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EXPLORING WHAT IT IS LIKE TO BE AN UNDOCUMENTED ALIEN IN
SEEK OF HEALTHCARE

by

ELIANY TORREZ PON

A thesis submitted in partial fulfillment of the requirements
For the Honors in the Major Program in Nursing
In the College of Nursing
And in the Burnett Honors College
At the University of Central Florida
Orlando, Florida

Spring Term, 2018

Thesis Chair: Victoria Loerzel, PhD, RN, OCN

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ABSTRACT

Currently, there are about 11.8 million undocumented aliens in the United States who are not eligible for public insurance or any type of private coverage obtained through the American Health Care Act of 2017. This creates barriers to healthcare for this *large* population and has negative implications for the healthcare system. Despite the availability of clinics and low-cost healthcare, this group tends to underuse resources or seek healthcare for emergencies only which leads to increased cost totaling approximately \$1.1 billion a year. The goal of this qualitative study is to better understand what it is like to be an undocumented alien seeking healthcare. Eight semi-structured interviews with Latino undocumented aliens were conducted. Interviews were transcribed into WORD™ documents and reviewed for accuracy. Data was analyzed using content analysis to code and identify prominent themes. Analysis of data from participants indicate the following themes embody the experience of being an undocumented alien in seek of healthcare: living in the *unsure*, high costs, system barriers, language and communication incongruences, perceived discrimination, exploitation and deportation, and relief in finally getting care. Undocumented aliens put off getting healthcare as long as possible due to these factors, despite having many needs. Healthcare practitioners must become familiar with these experiences to address and correct these barriers. Advocacy and healthcare changes take on increasing urgency to ensure the well-being of these individuals.

DEDICATION

For my mom and dad. You risked your lives coming to this country in hopes of giving me a greater opportunity in life. Thank you for your endless support and encouragement and for teaching me to never let my status bring me down. You gave me the wings to fly higher than you ever could.

For Ariana and Elsa. Together, we experienced the harsh tribulations of what it means to be undocumented. Together, we will be the change we see in healthcare.

ACKNOWLEDGMENTS

I would like to thank my thesis chair, Dr. Victoria Loerzel, for encouraging me to pursue my passion in research, and guiding me through all its milestones. I am honored to have the opportunity to work with you and learn so much in the process. Thank you for showing me that I can make a difference in healthcare and the lives of many.

Thank you to my committee member, Dr. Susan Chase. I am so grateful for your dedication in my project. I am appreciative of your time, interest in the project, and valuable insight.

A special thank you to the College of Nursing's Honors in the Major Grant that helped compensate the participants for their time in contributing to this research study.

Thank you to the participants who shared their stories that provided data for this research. Participation in the study took time and was emotionally challenging for some. However, their contribution of discussing their experience of being undocumented in seek of healthcare allows for a greater understanding in the needs and barriers that need to be addressed and corrected. Their narratives will allow nurses and healthcare providers to better provide care in the future.

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CHAPTER 1: INTRODUCTION

The “illegality” construct of being an undocumented alien is attributed to social, economic, political, and sociological factors. Immigration policies elicit criminogenic efforts to make undocumented aliens *criminals*, adding to their negative construct (Kline, 2017). Their illegal status places them at the bottom of the United States (U.S.) social hierarchy, limiting their life opportunities (Fernandez-Esquer, Agoff, & Leal, 2017). Faced with marginalization and the inability to prosper socially or economically, these individuals experience a great degree of stigma associated with their “illegal” status (Siemons et al., 2017). These forces create hardships confronting the undocumented, making them structurally vulnerable (Quesada, Hart, & Bourgois, 2011). The “co-occurring and mutually reinforcing insults” created by the structural vulnerability exacerbates exposure to illness, stress, and injury (Willen, 2012). Living without legal documentation adversely influences their health. Unfortunately, they do not qualify for healthcare coverage due to their lack of legal documentation that enables them to be a lawful resident.

Healthcare Legislative Background

Health insurance covers essential health benefits crucial to maintaining one’s health and treating illnesses (HealthCare, 2017). According to the 2015 National Health Interview Survey (NHIS), 28.4 million persons under the age of 65 were uninsured in the United States (U.S.) (Ward, Clarke, Nugent, & Schiller, 2017). This number accounts for nearly 10.5% of the U.S. population (321.4 million). During President Barack Obama’s administration, the Patient Protection and Affordable Care Act (PPACA) was enacted with the goals of decreasing the uninsured levels and increase in the quality of healthcare. Despite the efforts to create a

healthier American by expanding coverage, the bill did not cover those unlawfully present.

Recently, The American Health Care Act of 2017 (AHCA) was passed, continuing in the efforts to simultaneous decrease healthcare costs and increase healthcare outcomes. However, the Act carries the same exclusions found in the preceding healthcare bill. Key groups, such as the undocumented aliens, are still ineligible to receive healthcare coverage.

Challenges in Getting Healthcare

Without insurance or support from the political and healthcare system, the undocumented aliens are faced with great challenges when seeking healthcare. Due to the unprecedented rise in migration, policies that limit health care access have become prevalent, such as increased detention and deportation activities that discourage participation from undocumented community in the healthcare system (Hacker et al., 2015). Rumors of immigration officials being present in government facilities where health service agencies are present inhibits the participation of the undocumented to seek healthcare (Xu & Brabeck, 2012). Lack of access to transportation and decreased participation in driving to minimize the risk of being stopped by police, and possibly detained, also limits their use in the healthcare system (White et al., 2014). Fear of deportation, insufficient documentation to qualify for insurance, and limited access to health services are all detrimental barriers constructed through the harsh immigration policies for this population (Hacker et al., 2015). Living in a country where healthcare providers neither share their native language nor understand their attitudes and beliefs about healthcare leads to a reduction in the quality of care for the undocumented aliens (Zamora et al., 2016). The low utilization of health care services available to them may also be attributed to the lack of knowledge of health services due to lack of social networks and communication barriers (Sudhinaraset et al., 2017).

