available, translating the medical appointment can finally begin. Rubén describes the translation process as “rather slow, because it delays one, that is, I feel that it takes us more time.”\(^{13}\)

Sometimes the inconveniences associated with being an individual with LEP in an area with few translators can result in avoiding a doctor’s visit altogether. When asked if there has been a time when she did not go to the doctor due to lack of a translator, Zoe said, “Yes, here in [town of residence]. I do not want to be cared for here because they do not have a translator.”\(^{14}\) Responding to this same question, María said, “Yes, but almost [always] they searched for a way to communicate with… with me, or they searched for someone who would translate for me.”\(^{15}\) The fact that Zoe and María were forced to forego treatment altogether is incredibly concerning. Delaying or avoiding a visit to the doctor can have serious consequences. Medical issues left untreated could turn into major problems and neglected preventative healthcare measures could result in issues as well.

\(^{12}\) Muchas veces tengo que, que esperar. Esperar al traductor a que venga o que esté en línea, o esperar varios minutos para que me traduzca en el teléfono.

\(^{13}\) Más tardado, porque se tarda uno, o sea siento que se tarda uno más haciendo eso.

\(^{14}\) Sí, aquí en [ciudad de residencia]. Ya no quiero atenderme, debido a que no tienen traductor.

\(^{15}\) Sí, pero casi ellos buscaban la manera cómo comunicar con... conmigo, o sea buscaban a alguien que, que me traducía a mí.
Theme 3. Vulnerability. A third common theme that persisted throughout the interview data was vulnerability. Having to depend on and trust others during the healthcare process makes one very vulnerable. This is a current theme that can be found in all healthcare situations, but in the case of this study’s participants, it is taken to a whole new level.

Subtheme 1. Depending on others.

In seeking medical care, the participants had to depend not only on doctors and nurses to be able to care for them, but also on the translator in the middle. They had to depend on the competence of the translator to provide them with accurate translations, but to start with they had to depend on a translator to be available for them when needed. When one cannot count on a translator being available, Kimberly explained that Hispanics who speak little English turn to one another for finding help when it comes to going to the doctor. In the case of an emergency, when travelling an hour or two for medical services is not advisable, they try to assist each other in finding an available translator who could accompany them to the doctor. In some cases, this could mean that children with varying degrees of understanding will be used as translators. In other cases, it could mean that adults who are not exceptionally fluent in one language or the other will be used. Either case could result in an uncomfortable situation full of misinterpretations and misunderstandings.

Participants shared the types of translators that they have used in the past and how they felt about it. For example, Kimberly said that she brought her daughter to the doctor when her daughter was six or seven years old and described having her translate as being “really hard.” It can be particularly difficult when children are placed in such a position because they may not have the emotional or intellectual maturity to effectively deal with the situation. They may not

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16 bien difícil
understand what the doctor is explaining or they may be upset in finding that their parent or relative is sick. It could also be quite uncomfortable or embarrassing for both the child and patient when personal matters are discussed or when a procedure requires the removal of clothing.

For the comfort levels of all involved, when possible it is often better to depend on someone else, for example, a spouse, rather than a child for interpretation during medical appointments. A few of the participants mentioned relying on their spouses for interpretation assistance. For example, Gabriella relies on her husband a lot; she stated, “For all that we do, [my husband] is the, the one who helps me, well me, with the kids at the doctor, at school, and everything.” However, Gabriella does not want to always have to rely on her husband and on others for help. She mentions that it could be beneficial if she learned English so that she could go to the doctor alone.

Rather than relying on a family member, Luna had her friend translate her personal information at her medical appointment. When asked if she was comfortable with this, Luna responded, “Well yes. Well she had to help me because I could not.” In Luna’s situation along with many others', it is almost as if being in this circumstance where assistance is sparse forces one to accept that they must depend on others.

