Fear and Mistrust of the Health Care System among Undocumented Residents of North Carolina: Does Fear of Deportation Contribute to Underutilization of Care?
An Investigative Study

By
Gabriel John Blanchard

Senior Honors Thesis
The School of Nursing
University of North Carolina at Chapel Hill

Approved:

Theresa Raphael-Grimm, PhD, CNS, Honors Advisor
Acknowledgements

I would first like to thank Dr. Raphael-Grimm for her guidance, wisdom, and patience as I completed this project. I would also like to thank my friends in the local Latino community who brought this issue to my attention in the first place. The efforts of our hardworking Latino peers, friends, and neighbors will be the driving force behind improved access to care for this population here in North Carolina.
Table of Contents

I. Abstract ......................................................................................................................4

II. Introduction ..............................................................................................................5

III. Review of Literature ............................................................................................6

IV. Methods ..................................................................................................................14

V. Results ......................................................................................................................18

VI. Conclusion ............................................................................................................21

VII. References ............................................................................................................23

VIII. Appendix A: Transcribed Interview with Health Director of Latino Outreach

Organization ..................................................................................................................28

IX. Appendix B: Transcribed Interview with High-Level Administrator of Tertiary

Teaching Hospital ........................................................................................................33
I. Abstract

Introduction: North Carolina is home to a significant number of undocumented immigrants. These undocumented residents (URs) do not seek health care services at the same rate as the general population and this underutilization has serious implications not only for the health of those residents themselves but for the general population because transmission of communicable diseases is increased when a large segment of a population goes untreated. Several impediments contribute to these underutilization patterns and perhaps the most significant factor is fear of detection and deportation.

Methods: In this investigation, patterns of utilization are presented along with findings from interviews with key informants.

Results: Access to adequate health care services for URs is impeded by several factors. Deportation is a rare but powerful event that has far-reaching and long-lasting impact on the attitudes and behaviors of URs. Organizational policies around service delivery to, and confidential treatment of, URs are often unwritten and fluid.

Conclusion: Policies and practices around health care delivery to URs are continuing to evolve. Clear, consistent, explicit and compassionate policies would likely help to dispel fears and increase UR utilization of health care services. Those policies cannot be put in place until the state of North Carolina and the country as a whole establish consistent approaches to the compassionate care and treatment of our undocumented residents.
II. Introduction

The ability to feel safe in one’s daily life is something that most of us in the United States take for granted. Maslow’s second level on his famous “hierarchy of needs” defines safety as, among other things, security of body, resources, family, and health. The sense of being safe is not enjoyed equally by all of us in the United States, or in the state of North Carolina. Undocumented residents (URs) carry significant anxiety around the threat of possible detection and deportation, and do not feel free to access vital resources when attempting to maximize their wellbeing and that of their families.

If URs do not seek care due to fear of deportation, it could have broad implications on their health as individuals, and the health of the public in general. Without easy access to primary care for all, infectious diseases such as tuberculosis can proliferate and persist. Otherwise minor health issues have the potential to propagate and put undue burden on families, communities and the health care system.

I became interested in this topic after returning to the United States after a year in Argentina and a summer in Puerto Rico. In order to maintain my level of Spanish proficiency, I sought out opportunities to engage the local Spanish-speaking community. After getting to know various members of the Latino community, a number confided in me that they lacked documentation. I was shocked to learn that a majority of North Carolina’s foreign-born individuals were undocumented (Passel & Cohn, 2009). Through my friendships, I learned how “undocumented” status affects every area of these individuals’ lives. They deal with the burden of not being able to see family back in their home countries, being unable to obtain driver’s licenses, and constantly having to find ways to work around the roadblocks in our system. For example, a friend that I grew up with in school had to pay out-of-state tuition to attend a public
university because she was brought to the United States from Mexico as a young child. It became evident as I advanced in my nursing education that barriers also existed in the realm of health care for these individuals.

This paper examines the extent to which fear of deportation leads to URs avoiding or delaying needed medical care here in North Carolina. It also attempts to assess whether those beliefs are grounded in myth or reality; in other words, could accessing certain types of health care actually lead to detection and deportation for an undocumented resident living in North Carolina today. This paper also looks at the potential individual and social consequences of this fear, and suggests an intervention for addressing this issue at the local level.

III. Review of Literature

Utilization of health resources by Latinos in general

To begin this investigation, it was essential to examine the current literature, in order to gather information on the nature and extent of this issue. Access to care among the undocumented population was explored through an examination of health care utilization rates among Latinos, and it was found that utilization rates by Latinos across the country, regardless of immigration status, are lagging behind those of non-Hispanic Whites. Many factors contribute to this disparity. Several barriers to adequate care exist and prevailing perceptions of various resources contribute to the disparity in health care utilization rates among Latinos. Some of that literature is described and summarized below.