Carol Cleaveland and Emily Ihara conducted a qualitative study of Latino immigrant experiences seeking health care services in the wake of an anti-immigrant “crackdown” ordinance. The movement targeted this population for deportation and ordered healthcare staff to not provide social services other than those required by federal law. Data collected through semi-structured interviews with 57 Latinos found that communication and language incongruences, along with insensitive and hostile treatment from medical staff are themes identified to cause unnecessary suffering for an undocumented alien when seeking healthcare (Cleaveland & Ihara, 2012). Participants believed this treatment was a deliberate effort to discourage them from seeking help (Cleaveland & Ihara, 2012). Misconceptions, misperceptions, and misjudgments often prevents a healthcare worker from doing all they can to help someone with this status. Stigmatization and perceived discrimination creates tensions and difficulties for those seeking aid without legal documentation.

Health Behaviors

To complicate matters, over a third of undocumented aliens have children who are U.S. Citizens and this incongruence between the legal status of parent and child leads to parents avoiding health care in fear of being deported (Alcalá et al., 2016). Legal status is a potentially fundamental cause of insignificant health care for children (Oropesa et al., 2015). U.S. born children of undocumented parents may endure greater health disparities than those children born to legal citizens.

Because of the challenges in accessing healthcare, undocumented persons may opt to delay action to treat their medical concerns instead of treating acute or chronic problems in the primary care setting. The lack of support through the medical system may inherently lead to the

substitution of complementary and alternative care outside of the formal U.S. medical care system (Stimpson, Wilson, & Eschlbach, 2010) which may or may not be effective at treating their health concerns. Consequentially, an undocumented alien may wait until a health crisis to seek aid at a hospital's emergency department to treat an illness or condition that should have been addressed through routine examinations and procedures (Cleaveland et al., 2012) which increases healthcare spending by \$1.1 billion (CMS, 2016). Approximately one third of emergency room visits are avoidable and contribute to approximately \$18 billion in avoidable expenditures annually (Navratil-Strawn et al., 2014). In 1990, the total uncompensated care cost estimated around \$12.1 billion (6.0% of total health care expenses). Health care spending has drastically increased, now reaching \$35.7 billion in uncompensated costs (American Hospital Association, 2016).

Without the advocacy and support towards the undocumented community, countless individuals endure needless suffering and healthcare issues that, for most people, are easily treated in a primary care setting. The overall effects of not treating this population adequately can negatively affect the health status of the entire country.

Historically, an undocumented alien's chance of accessing health care was influenced by using brokers (Zuckerman, Waidmann, & Lawton 2011). A health broker is an agent who collaborates with politicians, policy-makers, private parties, and health promotion practitioners with the goal of improving the health of the community (van Rinsum et al., 2017). This term can be interchangeably used as navigator, access coordinator, or patient advocate (van Rinsum et al., 2017). Structural barriers among the undocumented population, such as lack of insurance,

language barriers, or social support were narrowed with the help of these brokers (Zuckerman et al., 2011).

Unfortunately, new health policies stress administrative action to enforce rules and regulations throughout healthcare organizations that directly affect a broker's ability to find healthcare for undocumented aliens. Currently, the pressure of accountability and efficiency discourages brokers to support this population (Zuckerman et al., 2011). Under strict regulations to meet requirements related to patient and enrollment qualifications, brokers are unable to *bend* rules that once enabled an undocumented alien to qualify for a service or aid (van Rinsum et al., 2017). They now struggle to simultaneously maintain their relationships with undocumented aliens and meet the expectations of their organization. The undocumented aliens are left with greater challenges than presented in the past and continue to have unmet medical needs.

Problem

With increasing formalization of the medical system and legislative healthcare changes, the system that once supported undocumented aliens by bridging the gap in health care is diminishing (López-Sanders et al., 2017). There are over 11 million undocumented aliens in the U.S (Stimpson et al., 2010). The impact of having such a large population not receiving sufficient healthcare can have detrimental implications for the nation. Pregnant woman, children, migrant workers, the elderly, and those with chronic illnesses all require specific attention regarding healthcare. These needs are not being met in the undocumented population (Hacket et al., 2015).

Significance

Currently, little is known about the experiences of an undocumented alien seeking healthcare. While several studies have attempted to identify factors that contribute to the illegal status-based disparities in healthcare, little is known about the healthcare experiences of the undocumented aliens (Martinez et al., 2015; Hacker et al., 2015). Exploring the decision-making process, barriers, and quality of care received by healthcare professionals may help researchers and practitioners understand and diminish the barriers that contribute to an unsuccessful healthcare experience. At the provider level, knowing what makes an undocumented alien apprehensive to seek formal medical care may have a positive effect on improving behaviors and actions of healthcare workers and allowing for more compassionate care for this group. Therefore, the purpose of this study is to explore what it is like to be an undocumented alien in seek of health care.

CHAPTER 2: METHODS AND PROCEDURES

Design

This study used qualitative description to better understand what it is like to be an undocumented alien seeking healthcare. Qualitative description is the method choice because it is aimed at acquiring straight descriptions of phenomena (Sandelowski, 2000). This method allows for the collection of comprehensive summaries of events in the everyday terms of these events (Sandelowski, 2000). Qualitative description offers a way to interpret events that is of low-interference, in which researchers will likely reach a consensus on the data presented. This method is consistent with the aim of the study, which is to understand the experiences of undocumented aliens in seek of healthcare from their point of view.

Sample

Participants were included if they were an undocumented alien currently or in the past, Latino, over the age of 18, speak and understand English, and are willing to participate. They were excluded if they were a US. Native citizen, unable to speak or understand English, or unwilling to participate. No names or contact information were collected during this study in order to maintain participant confidentiality. Recruitment was done through verbal communication with people known by the principal investigator (PI) who are undocumented. More participants were recruited through word of mouth and snowballing methods. Once identified by the PI, eligible individuals were approached about participating in the study. If they agreed to participate, they gave verbal consent to be interviewed.