The worst situation is when there is nobody one can depend on. Kimberly spoke on this topic. She stated,

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17 Para todo lo que hacemos, él es el que, el que me ayuda, pues a mí, para doctor de los niños, de la escuela, y todo.

18 Pues sí. Pues tenía que ayudarme porque no podía yo.
It is difficult to find help in your primary language... in your language like, for example, in this case the language is Spanish. It is difficult because, for example, here there are almost no people who can help you in Spanish. The doctors regularly only speak English and do not speak Spanish. And this, where we are living right now, is a very small city, which ninety percent or ninety-five percent of the... of the community is one hundred percent American or white. [...] Yes, it is one of the problems that we do not have assistance in our language. There are many people who sometimes... do not understand any English and... there is no one to help you. There is no one to help you.\textsuperscript{19}

\textit{Subtheme 2. Trusting others.} After finding someone who can be depended on to translate, one next has to worry about whether or not this individual can be trusted with one’s private matters. When one really trusts their translator, it makes for a much more comfortable experience. Lucía had one such experience when she was in the hospital for multiple days and had her adult daughter translating for her. Lucía described the experience with her daughter, stating, “She was with me and I felt protected because she was there, and she knew what was hurting me. And I was – what is the word? – trusting that she said everything correctly.”\textsuperscript{20}

Having that trust for a translator allows for better communication and care provided. It also takes away some fear, allowing the patient to be more relaxed, which is important for a quick recovery.

\textsuperscript{19} Es difícil. Es difícil encontrar ayuda en tu idioma principal...en tu idioma como, por ejemplo, en este caso la lengua en español. Es difícil porque, por ejemplo, aquí casi no hay personas que te puedan ayudar en español. Los doctores regularmente, solamente hablan inglés y no hablan español. Y esto, donde estamos viviendo ahorita, es una ciudad muy pequeña, la cual... el noventa por ciento o noventa y cinco por ciento de los... de la comunidad es cien por ciento americano o blanco. [...] Sí, es uno de los problemas de que no tenemos asistencia en nuestro idioma. Hay mucha gente que a veces... no entiende nada de inglés y... no hay quien te ayude. No hay quien te ayude.

\textsuperscript{20} Ella estuvo conmigo y yo me sentía protegida porque estaba ella, y sabía lo que me dolía, lo que tenía. Y yo estaba—¿cómo es la palabra? —confiando que ella estaba diciendo todo correcto.
Other participants interviewed did not always have quite so fortunate circumstances. Kimberly was one such individual. She explained why it is so important that one can trust their translator, stating,

Sometimes you have to have privacy, confidentiality too, and for example you are trusting this person, whom you don’t even know, with your health problems. You do not know how trustworthy they are, you just trust them because the people say so, but sometimes this turns out worse [than not having a translator], it turns out worse. I have had these bad experiences.²¹

If there is fear that everything communicated between one and one’s doctor will not be kept confidential, it can be hard to feel comfortable fully disclosing all symptoms and asking about all concerns. It can be difficult to find such an individual when professional translators are not available.

**Theme 4. Quality of service and care.** A fourth common theme that persisted throughout the interview data was quality of service and care. There are many ways in which this can be measured, but in this case, it seems most relevant to look at how culturally respectful medical personnel have been towards the Hispanic/Latino participants as well as the participants’ overall patient care satisfaction as these were two topics that were commented on in all interviews.

**Subtheme 1. Respecting culture.** A couple of the participants interviewed felt that their culture was not always respected by medical personnel, in fact, they said that they had felt discriminated against due to their race. In relaying a situation in which she did not bring enough

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²¹ A veces tienes que tener la privacidad, la confidencialidad también, y por ejemplo tú le estás confiando a esa persona, que ni conoces, tus problemas de salud. Tú no sabes qué tan confiable solamente te confías porque la gente dice, pero a veces sale peor, sale peor. Yo he tenido esas malas experiencias.
money with her to pay for her full appointment cost, María described a clinic worker who was harsh with her as “very racist.” She said “They are very hard with one, well, sometimes because one is not of the same color or… or one is not from, born here, in the United States or is not a gringa. In that moment, I said ‘why do they treat people like that?’” María tried to reason that maybe it was just the lady’s job or just her personality that caused her to be so harsh, but she had felt singled out and discriminated against.