Well-documented barriers to care include lack of financial resources, inability to qualify for health insurance, lack of health literacy, lack of awareness of resources, the language barrier, cultural issues, fear of pain or personal harm, and fear or mistrust of the health care system
FEAR AND MISTRUST OF THE HEALTH CARE SYSTEM AMONG UNDOCUMENTED RESIDENTS


The disparity in access to insurance was a major factor in health care utilization differences between Latinos and their peers. One survey found that up to 27% of all Latinos living in the US do not have health insurance, and 34% do not have regular access to health care (Ai, Noel, Appel, Huang, & Hefley, 2013), which lags significantly behind other ethnic groups. The Affordable Care Act will not serve to rectify this disparity, and its effect on this population will be discussed more in depth later in this paper.

Latino individuals, especially recent immigrants, were found to have received less care overall and sought care only at more acute stages. Oliveira, Clark, Dunn, and Mangram (2011) found that Latina women who declared that English was not their first language presented with late-stage breast cancer at a 12% higher rate than their non-Hispanic White counterparts. This shows that these women did not utilize screening services at the same rate as Whites (Oliveira et al., 2011). In the same vein, Rodríguez, Vargas Bustamante, and Ang (2009) reported that Latinos “have fewer physician visits, lower utilization of emergency services, and a lower likelihood of having a regular source of care than non-Latino groups,” and found that undocumented status was correlated to perceived low quality and less frequent care among the surveyed population. Latinos overall were also more likely to report feelings of discrimination in their care and describe their health care experiences using negative terms (Abraído-Lanza, Céspedes, Daya, Flórez, & White, 2011) (Rodríguez et al., 2009) (Davis et al., 2012). The ultimate result of these negative perceptions is a lessened willingness to seek treatment among Latinos in the United States (Davis et al., 2009).
Trust as a factor in utilization by Latinos

A lack of personal trust in providers has been found to be an important factor in the negative perception of the health care system among Latinos. One study found that Latinos were twice as likely to report “fear of being a ‘guinea pig’ and lacking trust in medical people” when compared to non-Hispanic Whites (Davis et al., 2012).

However, mistrust was not found to be ubiquitous in the Latino population. For example, Abraído-Lanza et al. (2011) reported low levels of medical mistrust among women from the Dominican Republic living in New York City, but did find that mistrust, when present in that group, negatively affected satisfaction with health care. When health care staff speak Spanish or originate from a Hispanic background, it increased trust in the health care system and improved treatment adherence for Latino immigrants (Abraído-Lanza et al., 2011) (Morano, Walton, Zelenev, Bruce, & Altice, 2013) (Cruz-Flores et al., 2011). In examining the social context of adherence to health interventions, Shelton, Goldman, Emmons, Sorensen, and Allen (2011) quote one Latina woman who stated, “I only have my husband’s family here, after that I don’t trust anyone here.” Deference to family or cultural bonds can serve to further the divide between Latinos and the health care system.

The Affordable Care Act of 2010 helps to address some of the problems of access for Latinos by providing health insurance to those who had previously been unable to afford it. This policy shift addresses one aspect of access: affordability. However, when the Affordable Care Act was passed, it categorically excluded URs from its provisions, which further excludes this population from access to health care, even when controlling for economic factors (Zuckerman, Waidmann, & Lawton, 2011).
The Impact of Illegal Status

There were roughly 11 to 12 million URs in the United States in 2013, according to Sommers (2013), in a study that analyzed the effect of changing health care and immigration policies on URs. That number constitutes approximately one-fourth of the total population of immigrants in the US (Suarez-Orozco, C., Yoshikawa, Teranishi, & Suarez-Orozco, M., 2011). Of these estimated 12 million URs, about 35% have no regular source of health care, only 28% had seen a doctor in a one-year period, and only 12% had visited the emergency department in the past 12 months. According to Wallace, Torres, Nobari, and Pourat (2013, these rates are all significantly lower than those of their naturalized counterparts, and demonstrate underutilization of needed health care services by URs.