A total of 8 participants were interviewed for this study. All participants were Hispanic/Latino in origin and at least 18 years of age. Four participants were undocumented at one time

and four were undocumented aliens at the time of the interview. Most of the participants were female (n=6), and the others male (n=2). All the participants had at least some high school education. Half (n=4) of the participants lived as undocumented aliens for over 10 years. The other participants (n=4) lived at least one year with undocumented status. Many of these participants also have immediate family members who are undocumented aliens. The mean age of participants was 39 years.

Data Collection Materials

A sociodemographic survey obtained characteristics of study participants such as: current legal status, age, gender, ethnicity, members of the immediate family (spouse and children), how the participant arrived in the U.S., and if relevant, how long they lived as an undocumented alien in the U.S. (APPENDIX B) The study data were originally collected via 8 semi-structured interviews with open-ended questions. An audiotape recorder recorded the interviews. The interview questions are: 1) Tell me what it is like to be an undocumented alien in need of healthcare 2) Give me an example of a time when you had to decide if you were going to seek medical care or not. 3) How do you get your healthcare needs met? 4) What would make you more comfortable seeking healthcare? 5) What do you need or what would you like to have access to?

Procedure

The Principal Investigator approached potential participants and briefly explained the study and provided an information document about the study's purpose. Interviews took place at a mutual choice for safety and confidentiality. Interviews were audiotaped once participants verbally consent.

The above open-ended questions about the participant's experiences on seeking healthcare were asked. Prompts were used to elicit more elaboration when needed. Participants were encouraged to provide responses in English, however, phrases or opinions that were not easily translatable in English were spoken in Spanish when necessary. Field notes and bracketing to record the interviewer's perceptions of the interview were kept. Interviews were transcribed into WORD™ documents and reviewed for accuracy. Participants were compensated for their time with a \$25 gift certificate to a local store. IRB approval was obtained for this study and received determination of exempt human research (Appendix A).

Data Analysis

Data was analyzed using the principles of content analysis to identify prominent themes and patterns among the themes. After each interview, the PI reviewed the recording and wrote a summary of what was said in the interviews in her own words. This provided perspective of each person's story. Once the transcripts were received, the PI coded original and recurring ideas from each of the participants' interviews. Early in the analysis process, unique experiences pertinent to be an undocumented alien were coded. These codes were listed in a separate document and then discussed with the chair so that they could be grouped into similar categories. Underlying themes were also noted, and codes applied to similar situations in subsequent transcripts. Saturation was achieved after 8 participants, when no further codes and themes were noted. The codes and emerging themes were sent to the Thesis Chair and Committee member to be reviewed. The PI, Thesis Chair, and Committee member met to review data, codes and themes. Consensus about the major themes was reached and these became the final themes,

CHAPTER 3: FINDINGS

Interviews lasted from approximately 15 minutes to 1 hour. The quality and length of the interview varied depending on whether the participant currently had insurance or not. Those that had insurance gave great insight about the differences in care between being undocumented to having documentation with insurance. Most individuals were receptive to answering the interview questions and provided detailed anecdotes of their experiences. Others were less open, responding with short answers and/or not providing specific details or explanation of events. Most participants expressed their gratitude for having their stories be told through the research project

All the participants reported difficulty in seeking healthcare, describing their experience as bring *scary, not easy, stressful, hard, and sad*. These feelings manifested through many challenges such as *expensive* healthcare and making *minimum income*, the *hardship* of becoming sick and not taking their children to get healthcare, and much more. Most of the participants, at one time or another, reported eventually deciding they needed to seek care despite the risks. Being illegal or an undocumented alien made them think twice about getting healthcare – but eventually, being illegal became secondary to the need to obtain healthcare for serious health issues. The participants who were able to put their illegality aside contrasted with the ones who did not seek healthcare due to the barriers of their illegality. For these participants, the risk associated with their illegal status remained the reason to avoid seeking care or seeking alternative care.

Analysis of the interview data revealed similar experiences that provide a testimony of what these undocumented aliens endured in seeking healthcare. While many themes manifested

across narratives, not all experiences were the same. Major themes include: Living in the *Unsure*; High Costs; Healthcare Barriers; Language and Communication Incongruencies; System Discrimination; “We Are People Too;” Exploitation and Deportation; and Physical and Financial Relief in the Healthcare System. The overarching theme of *stress, worry, and fears* transcended throughout the narratives. The themes and subthemes are described in more detail below.

Living in the *Unsure*

The majority of participants believed their health and healthcare were important, however, many of them described the uncertainty of their health status, how they would receive care, and what would happen to them without healthcare. When experiencing a symptom that was unprecedented or never seen before, many participants described feeling unsure about what the symptom was or if they should seek care. Many also shared the uncertainty of what would happen to their health if they didn’t seek treatment, what needed to be done to get treated, how to seek treatment, and what would happen if they pursued healthcare as an illegal alien?

When a participant recognized the need to obtain care, uncertainty was related to how they would afford or pay for the services, how they would travel to the healthcare facilities, and what would be asked of them to receive care, such as a driver license or other form of legal identification. Requesting to have payment upfront to be seen by a healthcare provider or being unable to seek specialty care due to the high costs led to more uncertainty regarding paying for the care needed. One participant discussed how she was even unsure about where to get care. She felt that there simply were not enough resources that provided education about where an undocumented alien could seek care and other services. She stated “There is no or not enough

resources up there to inform the community in general of where to go, how to get it. Those non-profit group, they not advertise, so it is hard to find it.” Lack of knowledge for accessing care is a factor that contributes to the uncertainty experience in seeking healthcare.