A second participant reported feeling discriminated against as well. When asked if she had experienced any cultural differences when visiting the doctor, Kimberly stated,

Yes. And in some form also, racist also, a little bit. Not all. Not all. Not all. I cannot say all. But yes, sometimes they think that Hispanics, that because we do not speak English, we are not educated people, that we are not people who study, and it’s not like that. The fact that you live in another country does not mean that in your country you did not go to school. […] I have seen it more among, for example, the nurses. The nurses treat you more like you are very stupid, like you don’t know anything, or like… I don’t know. I do not want to talk bad, but that is the way I have seen it. And it is not like this. It is not like this.

Other participants disagreed and said that they have never experienced a cultural barrier or felt discriminated against while visiting the doctor. When asked if she had ever gotten the impression that medical personnel were treating her any different than other patients, Gabriella responded,

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22 muy racista
23 Ellos son muy duros con una, pues, tal vez porque uno no es de su mismo color verdad o… o uno no es de, nacida de aquí, de Estados Unidos o no es gringa. De ese momento, yo dije ¿por qué tratan a la gente así?
24 Sí. Y en cierta forma también, de racista también, un poquito. No todos. No todos. No todos. No puedo decir todos. Pero sí, a veces piensan que los hispanos, que porque no hablamos inglés, no somos personas preparadas. No son personas que estudiaron, y no es así. El hecho de que viva en otro país no quiere decir que en tu país no fuiste a la escuela. […] Yo lo he visto más en el área, por ejemplo, de las enfermeras. Las enfermeras te tratan más como que eres muy tonto, como que no sabes nada, o como que… I don’t know, no quiero hablar mal, pero así de esa manera lo he visto yo. Y no es así. No es así.
“No. No, for me they have always treated me well.”25 Luna agreed with this sentiment saying, “No, they treat me like any patient.”26

**Subtheme 2. Patient care satisfaction.** General patient care satisfaction was high. There were very few complaints about the care received.

Rubén stated that he has received good care and that he has no complaints.

Luna described the medical services she has received, saying, “Good. Very good. Very good service. I have had a good experience with doctors here.”27

On describing her healthcare experiences, Lucía said, “They always treat me well. There have been no problems. Only the language.”28

Gabriella had stated that while she felt uncomfortable having her husband translate at the clinic for her, she was satisfied with her care. She said, “but, as for the doctor’s care there, it is very good. They care for me well.”29

Kimberly was not quite as satisfied with the healthcare services she has received. When asked if she has received good services when visiting the doctor, Kimberly stated,

> It is more or less good. It is not excellent. I am going to tell you why. I always have complained about this. To me, if somebody asks me to speak, I am always going to speak my mind. For example, in the area where we are there is a thing that, for example, at night in the hospital they do not have, they have doctors that they call umm... ‘on call.’ Or what do you call it? The doctors that they only call when an accident happens or something happens and a sick person arrives. The doctor arrives, does not arrive

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25 No. No, para mí siempre me han tratado bien.
26 No, me tratan como cualquiera paciente.
28 Siempre me atienden muy bien. No ha habido ningún problema. Solo el idioma.
29 Pero, de la atención allí de los doctores pues, muy bien. Me atienden bien.
immediately or they have him/her there in the hospital. S/he arrives like fifteen, twenty
minutes, an hour sometimes, late. And the doctor arrives in flip flops, he arrives in shorts
like he was at his house, tending to, I don’t know what. I say, one has to have respect for
the patient. I think. I was not surprised or anything like that, but I think that respect
comes first.30