Another notable statistic about URs’ access to health care is the fact that 59% of them have no health insurance (Passel & Cohn, 2009). Among the children of URs, of which there are 5.5 million living in the US (Suarez-Orozco et al., 2011), 45% of those who are foreign-born themselves and 25% of those who are native-born are uninsured, as well (Passel, & Cohn, 2009). For many of the millions of undocumented, uninsured individuals, the only health program available to them is Emergency Medicaid. This program covers acute, inpatient care and emergency department care for individuals who meet the requirements, but “given the small numbers… eligible and the limited scope of services covered, [it] does little to facilitate meaningful access to care for most immigrants” (Sommers, 2013).

Vargas Bustamente et al. (2012) found that if “undocumented immigrants from Mexico had the same characteristics of the documented population, they would enjoy a 27% higher probability of having a doctor visit and a 35% increased probability of having a usual source of care.” URs currently use health care resources to a lesser extent than their documented peers in
all areas of care, with the exception of charity care (Stimpson, Wilson, & Eschbach, 2010). This underutilization is especially noteworthy when considering the high rates of some chronic diseases evident in this population such as diabetes, hypertension and stroke (Rodríguez et al., 2009).

Because resource availability and resource utilization rates vary, it is important to examine local issues and trends. Do the utilization patterns heretofore described apply to the health care experience of URs in North Carolina? Chavez (2012) emphasized “the need for empirical research on undocumented immigrants and their use of medical care, especially at the local level.” He argues that the need for local research lies in the fact that “it is the local level where health care is provided” (Chavez, 2012).

*Fear of Deportation Specifically*

In addition to those previously mentioned, one major factor found in the literature, and the one that will be examined more closely, is the role that fear of deportation plays in deterring URs from seeking and utilizing health care resources.

This fear of deportation was highlighted in a case study by Deeb-Sossa, Díaz Olavarrieta, Juárez-Ramírez, García, and Villalobos (2013) that found that women in their study, all URs living in California, were afraid to seek treatment or afraid to seek help navigating the health care system. The authors attributed this fear to statewide policies that prohibit URs’ use of public services. Policies, such as California Proposition 187, passed in 1994 have significantly influenced this fear. Proposition 187 was never enforced, but it did serve to create a culture of fear among URs, and increase their wariness around use of health care services nonetheless. Under this legislation, health care providers would have been mandated to report URs to the proper authorities (Berk & Schur, 2001). Despite residing in the US for ten to twenty years, some
women in the case study reported having no idea how the health care system worked because they had never accessed care. The main cause of their underutilization was the fact that fear of deportation can be paralyzing (Berk & Schur, 2001).

Viruell-Fuentes & Schulz (2009) found that many undocumented women feel a continuous sense of anxiety about their status in the US and they believe that this anxiety can lead to a strong aversion to reaching out, especially to established governmental systems that represent the source of these women’s fear in the first place.

URs not only avoid seeking care for themselves, but also their families. Wallace, Leite, Castaneda, and Schenker (2009) focused on the health challenges faced by the children of URs, and found that undocumented parents are reluctant to seek out more information about their children’s rights or apply for health insurance for their children, due to fear of being deported themselves and having to leave their children behind.

Even though URs make up 3.2% of the US population, their healthcare accounts for only 1.5% of medical costs, according to López-Cevallos (2014). The author determined that this disparity stems from a number of variables, such as prohibitive costs, lack of health insurance, discrimination, mistrust, and fear of deportation, which is consistent with previously discussed research. This atmosphere of fear and mistrust is not new among this population. In 2001, 39% of the adult undocumented population reported fear of using the health care system because of their immigration status, which prevented them from seeking and receiving care (Berk & Schur, 2001).

National events have fueled the fear. In 2011, Hacker et al., described growing fear in the immigrant communities of Everett, Massachusetts in the aftermath of the September 11th terrorist attacks. Fear of deportation escalated, immigrants often felt insecure seeking care, and felt
vulnerable in their host communities (Hacker, et al., 2011). The authors called for more research into how fear of deportation affects immigrant health.

A study by Portes, Fernández-Kelly, and Light (2012) that looks at the immigrant experience with the US health care system stated that the climate of fear and suspicion led to numerous health crises among URs. According to field interviews with health care providers in San Diego in 2008, URs often only sought health care in dire situations, and the principle reason was fear of deportation. This created a lower class of people who lacked access to care (Portes et al., 2012). The study highlighted the fact that this fear among URs in San Diego was justified. To use an example referenced in the study, Immigration and Customs Enforcement (ICE) agents were known to monitor Latino radio stations to find free health clinics in migrant neighborhoods and use that information to conduct immigration raids.