When pursuing healthcare, some participants used free clinics and others used the emergency department. However, not knowing where to get healthcare or what would happen if they exposed their illegal status was a source of stress for them. Many described feelings of *fear*, *stress*, and *worry* due to this uncertainty. One participant elaborated: “You really worry 'cause you don't know what will happened. You don't know what's going on.”

For some, living in a state of uncertainty was not an option when threatened by a life-or-death situation, or when a family members health was compromised. Participants reported seeking care because finding the answers to their health problem was their only solution, and they could not accept a state of uncertainty. One participant expressed: “I gotta do my part. It's not too hard. We solved the problem. You have to be ready to start looking for help.”

Consequences of Living in the Unsure

For some participants being uncertain was enough to simply prompt them not seek care. For others, the uncertainty of recognizing a healthcare need or when to seek care led to a compromised health status. Some participants reported avoiding getting care for themselves and their family members, expressing this was a *hard* decision for them. Many also expressed that seeking care was a *risk*, in exposing their illegal identity and/or cost of care. Questioning the worth of seeking care, many opted for home remedies or home treatment rather than seeking professional medical care. Some described the repercussions of not seeking care, or simply not recognizing the need to seek care, resulting in untreated health needs and worsening health

symptoms and conditions. One participant elaborated on her experience with this: “I thought I had a really bad cold. Apparently, what I had it was bronchitis. I know it was because I never went to the doctor, and I could barely speak. I felt even pain by breathing bad. It wasn’t a good decision that I took because I know for even months and even years, I can still feel my breathing bad due to that time that I didn’t go.” Being unsure led to feelings of *stress*, *hardship*, and *worry*. These feelings are elaborated by another participant: “Not knowing what to do, especially in a country that you don’t know the language, or you don’t know many people, then it makes you scared.”

Turning-Point to Seek Healthcare

Typically, the participants made decisions related to their healthcare by first identifying and interpreting their signs or symptoms. Deciding if the condition was manageable at home or if it needed professional attention was the first step in the decision-making process related to seeking care. When experiencing a distressing symptom that was unfamiliar to them and not being successfully treated through home-healing was the turning-point for many in seeking care. For example, If the participant felt like the condition was *life-or-death* or a *critical emergency* such as *open wounds* or *unimaginable pain*, then they would seek care. Specifically, Participants described times where they developed *cysts* or a *lump* that felt like breast cancer, which was severe enough for them to seek medical attention.

Others consulted friends or family members about their conditions. The opinions and encouragement to seek care from these friends or family members was the deciding factor to seek care for some participants. These participants shared that they would not have gone to seek care if it weren’t for this encouragement from others to seek medical care. Many also reported

that friends and family were the sources of information as to what clinics or facilities to go to. For others, the cultural influence, or outlook, of healthcare inhibited the decision to seek care, putting their health at a lower priority.

High Costs

The concern for paying medical bills is consistent through the participant's experiences. All participants reported costs as being one of the greatest influences in their experience in seeking healthcare. The high costs of healthcare emphasize the barrier to obtain care for the participants, regardless of their awareness and efforts to seek care. For some, the high costs were the defining factor in not seeking care. Many shared trying to *heal self* through *home remedies* instead of seeking care. An example is explained by a participant: "Even though you have a high fever or anything that you have, you still look for over-the-counter medicine or just helping yourself with anything that you can. A lot of times, for some reason, yeah, you get better." Some shared their experience in seeking alternative care, rather than the standard form of professional care due to costs. Others described their experience seeking professional care despite its high costs.

Many participants reported that their main concern in seeking healthcare was the *money*, even when they knew they were sick and needed medical attention. Ineligible for insurance, many participants sought care in the emergency room because they did not have to pay anything up front before receiving care. Again, worry and stress was related to money. Confronted with an unfamiliar health issues, one participant explains about a time where she knew that she must seek medical attention, but she worried about "how can I pay the whole bill to the hospital?" Although, able to avoid the initial payment, many described the financial strain of *billing* as a

constant worry and a consequence to seeking healthcare. One participant reported the *devastation* in getting care and dealing with emotional strain of being *harassed* by the billing and collections agencies. Another participant shared: “This kidney stone did not kill me. What had killed me was the bill.”

The financial burden that followed their decision to seek care added to the *stress* and apprehensions of seeking it in the future. However, when a health concern was too great for the participants to stay at home, many had no other option, except to go the emergency room despite the knowledge of the cost. In contrast, some participants described how their healthcare needs outweighed the financial burdens of seeking care. A participant whose undocumented mother was diagnosed with breast cancer states: “Breast cancer is something serious. It outweighed the whole paying.”

Trying to Heal Self

Many participants shared experiences in which one would try to heal themselves through alternative methods, instead of seeking professional attention due to the financial burden of seeking primary or emergency care. Many participants described that if a symptom was minor, one would seek treatment through over-the-counter medicine, or through *back-home-recipes*. These participants also reported the repercussions of not seeking professional care, with worsening symptoms and long-term negative health effects. One participant who struggled with untreated bronchitis elaborated on her repercussions of not seeking care and trying to heal herself: “It wasn’t a good decision that I took because I know for even months and even years, I can still feel my breathing bad due to that time that I didn’t go.”

Others reported seeking alternative care with providers that may not have the same licenses or accreditation as traditional doctors. Participants reported being prescribed medications, describing them as looking different than traditional pharmaceutical medications and being unaware of their content. Also, the alternative doctors suggested operations and treatments that made the participants feel uncomfortable and not confident in their care. Participants had varying luck in seeking alternative practitioners. One participant described the care as being *helpful* and tending to his health issue. Another, driven by the lack of confidence in his consultation, sought traditional care at his local hospital after this encounter

System Barriers

There are many barriers that the participants were confronted with when seeking healthcare. This theme showcases the challenges in the system, such as healthcare access difficulties and lack of legal identification that affected the participants' experiences.