When asked if they had any suggestions for bettering healthcare visits, participants had
one main suggestion – that the language barrier between them and the doctor be somehow
bridged. One of the most popular proposals mentioned was that doctors learn even a little bit of
Spanish so that there could be at least some understanding between the patient and the doctor.
One participant proposed that Avera or Sanford clinic could maybe offer language classes to
medical workers. A final suggestion and one which I found to be quite intriguing, was given by
Kimberly. She said,

My idea is that we should have umm, maybe it is small, but at least one, ONE... they are
bringing many doctors from different places, at least one who umm, let’s say who doesn’t
see patients every day but, for example once a month or something, who sees us
Hispanics... because this population right now is growing. Before we were very small
when I arrived here. Right now, we are already almost more than double than what we
were six years ago. So umm, I think that if it is growing, it would be good that they
helped us with that, and people would feel better also, more comfortable to go to the

30 Es más o menos bueno. No es excelente. Le voy a decir por qué. Yo siempre me he quejado de esto. Yo a mí, si
me dicen que diga, yo voy a decir siempre. Por ejemplo en el área donde estamos hay una cosa que, por ejemplo,
en la noche el hospital no tiene, tiene doctores que le llaman, este... ‘on call’. ¿O cómo le llaman? Los doctores
esos que solamente los llaman cuando pasa un accidente o pasa algo y que llega un enfermo. El doctor llega, no
llega inmediatamente o lo tienen allí en el hospital. Llega hasta como a los quince, veinte minutos, una hora a
veces tarda. Y el doctor llega en chandal, llega en short como que estuviera en su casa, atendiendo yo no sé qué.
Digo yo, uno tiene que tener respeto por el paciente. Pienso yo. Digo no me asombro ni nada de eso, pero yo
pienso que el respeto es primero.
doctor. I told you s/he doesn’t have to see patients every day that they are there, but umm, at least once a month that they treat patients in Spanish, or something like that. That would be good because many of us sometimes will wait until the last minute to go to the doctor because we don’t speak the language well and when you feel really sick you have to go because you do not have another option. I think that is a proposal that I hope could be accomplished.\footnote{Mi idea como digo es eso, que, de que deberíamos tener este, como te digo, a lo mejor que está pequeño, pero por lo menos, uno, UNO, pues vienen, están trayendo muchos doctores de diferentes lugares, por lo menos, uno que este... ponle que, que no dé consultas todos los días, pero si por ejemplo, una vez al mes o algo, que a nosotros los hispanos... porque esta, esta población ahí está creciendo. Antes éramos bien poquitos cuando yo llegué aquí ahí está ya somos casi más del doble de lo que estaba hace seis años. Entonces este piensos que, si está creciendo, sería bueno que nos apoyaran con eso y la gente se sentiría más a gusto también, más cómodo ir al doctor. Te digo, no tiene que ser la consulta todos los días como están allí, sino este, por lo menos una vez al mes que dieran una consulta en español, o algo así. Eso sería bueno porque mucha gente a veces nos esperamos hasta el último minuto para ir al doctor porque no hablamos bien el idioma y ya cuando de plano te sientes muy enfermo tienes que ir porque no tienes otra opción. Pienso que esa es una propuesta que ojalá que se pudiera cumplir.} 

\textbf{Reflections}

\textbf{Limitations of Study}

One limitation of this study is that a convenience sample was utilized. All participants lived in the same town. They may have also belonged to the same social circle because most participants were recruited for the study at the social event that I attended. Being at the same social event may mean that the individuals who participated have more characteristics in common than a random sample would provide. Because all participants reside in the same town and may have more similar characteristics than average, it is possible that this study may not be able to be generalized to other populations.
A second limitation to this study is that six of the seven participants are female. Again, this may mean that the study may not be able to be generalized to other populations, in this case, to males.