A study by Cavazos-Rehg, Zayas, and Spitznagel (2007) raised the issue of location within the US as potentially magnifying fear of deportation and mistrust. In areas outside of the immigration hotbeds of California, Texas, Florida, and New York, immigrants may feel isolated and even less inclined to seek help (Cavazos-Rehg, et al., 2007). North Carolina was expressly mentioned as a state that was not a traditional location for settling for Latino immigrants until recent years, and therefore, a place where immigrants would feel even less able to safely use health care services because few service patterns had yet been established and few “safe” clinics had been identified.

A very recent study into the health care access of Latino “DREAMers” found that with or without the Deferred Action for Childhood Arrivals policy, URs demonstrate hesitation to interact with health care services due to fear of deportation or other legal consequences (Raymond-Flesch, Siemons, Pourat, Jacobs, & Brindis, 2014). It also mentioned that the recent
Immigration and Customs Enforcement (ICE) policy statement may help to alleviate fears of deportation among URs.

The ICE policy statement, “Clarification of Existing Practices Related to Certain Health Care Information,” states that the agency will “not use [health care information of URs] or members of their household that is obtained for purposes of determining eligibility for such coverage as the basis for pursuing a civil immigration enforcement action against such individuals or members of their household” (2014). In other words, ICE has clarified that no one will be deported for the sole reason of using the health care system in a legal manner.

Mobile health centers may represent a more accessible form of health care for URs. In one recent study, researchers analyzed patterns of utilization of medical and dental services provided to migrant farmworkers by mobile, church-sponsored health centers (López-Cevallos, Lee, & Donlan, 2014). The authors found that 87% of survey respondents were afraid of deportation, but that this fear of deportation did not affect their use of this particular type of health service. While fear was found to be a large factor in this population’s health decisions, mobile clinics sponsored by churches (which are viewed as trustworthy by many URs) might be an effective method of improving access to health care for migrant farm workers and their families (López-Cevallos et al., 2014).

Some of the best evidence for this proposed relationship between fear of deportation and poor utilization of health care among URs comes from a recent meta-analysis on this topic. Completed by Pérez-Escamilla, Garcia, and Song, this systemic review analyzed 77 studies and identified patterns in health care access among Latino immigrants (2010). The authors determined that URs are at a very high risk of not having access to health care, and that undocumented status represents one major barrier to access, due to fear of deportation.
Note: After this review of literature was completed, a noteworthy segment aired on the WUNC radio program, The State of Things, titled “The Life, Culture and Economic Impact of Latino Immigrants in North Carolina.” In this segment, the host Frank Stasio interviewed Luke Smith, psychiatrist and executive director of El Futuro, a behavioral health treatment organization for Spanish-speaking individuals in Durham, North Carolina and the surrounding area. Smith spoke about the access to mental health services among URs here in North Carolina:

“...And then to come against some barriers and some realities here that engender such fear, really does impact the psyche. And as we see people come into interactions with us in the health care system, we start to see people articulate that... they feel nameless and voiceless. And oftentimes they only come in when things have gotten worse, because they’re afraid to come in when things aren’t that bad” (2015).

IV. Methods

This investigation started with a thorough search of the literature. Librarians at the Health Sciences Library at UNC-Chapel Hill suggested using the search terms “trust OR perception OR belief OR experience AND Latino OR Hispanic AND healthcare OR health services OR immigrant health AND access OR barriers.” However, this was unsuccessful in revealing pertinent research on various databases such as PubMed, AMED, and CINAHL. The search was then modified using the terms: “trust OR perception OR belief OR experience AND Latino OR Hispanic,” but that was unsuccessful, as well.

PubMed and CINAHL databases were searched using the term: “Medical mistrust undocumented” with the bounds of “last 5 years” and “free full text available.” The only result that this uncovered was an article entitled “There is no help out there and if there is, it's really hard to find”: a qualitative study of the health concerns and health care access of Latino “DREAMers” (Raymond-Flesch et al., 2014). This study contained a considerable amount of relevant information, and the references section provided many useful leads. From those
references, new search terms emerged and revised PubMed searches were run with the same bounds as before but using the search terms: “uninsured Latino patients” and “medical mistrust Latinos.” These searches provided more helpful results. These searches and a culling of the reference sections of the most recent, pertinent articles provided a good picture of the current body of literature on this topic.

After developing a solid base of the current literature on this topic, the next step was to contact various key experts or representatives for interviews to assess the perspectives and practices of local organizations and agencies. Talking to key informants would help answer the ultimate question of interest: does the fear of deportation prevent URs in North Carolina from accessing health care resources? And is this fear justified?