Access Difficulties

The participants reported difficulty in accessing healthcare due to the lack of availability of appointment, length of time to be seen at each appointment, transportation, and the distance of available resources. Many had a choice but decided not to seek care due to these barriers. Others expressed the importance of seeking care and explained the efforts they put in to access care.

Participants expressed frustration because the clinics available to them offered untimely appointments that were weeks, sometimes months away. Many described their walk-in experiences as taking the whole day, waiting for hours, just to be seen. Many also reported clinics being too far away or having conflicting scheduling hours that interfere with work. The

participants described having to work in jobs that require labor for many hours throughout the day. One participant explains that he used to “Stay as late as 8:00, 9:00, or 10:00 PM” from his job. Without flexibility in hours, the participant wasn’t given the opportunity to get care. Many avoided getting care instead of not sacrificing work.

Although the participants were aware of the healthcare resources available to them, accessing it was difficult for those that did not have transportation. Unable to qualify for a driver’s license, many depend on public transportation, or relying on family or friends to take them to appointments. Some reported that the cost and time it took to take public transportation to an appointment was a greater burden than seeking care. Another explained that relying on others, and their schedules for availability and transportation, involved delaying their opportunity to seek care. Another setback was the difficulty in accessing the clinic due to the distance. Some participants reported clinics that would attend to their needs, regardless of their illegal status, but were in different cities, hours away.

A participant shared that although he found resources, he did not qualify to obtain them. He expresses that the policies against the undocumented alien prevented him and others to receive care. He elaborates: “Once again, you come into a new country, a new culture, new language, new policies, new rules, new everything that you have to follow. There aren’t enough educational resources.”

On the other hand, there were other participants who not allow these barriers to prevent them from accessing care. These participants expressed not letting the disadvantage of not having a vehicle prevent them for accessing care, stating “I can go by bus,” and giving insight on

the of going out of their way to seek care and receive it. These participants expressed that facing a health-related problem must be solved through *effort*.

Lack of Legal Identification

Many participants did not seek healthcare due to their lack of legal identification. As many recalled, the first thing the healthcare providers will ask for upon admission is a form of identification (ID). Ineligible for a driver's license, many participants did not have a U.S. legal document to present to the facilities. Many expressed hesitating to present their birth certificate or foreign passport, in fear of being identified as an illegal immigrant.

Other participants reported obtaining care, regardless of lack of legal identification. They described being seen in clinics that did not require U.S. identification, only their name and contact information, or their foreign passport, to receive care.

Language and Communication Incongruency

The participants expressed that language and communication incongruencies was another barrier in seeking healthcare. Unable to communicate what was wrong with them, ask questions, or fully understand what was being told to them from medical providers, many participants described feeling *frustrated* and *sad* about this challenge. Many stated that if people at the medical facilities spoke their language, they would feel like they would get better care and would be willing to go back. One participant shared "If you could find a doctor that even if you had to travel miles, hours, or days to get to that doctor because they do speak your own language, you will travel there." Some shared that regardless of the efforts to seek care or more information on how to seek care, many could not find the answers they were looking for due to problems communicating.

Due to language barriers, participants were apprehensive about seeking care again. Participant elaborate “Even if you want to look for assistance, if you don't know the language, it's extremely hard. It is really hard because when only one language is really explained, how can you explain what’s going on?” Another explained that the limited resources, such as lack of translators or doctors that speak one’s native language, made the healthcare experience *extremely hard*. Many relied on bilingual family or friends to make appointments and take them to be seen. Another participant expressed his desire to seek information on how the healthcare system worked and what resources were available to him. Unable to speak or understand the language in the U.S., he shared how *hard* it was, regardless of his efforts to seek aid. Participants expressed their willingness to travel *miles, hours, or days* to get treatment from a provider that speaks their same native language. This was elaborated by one participant by comparing the doctor that spoke her language as being “an angel.”

Perceived Discrimination

Providing perspective on their experience in healthcare, many participants described moments where they felt like they were treated poorly compared to those with legal status. Participants that now have insurance discussed the discrimination that they lived through and see with friends and family members who do not have insurance. Their illegal status, inability to provide social security or identification, and lack of insurance made many participants feel that this was the cause of their insignificant care. Many still feel the frustration and anger of being treated differently.

Several participants noted differences in healthcare care between themselves and others who had insurance. Participants who were not insured observed that individuals with insurance were

called back to see practitioners quicker than they were. For the uninsured, sometimes it took many hours to be seen by a practitioner. Many participants felt as though their uninsured status made them a low priority. They also noted that often they never got to see the physician. Sometimes, a nurse would come out to speak with them in the waiting room and the nurse would relay information to the physician. These left participants feeling like their care lacked privacy, that they were insignificant, and were *forgotten* by the providers they needed to see. Other times, the participants reported being seen by medical residents. This also made them feel discriminated against because they knew residents were less experienced than the doctors. Many reported being aware that they were not receiving equal care, feeling like the medical staff did not order needed lab work or tests which prevented them from getting all the answers to what was wrong with them.

In contrast, other participants did not perceive that they were discrimination. These participants felt that they were simply treated as a patient and not judged based on one's legal status. One participant noted that she spoke fluent English, and therefore, believes that was the reason why they did not treat her differently. Those who reported discrimination stated they believed the facility used certain *codes* that notified the providers that they were undocumented and unable to pay for care. Explained further by a participant "I guess they have some kind of codes or something for people that have insurance, don't have insurance, and *especially* the ones that don't have a social which means you're undocumented. They know they will not be able to even go after you because if you don't have a social that means that they will not be able to collect or put that on your social security. It makes you feel really bad. It makes you feel very *different* from other people."