A third limitation is a language/cultural barrier. This barrier may come into effect in a couple of different ways; communication may have been misinterpreted or stunted. Participants may have misunderstood questions or we may have misunderstood answers due to the fact that my Spanish is not at the most advanced level and some of the language that Dr. Helmer and I used may have been too formal or unfamiliar. The participants interviewed came from a wide variety of educational levels and some may have understood our questions more or less due to this educational variation. Communication may have also been stunted due to unease or fear to speak one’s mind. Participants may not have been fully comfortable disclosing their true feelings to me as I am not from their culture. My presence, as an outsider, may have affected what was said. Participants may have also been hesitant to speak their minds because of Dr. Helmer’s title as a USD professor.

**Recommendations**

I recommend that South Dakota legislators take action in creating regulations for interpreters. Based on the results of this study, it can be deduced that having trained and certified interpreters readily available would greatly improve the challenges that were touched on in all four of the study’s themes: inadequate communication, inconvenience, vulnerability, and quality of care and service. Having a trained interpreter available would likely decrease miscommunication between the patient and doctor, and in some cases would increase comfort levels, allowing patients to divulge more to their doctors without the discomfort of sharing personal information with a nonprofessional. Inconvenience levels would also decrease if these individuals could be readily available to translate. Patients would also feel less vulnerable, no
longer having to worry that no one will be able to help them. Overall, patient care satisfaction would be likely to increase as patients begin to feel that they are able to visit the doctor more easily while feeling less vulnerable, and they are able to communicate more effectively to get everything out of the experience that they want.

I recommend that more research concerning healthcare professionals’ point of view on this topic be completed. Looking at a situation from the viewpoint of each person involved may be helpful in coming up with the best solution. Healthcare providers may have some useful feedback and suggestions that could be helpful in creating the best possible care methods for this population. I also recommend that healthcare providers take the effort to become knowledgeable about providing care for LEP individuals so that they understand the challenges involved and are able to sympathize with and better help these persons.

I recommend that additional studies be performed, further studying the healthcare experiences of Hispanic/Latino persons of LEP in the rural Midwest. This is a very specific population and little research has been done in this area. Additional studies are necessary in order to determine if the findings of this study are consistent with the results of other studies and can be generalized to other individuals.
References


Appendix A

Flier – English version

Share Your Voice
Research participants needed

Have you ever had trouble communicating with your doctor? Have you ever needed to bring a
translator to a doctor visit? A research study is being conducted to learn more about possible
language barriers in healthcare experiences. We are interested in interviewing research
participants in order to hear their stories and better understand how these barriers affect care
received.

When: Weekends in October and
November

Where: [name of school]

Participants will be interviewed in a private classroom at [name of school]. The interviews will
last approximately an hour and the identities of participants will be kept confidential. There are
no apparent risks for participating in this study. The only benefit will be the possibility that the
information gained from this study may help people in the future.

Eligibility to participate:
- You are 18 years old or older
- You identify as Hispanic/Latino
- Your English speaking abilities are limited
- You have received healthcare in South Dakota or the Midwest

Contact Information:
Randy Quevillon
Emily Pauli
USD Department of Psychology
414 E. Clark St.
Vermillion, SD 57069
Emily.Pauli@coyotes.usd.edu
Comparta su experiencia
Se necesitan participantes para investigación

¿Ha tenido problemas de comunicación con su doctor? ¿Ha necesitado llevar un traductor a una cita con el doctor? Estamos realizando un estudio de investigación sobre posibles barreras lingüísticas en la asistencia médica. Tenemos interés en realizar entrevistas para escuchar sus historias y comprender mejor cómo estas barreras afectan la atención recibida.

Cuándo: los fines de semana en octubre y noviembre
Dónde: [nombre de escuela]

Las entrevistas se llevarán a cabo en un aula privada en [nombre de escuela]. Las entrevistas durarán aproximadamente una hora y la identidad de los participantes se mantendrá confidencial. No hay riesgos evidentes para participar en este estudio. El único beneficio será la posibilidad de que la información que se obtenga de este estudio pueda ayudar a otras personas en el futuro.