Another aspect of discrimination was that the treatment as uninsured persons that they experienced made some participants feel like less of a human or insignificant. When asked about what participants would like to see changed in the current healthcare system for them, many stated that they would like to see in the healthcare system treat them like a *human being*. Many emphasized their desire to be treated like a human person, stating that regardless of legal status or documentation, all should have the right to basic healthcare. One participant stated: “Being undocumented doesn’t mean that you’re not human. It doesn’t mean that you don’t have medical needs. Being undocumented doesn’t exclude you from being in the human race. You are still a human person. You’re still a human being that deserve—and not only deserve, but you have the right for that medical attention.”

Exploitation and Deportation

Running the risk of getting reported and turned in to homeland security was a big fear in seeking care for many participants. With the fear of exploitation and deportation, many reported this being a factor that prevented them from seeking care. The participants described being requested to present legal documentation, or social security, to be seen in a facility. Many participants described how *scary* it was to be unable to present this information, and the fear of being reported as being illegal. For others, the risk of getting reported was not as important as seeking and obtaining care. One participant report driving without a license and running the risk of getting pulled over and deported. This participant explains that seeking care and obtaining treatment was worth the risk of getting caught.

Relief in Finally Getting Care

Overall, despite the barriers and difficulties in getting care, participants felt relief when they finally got care. This relief came from experiences with compassionate physicians, charity, and affordable care in community clinics. Hearing “all the rumors” of the costs and treatment of care towards undocumented aliens, many expected similar treatment to be done to them. Below, the narratives describes their relief in getting their needs met and shows that positive encounters with healthcare providers could be had.

Community Clinics

Many participants accessed community clinics that provided healthcare services, regardless of status and finances. The clinics described by the participants included services for a minimal cost or based off a *sliding-scale* to charge based on income. This sliding-scale assessed the financial income of a client and determined a set rate based of their income. This set cost would provide basic services such as physicals, assessments, and sometimes labs. One participant explains: “I remember paying probably \$20 co-pays, and they took care of for basically everything else.” For some, Additional services, such as specialized tests, were offered for low costs, if needed. Others reported being give medications, or samples of medications, for free. These clinics would also provide coupons for over-the-counter medications, such as Tylenol. Alleviation from the financial stress allowed many to obtain medical attention and get treated.

Many described that some of the clinics made them feel “A little more human.” Some found good care where they did not feel discriminated against, nor were they required to pay a lot of money up front. In addition, Participants reported being given *choices* in their treatment.

They felt like they were being *heard*, and that their illegality was not taken into consideration when planning their care. They described that the physicians were aware of their struggle, pertinent to being illegal, and tried to work with them by providing reasonable time frames for the next appointment, giving them an *expectation* to be seen again, and giving them ample time to coordinate their transportation to the clinic.

To one participant's surprise, she stated that she was aware that a lot of the doctors at the community clinics donate their time to help people. These doctors also did not charge them. She described it as being "amazing," to know she was being treated by someone who *loves* their career, *loves* their job, and *loves* helping people.

Charity and Financial Relief

Some participants reported finding financial relief through charities and generosity of physicians. Many shared that they are alive today due to this relief. One participant described her experience when seeking treatment for breast cancer. She reported finding a doctor who treated her with compassion, knowing that she is an illegal immigrant. The treatment that would save her life was a surgical intervention. The physician, knowing her background and financial status, ask to be paid "Whatever you can give" and covered the rest of the cost for the entire procedure. The participant expressed her gratefulness and gratitude towards this physician, knowing she would have died without the treatment.

Another participant shares how financial relief saved her undocumented friend from dying of complication from a ruptured appendix. The participant reported that an anonymous donor paid for her friend's surgery, saving his life and giving him relief from the financial burden of getting surgery and treatment. Many participants attribute their good health and life

towards the generosity of the physicians and charities. One participant expresses his surprise in the generous by stating “That opened my eyes that you got options here, in this country, even under the situation, right?”

CHAPTER 4: DISCUSSION

Discussion

In this study, the experience of being an undocumented alien in seek of healthcare is shaped by both system and interpersonal barriers. The participants' experiences were complex and making the decision to seek healthcare was multifactorial. For them, seeking healthcare was not a simple decision. The system barriers that influenced these experiences include high costs, access difficulties, and the required legal identification to be treated. The interpersonal barriers discussed included fear in seeking care, not knowing when to seek it, how to seek it, or where to seek it. Many studies have supported that in general, Hispanic immigrants with low language acculturation were also more likely to lack health insurance, a routine source of health care, and to have lower levels of education (Murguia et al. 2003, Viladrich 2007). Financial burdens, personal discrimination, language and communication incongruences, and fear of exploitation and deportation were influences that also affected the experiences of the participants. Many reported relief in finally getting care is from community clinics, dedicated physicians, charity and financial relief. Participants who made their illegality secondary to their need to obtain healthcare reported getting their healthcare needs met. Others did not seek care due to the system and interpersonal barriers.

The findings suggest that documentation status itself serves as a significant barrier in seeking healthcare, along with experiences of personal discrimination. Many may feel insecure about their status and feel targeted by healthcare professionals. These participants noticed how their treatment was different than those who had legal status or insurance. The impact of legal status has also been noted in other studies. One study compared the experiences of three groups

of migrant women (undocumented, documented, and refugees) when seeking healthcare. This study identified documentation status as the most important factor in not seeking healthcare, and also found that participants noted quality issues in the care they received (Campbell, Klei, Fisman, & Kitto, 2012).

Participants reported personal discrimination in their experience and described their changed identity from being a human to a less significant person in terms of personal and medical treatment. These findings support previous work which has recognized undocumented aliens' experience of seeking healthcare as unique because their illegal status is used to justify denying them basic human rights, privileges, healthcare, and their dignity of being human beings (Fassin, 2009; Willen, 2012). Immigration status was also a pervasive source of insecurity and anxiety for many participants of this study. This finding supports data from other studies that show that illegal immigrants live in *fear* of getting caught and deported (Walter, Bourgois, Loionaz, & Scillinger, 2002). Zamora et al. (2016) has also shown that concerns over undocumented immigration status causes illegal parents to avoid or delay seeking medical care for their children.