Requisitos para participar:
-Ud. tiene 18 años o más
-Ud. Se identifica como Hispano/Latino
-Su habilidad de hablar inglés es limitada
-Ha recibido asistencia médica en South Dakota o en el medio oeste de los EE.UU.

Información de contacto:
Randy Quevillon
Emily Pauli
USD Departamento de Psicología
414 E. Clark St.
Vermillion, SD 57069
Emily.Pauli@coyotes.usd.edu
Appendix B

Informed Consent – English version

UNIVERSITY OF SOUTH DAKOTA
Institutional Review Board
Informed Consent Statement

Title of Project: \textit{Addressing Healthcare Needs of Hispanic/Latino Populations of Limited English Proficiency in the Rural Midwest}

Principal Investigator: Dr. Randal Quevillon; Department of Psychology
Student Investigator: Emily Pauli; Department of Psychology
Other Investigators: Dr. Angela Helmer; Department of Modern Languages and Linguistics

Purpose of the Study:
The purpose of this study is to give a voice to the limited English proficient Hispanic/Latino population in the rural Midwest and hear what they have to say about the healthcare they are receiving. Cultural and language barriers and their effect on healthcare received are also of interest.

Procedures to be followed:
As participants in this study, you will be asked to answer some open-ended questions in an interview that will be voice recorded. During the interview Dr. Angela Helmer will be present via Skype in order to ensure that the student investigator and you do not have any miscommunications.

Risks:
Some of the questions are personal and might cause discomfort. If you would like to talk to someone about your feelings regarding this study, you are encouraged to contact The University of South Dakota’s Psychological Services Center at 605-677-5354 which will provide you with counseling services at no charge.

Benefits
You may not benefit personally from participating in this research project however:
- You may learn more about the challenges that other limited English proficient Hispanics/Latinos in the rural Midwest face. You might also learn more about yourself by participating in this study.
- This research might help healthcare providers improve their services to limited English proficient individuals. It might also increase awareness about cultural differences and provide insight into overcoming language barriers.

Duration:
The interview will last approximately one hour.
**Statement of Confidentiality:**
The survey interview does not ask for any information that would identify who the responses belong to. The voice recordings will be transcribed, any identifying information will be removed, and then the recordings will be destroyed. Your responses will be kept completely confidential. If this research is published, no information that would identify you will be included since your name is in no way linked to your responses.

**Compensation:** You will not receive compensation for your participation. You may withdraw from the study at any time.

**Voluntary Participation:** You do not have to participate in this research. You can stop your participation at any time. You do not have to answer any questions you do not want to answer.

For this study you must be 18 years of age older and a native Spanish speaker to consent to participate in this research study.

**Right to Ask Questions:**
The researchers conducting this study are Emily Pauli, Dr. Randy Quevillon, and Dr. Angela Helmer. You may ask any questions you have now. If you later have questions, concerns, or complaints about the research please contact Emily Pauli at (605) 467-0330 or Dr. Randal Quevillon at (605) 677-5351 during the day.

If you have questions regarding your rights as a research subject, you may contact The University of South Dakota- Office of Human Subjects Protection at (605) 677-6184. You may also call this number with problems, complaints, or concerns about the research. Please call this number if you cannot reach research staff, or you wish to talk with someone who is an informed individual who is independent of the research team.

**Consent**
Your signature indicates that this research study has been explained to you, that your questions have been answered, and that you agree to take part in this study. You will receive a copy of this form. Your signature also indicates that you consent to being audiotaped and that your quotes can be used in the research, however, you will not be identified.

Subject’s Name: ________________________________________________________________

Signature of Subject ___________________________________ Date ____________________
Informed Consent – Spanish version

UNIVERSIDAD DE DAKOTA DEL SUR
Junta de revisión institucional
Declaración de consentimiento informado

Título del proyecto: Atendiendo las necesidades de cuidado de la salud de la población hispana/latina con dominio limitado del inglés

Investigador principal: Dr. Randal Quevillon; Departamento de Psicología
Estudiante-Investigadora: Emily Pauli; Departamento de Psicología
Otros investigadores: Dra. Angela Helmer; Departamento de Lenguas Modernas y Lingüística

Propósito de este estudio:
El propósito de esta investigación es dar una voz a los hispanos con manejo limitado del inglés que viven en zonas rurales medio oeste de los EE.UU. y escuchar sus opiniones sobre la atención médica que están recibiendo. Las barreras idiomáticas y culturales y sus efectos en la atención médica recibida son de interés también.

Procedimientos a seguir:
Como participante en este estudio, se le pedirá responder a algunas preguntas abiertas durante una entrevista que va a ser grabada (grabación de sonido). Durante la entrevista, la Dra. Ángela Helmer estará presente por Skype para asegurar que no hay errores de comunicación entre la estudiante investigadora y usted.

Riesgos:
Algunas de las preguntas son personales y pueden causar incomodidad. Si usted quiere hablar con alguien sobre sus sentimientos con respecto a este estudio, le recomendamos contactar el Centro de Servicios Psicológicos de la Universidad de Dakota del Sur, teléfono 605-677-5354, que le proveerá con servicios asesores sin costos alguno.

Beneficios:
Ud. no se puede beneficiar personalmente por participar en este proyecto de investigación; sin embargo:
• Usted puede aprender más sobre los retos a los que otros hispanos/latinos con inglés limitado en las áreas rurales del medio oeste estadounidense se enfrentan. Además, Ud. puede aprender más sobre sus propias perspectivas en este estudio.
• Esta investigación puede ayudar a los proveedores de atención médica a mejorar sus servicios para personas que no hablan mucho inglés. Además, puede contribuir a aumentar el conocimiento sobre diferencias culturales y proporcionar ideas para superar las barreras del idioma.

Duración:
La entrevista durará aproximadamente una hora.
Declaración de confidencialidad:
La entrevista no pide ninguna información que identificaría al individuo a quien las respuestas pertenecen. Las grabaciones de voz serán transcritas, cualquier información que lo/la pueda identificar será eliminada y después las grabaciones de voz serán destruidas. Sus respuestas se mantendrán completamente confidenciales. Si esta investigación es publicada, ninguna información que lo/a identifique va a ser incluída porque su nombre no está conectado con sus respuestas.

Compensación: Usted no recibirá compensación por su participación. Se puede retirar de este estudio en cualquier momento.

Participación voluntaria: Ud. no tiene que participar en esta investigación. Usted puede cancelar su participación en cualquier momento. No tiene que responder a ninguna pregunta que no desee contestar.

Para este estudio, tiene que tener 18 años de edad o más para dar consentimiento y participar en esta investigación.

Derecho de hacer preguntas:
Los investigadores del este estudio son Emily Pauli, el Dr. Randy Quevillon y la Dra. Ángela Helmer. Usted puede hacernos cualquier pregunta que tiene ahora. Si más adelante tiene preguntas, inquietudes o quejas sobre la investigación, por favor póngase en contacto con Emily Pauli, teléfono (605) 467-0330 o con el Dr. Randal Quevillon, teléfono (605) 677-5351 durante el día.

Si tiene preguntas sobre sus derechos como sujeto de investigación, usted puede comunicarse con la Universidad de Dakota del Sur – Oficina de Protección de Sujetos Humanos, teléfono (605) 677-6184. Además, puede llamar a este número en caso de tener problemas, quejas o preocupaciones acerca de la investigación. Por favor llame a este número de teléfono si no puede comunicarse con los investigadores del estudio, o si desea hablar con una persona informada pero independiente del equipo de investigación.