In this study, high costs, access difficulties, and system barriers influenced the experience in seeking care. Findings confirm what Cleaveland found, that undocumented aliens waited until a health crisis to seek aid at a hospital's emergency department to treat an illness or condition that should have been addressed through routine examinations and procedures (Cleaveland et al., 2012). The literature shows that one of the greatest influences for lack of access was due to cost, transportation, not knowing where facilities were, followed by lack of health insurance (Sandoval-Rosario et al. 2016). Participants in our study also revealed the influence friends and

family had on facilitating their overcoming of barriers with providing knowledge on resources or encouraging the participant to seek care. On the contrary, if the family or friend did not provide support to seek healthcare, the participant was less likely to pursue medical care. Previous research shows that strong social networks provide migrants with emotional support and resources (Ryan et al., 2008).

Participants shared the conflict between work and seeking care. Many were burdened with the financial responsibility to go to work and earn money, rather than lose a day seeking care. Literature has shown that many people without documentation, like migrant workers, also experience the economic pressures that make day laborer's reluctant to leave their jobs, even if injured or have a health problem that needs attention (Walter et al., 2002).

Language and communication incongruencies was a barrier in seeking healthcare, as reported by participants. This finding supports the literature that has shown that Spanish-speaking, undocumented caregivers of patients with pediatric cancer immigrants were more likely to have a knowledge gap regarding their child's health, avoided calling the on-call doctor at night or weekends because they were concerned the provider would not speak Spanish, and felt that their child had been put in danger because of the inability to communicate effectively with a healthcare professional (Zamora et al., 2016). Our findings affirm prior findings, which suggest that individuals who have limited English proficiency, like most participants in our study, are more vulnerable to misunderstanding medical information and may experience disparity in accessing healthcare.

Another experience that was prominent through stories was the use of over-the-counter and/or alternative medical practitioners due to high costs and apprehensions of seeking

professional medical care. Previous research suggests that the fear of detection drives undocumented immigrants to pursue treatments through *underground channels*, which also fuel the emergence of drug-resistant microbes (Kullgren, 2003). Participants in our study often started with low cost options and worked to more costly decisions like going to the emergency department. While the current study did not ask participants how much they spent before seeking medical care, it is possible that they spent a significant amount of money to self-treat and medicate before seeking care.

Findings from this study support previous work in recognizing and undocumented aliens' experience in seek of healthcare, but this study added to the current literature by describing how many undocumented aliens push aside their illegality, system, and interpersonal barriers to obtain care. Also, to some extent, this study provides insight as to what prevents them from doing so as well. In addition, experiences in relief of finally getting care contributes to the data of experiences of seeking care as an undocumented alien.

Limitations

Due to the nature of the study and qualitative method, these findings may not be generalized to all undocumented individuals. The small sample size only captures the experiences of Latino undocumented aliens. This may not represent other diverse ethnic populations or cultures. In addition, the experiences of undocumented participants in this study may not reflect the experiences of undocumented populations who are below the age of 18 or those living in more rural areas where access to healthcare is more limited and bilingual predominance is scarce.

Clinical Implications:

These findings support that undocumented aliens are confronted with many barriers when seeking care and are important for healthcare providers to be aware of when caring for this population. Healthcare providers need to better understand the barriers, apprehensions, and fears of this population in order to address and correct them. Providers should also understand what would make an undocumented alien more comfortable in seeking care. More clinics, understanding, and advocacy is what is needed.

Culturally sensitive programs are needed to assist these individuals in promoting their health and building healthy lifestyles. These clinics should be located in low socioeconomic areas, known to have high undocumented populations. These clinics should be in locations that are accessible, or within route of public transportation, such as city bus routes. Clinics should advertise, either in the name or sign, of its multi-lingual services. Although great care is required to protect this vulnerable population from exploitation and deportation, more effective measures are needed for disseminating information on health programs, resources, and services available to undocumented aliens. Community resources are especially needed in the healthcare setting, as our findings suggest the need for culturally appropriate services.

There is disconnect between undocumented aliens and healthcare workers, and it is possible that practitioners are unaware of barriers and the struggles of these individuals. Translation services are imperative to the communication and effectiveness of care for undocumented individuals. Providers can be a part of the solution to these clients who feel like they are not being treated like human beings, or who feel like they are discriminated when they seek healthcare. Understanding this problem, nurses must be advocates for this population and

ensure the safety and treatment of these clients. Providers should take steps to address the concerns of these individuals and take steps to provide services and health education.

Advocacy is needed for this population. Although undocumented clients come from foreign countries and speak different languages, good service is expected, providers should ensure that the clients voices are heard. They should be sensitive to the client and his or her perception of health. Nurses must also be aware that many do not have access to healthcare, apart from the encounters in the emergency room or clinics. Collaborative care among various healthcare workers is imperative in addressing the needs of the clients, as well as assessing their resources outside of the facility. Discharge planning must be thoroughly reviewed with the clients to ensure accommodation of care based on their unique lifestyle. Undocumented clients should be given the time to think about their treatment and plan of care.

Educational Implications

It's imperative that healthcare providers become more aware of resources of education for immigrant patients. Spanish, or multi-lingual handouts that contain pertinent diagnosis or treatment related information should be provided. Other handouts that include resources, such as clinics other health organizations that can deliver treatment for those who do not speak English should also be provided. Nurses and healthcare providers must take the steps to narrow the gaps in knowledge by using clear and simplified language, verifying information has been understood, and ensuring the patients and their families are given options for care to instill power and choice in their treatment of care. Translation services must be available to teach these individuals if he or she does not speak English.

Healthcare providers should assess the clinics or other facilities that are utilized by this population. That way, the providers can use this information to pass onto the next client who is undocumented or has needs that can be met through these other resources. Educating and teaching the signs and symptoms that can be addressed through primary care versus emergency care is also pertinent to prevent unnecessary suffering. The nurse must assess the unique needs of every undocumented client and considering their lifestyle and nature of work when planning the education. They must educate undocumented individuals on the signs and symptoms that need to be addressed at a clinic or primary care office, and ones that require immediate attention. This will allow undocumented clients to make informed decisions for themselves and their loved ones, increases the chances of a positive experience in seeking healthcare.

Research Implications

Further research is needed to continue understanding the experiences of an undocumented alien in the healthcare field and their healthcare needs. Understanding the undocumented experiences in seeking healthcare and quality of care is important in determining health status and outcomes. Additionally, understanding the decision-making process and health status of the undocumented aliens could help address areas where care is needed and help formulate interventions that allow for effective care or better education on the topics. It would be beneficial to further address the evaluation of undocumented clients' healthcare needs. Chandler et al. (2012) began to identify the ways communication between patient and provider can be improved using *cultural brokers*, who assist with the management of healthcare, increase patient empowerment, and improve health outcomes in the clinical setting. More research in this area is needed to generate successful communication and evaluation of a client's understanding

of health and care. Future research should also focus on a migrants' interpretation of health and influences that impact their willingness to seek care.

Policy Implications

The literature reveals that the experiences of undocumented aliens are also shaped and/or exacerbated by the political contexts of their lives (Cleaveland and Ihara, 2012). As evidenced by recent healthcare reforms, policy has yet to create equally accessible coverage to all, excluding groups such as the undocumented population. Healthcare providers have the capability—and some may argue the duty—to bring these human stories to the attention of policy makers in order to repeal the enacted laws or healthcare coverage. Providers can support eligibility for a legal work status so that undocumented aliens could begin contributing to programs such as Medicaid, Medicare, and the Children's Health Insurance Program, or could become eligible for insurance (Medicaid, n.d.). Healthcare providers may also use these stories to oppose proposals that will further create barriers to access to healthcare for undocumented aliens. For example, providers may advocate and support amnesty for undocumented aliens for work and healthcare opportunities. Findings from previous research supports that amnesty for undocumented workers, such as the efforts under the leadership of the Reagan Administration in 1986, could potentially benefit immigrants, as well as the healthcare system (Cleaveland and Ihara, 2012).

Conclusions

This qualitative study demonstrates that being an undocumented alien affects the experience of seeking healthcare. Various system and personal barriers create challenges for this population. These barriers often created feelings of *uncertainty, fear, stress, and worry* when

seeking care. For others, feelings of *relief* due to finally getting care provided another perspective on what it was like to seek care. These experiences are different for everyone, but there were some common and recurring themes such as high costs, trying to heal self, and language and communication incongruences. Community and healthcare providers must find better ways to care for this vulnerable population. The negative effects of increased policy change towards the growing Latino immigrant population in the United States is likely to have repercussions in the larger American society (Fernandez-Esquer, 2017). Advocacy and policy interventions thus take on an increasing urgency to ensure the well-being of these individuals.

**APPENDIX A: INSTITUTIONAL REVIEW BOARD APPROVAL OF
EXEMPT HUMAN RESEARCH**



University of Central Florida Institutional Review Board
 Office of Research & Commercialization
 12201 Research Parkway, Suite 501
 Orlando, Florida 32826-3246
 Telephone: 407-823-2901 or 407-882-2276
 www.research.ucf.edu/compliance/irb.html

Approval of Exempt Human Research

From: UCF Institutional Review Board #1
 FWA00000351, IRB00001138

To: Victoria Loerzel and Co-PIs: Eliany Celeste Torrez Pon, Susan Chase

Date: October 04, 2017

Dear Researcher:

On 10/04/2017, the IRB approved the following activity as human participant research that is exempt from regulation:

Type of Review: Exempt Determination
 Project Title: Exploring What it is Like to Be an Undocumented Alien in Seek of Healthcare.
 Investigator: Victoria Loerzel
 IRB Number: SBE-17-13436
 Funding Agency: University of Central Florida(UCF)
 Grant Title: Honors in the Major Research Grant

Research ID: N/A

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 in iRIS so that IRB records will be accurate.

In the conduct of this research, you are responsible to follow the requirements of the [Investigator Manual](#).

On behalf of Sophia Dziegielewski, Ph.D., L.C.S.W., UCF IRB Chair, this letter is signed by:

Signature applied by Patria Davis on 10/04/2017 03:20:28 PM EDT

IRB Manager

APPENDIX B: SOCIODEMOGRAPHIC SURVEY

1. What is your gender?

Male	Female
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2. What is your age at your last birthday?

3. What is your race/ethnicity?

American Indian or Alaska Native	Asian	Black or African American	Hispanic or Latino or Spanish Origin	Native Hawaiian or Other Pacific Islander	White	Other
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4. Are you Hispanic or Latino?

Yes	No
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5. What is your current legal status?

U.S. Citizen	U.S. Permanent Resident	Non-Citizen Legal Alien	Undocumented Alien	Other
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If other, explain: _____

6. Marital status?

Single	Never Married	Married/Partnered	Divorced	Widowed
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7. Do you have children?

Yes	No
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a. If so, how many?

1-2	3-4	>5
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8. What is the legal status of the members of your immediate family living here in the U.S.?

Spouse	U.S. Citizen	U.S. Permanent Resident	Non-Citizen Legal Alien	Undocumented Alien	Other
Children					
Siblings					
Parents					
Grandparents					

9. How long have/did you live(d) in the United States as an undocumented alien?

< 1 year	1-5 years	6-10 years	>10 years
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10. What is your highest level of education?

Grade School	High School	Trade School	College or Graduate School
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11. Do you have a primary healthcare provider?

Yes	No
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12. Where do you go for your healthcare?

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