Consentimiento
Su firma indica que Ud. ha recibido información sobre este estudio de investigación, que sus preguntas han sido contestadas y que Ud. acepta participar en este estudio. Ud. va a recibir una copia de este documento. Su firma indica también que Ud. da su consentimiento para que la entrevista sea grabada (audio) y que sus citas pueden ser utilizadas en la investigación; sin embargo, Ud. no será identificado/a.

Nombre del participante: ________________________________

Firma del participante ________________________________ Fecha ________________________________
Appendix C

Interview Questions – English version

Preliminary questions. (These questions were asked after signing the consent form and prior to the commencement of the main interview.)

• What is your primary language?

• How would you rate your English-speaking abilities?

Grand tour question. (This question was not asked directly, but it provides the major overarching idea of the research.)

• What is the essence of the phenomenon of seeking and obtaining healthcare as a Hispanic/Latino individual with limited English proficiency in the rural Midwest?

Main questions. (These questions were asked directly and are our main points of interest in this study.)

• In regards to communication, can you describe what went well during healthcare visits?

• In regards to communication, can you describe what was challenging during healthcare visits?

Probing questions. (These questions were asked when we needed participants to further expand on their answers.)

• How have language issues made seeking healthcare in the United States more difficult?

• What has your experience of seeking healthcare in the United States been like?

• How have your doctors been sensitive to the communication problems?

• What have you or your healthcare providers done to help overcome language barriers?

• Have you ever had a hospital offer to provide a translator for you during a doctor’s visit? If so, what did you think of the experience?

• Have you ever brought a translator with you to the doctor? If so, how did you know the translator and did you feel comfortable having them translate personal information?

• How would you feel about visiting the doctor without a translator?
• Would you prefer to have a translator provided at appointments or have a friend or family member translate for you? Why?

• Have you ever avoided seeking medical attention due to lack of a translator?

• Do you have any ideas for bettering healthcare visits?
Preliminary questions. (These questions were asked after signing the consent form and prior to the commencement of the main interview.)

- ¿Cuál es su idioma principal?
- ¿Cómo califica usted su habilidad de hablar inglés?

Grand tour question. (This question was not asked directly, but it provides the major overarching idea of the research. Because this question was not asked directly, it is not translated.)

- What is the essence of the phenomenon of seeking and obtaining healthcare as a Hispanic/Latino individual with limited English proficiency in the rural Midwest?

Main questions. (These questions were asked directly and are our main points of interest in this study.)

- ¿En lo que respecta a la comunicación, puede usted describir qué funcionó bien durante las citas de atención médica?
- ¿En lo que respecta a la comunicación, puede usted describir qué fue difícil durante las citas de atención médica?

Probing questions. (These questions were asked when we needed participants to further expand on their answers.)

- ¿De qué manera el no hablar inglés con fluidez ha hecho más difícil para Ud. buscar servicios de atención médica?
- ¿Cómo ha sido su experiencia con la atención médica en los Estados Unidos?
- ¿De qué manera sus médicos han mostrado sensibilidad ante los problemas de comunicación?
- ¿Qué ha hecho usted o qué han hecho sus proveedores de atención médica para superar las barreras del idioma?
- ¿Alguna vez el hospital le ofreció un traductor para su cita médica? ¿Si es así, qué pensó Ud. sobre la experiencia?
- ¿Alguna vez ha llevado Ud. un traductor a una cita médica? ¿Si es así, como conoció al traductor? ¿Se sintió Ud. cómodo/a que esa persona tradujera su información personal?
• ¿Cómo se sentiría si visitara al médico sin traductor?
• ¿Prefiere Ud. que se proporcione un traductor para sus citas o prefiere que un amigo o un miembro de la familia traduzca para Ud.? ¿Por qué?
• ¿Ha evitado alguna vez acceder a la atención médica debido a la falta de un traductor?
• ¿Tiene ideas para que las consultas médicas se desarrollen de manera más satisfactoria?