At this point the faculty advisor and principle investigator determined that interviews should be sought with representatives of the Immigration and Customs Enforcement (ICE) agency, a community outreach organization that focused on the Latino population, the LATCH program, the immigration clinic at the UNC School of Law, and a large hospital in North Carolina. An interview with a representative of ICE would help the researchers determine the validity of UR’s fear of deportation through interaction with health care. If said representative could point to an example of this occurring or to a certain policy, then the researchers could determine that the fear had at least a degree of validity. An attempt was made to contact ICE for an interview on November 24, 2014. After calling the Office of Enforcement and Removal Operations Information Line, which was open to “inquiries from the general public” according to the ICE website, the principle investigator was put on hold and transferred to the ICE Public Affairs Office, where he was instructed to leave a message. He did so, clarifying that according to their website, as an interested member of the public he was entitled to a meeting with a local
ICE representative. After two weeks, a follow-up call was made and another message left, but a response was never received.

Contact was also made with the UNC School of Law, explaining the investigation and requesting an interview with the Director of the Immigration Clinic to hear his or her perspective on the legal aspects surrounding detainment and deportation of URs due to accessing public services such as health care. The principle investigator was transferred to the director’s office and left a message. Unfortunately, due to the limited scope of this investigation, it was impossible to aggressively pursue all avenues, and after receiving no reply, an interview was never completed.

The principle investigator also attempted to schedule an interview with a representative of the LATCH program, or Local Access to Coordinated Healthcare. LATCH is a program that is run out of the Duke University School of Medicine that pairs local residents who lack health insurance with care coordinators. These coordinators work with their clients to connect them with resources available to them in the community, such as free clinics, transportation services, or Emergency Medicaid. The majority of LATCH’s clientele is Latino; a large (but undetermined) portion of which is undocumented. The administrative assistant put the principle investigator in touch with a representative of the organization, Katherine Ruiz, who stated that she was willing to answer a few questions over the phone but was unsure of how much she could help with the project’s main goal. She shared some information about Emergency Medicaid, which is covered in more depth in another interview, to be discussed shortly.

It was then clear that an interview with a representative of a local health care system was essential to ascertain current policies within local health care facilities regarding the care of URs. The identities of this expert and her organization have been kept confidential in order to comply
FEAR AND MISTRUST OF THE HEALTH CARE SYSTEM AMONG UNDOCUMENTED RESIDENTS

with IRB stipulations. Through accessing networking channels, the principle investigator was put in contact with a high-level administrator of a tertiary teaching hospital in North Carolina. This administrator reported that through working with the Mexican Consulate and the Latino Health Coalition, she had a good deal of experience in the area of care for URs. She agreed to meet to discuss her experiences and describe her organization’s positions on this topic.

Concurrently, contact was made with the Director of the Health Services of an outreach organization dedicated to serving the needs of the North Carolina’s Latino population. It was crucial to meet with her to discuss how their organization’s work with the undocumented population was influenced by fear of deportation. After obtaining a more accurate assessment of how the tertiary teaching hospital, a major site of indigent care in the state of North Carolina, addressed care of URs, it was important to understand how URs perceived the care they received. Through the interview with the Health Director of the Latino outreach organization, perceptions and beliefs of URs were ascertained. It was especially important to have this interview in person, as it was in Spanish. With a proficient, but non-native speaker conducting the interview, the face-to-face interaction was essential. The identities of this expert and her organization have also been kept confidential in order to comply with IRB stipulations.

The original goal of this project was to create an intervention; an informational pamphlet or brochure available to URs in North Carolina and the organizations serving them that could provide accurate information about health care services policies on URs, that could dispel deportation myths, and reassure the undocumented population that the act of accessing health care resources would not lead to the possibility of deportation. However, through examining existing information, it was determined between the faculty advisor and principle investigator that regardless of the quality and quantity of information gathered, the inherently limited scope
of this study and inability to predict the behaviors of individual health care providers, made it impossible to determine whether URs would, indeed, be safe. While institutions may enact practices that ignore immigration status, the behaviors of specific health care providers cannot be predicted. While unlikely, it is possible for a physician or nurse to take it upon him or herself to reveal the identity and address of a UR to immigration officials. Therefore, the aims of this project were reconsidered. The revised purpose became to share information and make recommendations. To that end, interviews with the Health Director of the Latino outreach organization and the high-level hospital administrator were conducted, transcribed, analyzed, and conclusions were synthesized based on the review of literature and these interviews.

V. Results

Common themes were found to exist between the responses in both interviews. Both experts recognized that fear of deportation existed among the URs of North Carolina, and that it represented one factor among many that contribute to low utilization rates. Both the Health Director and high-level hospital administrator reported that in their experience working with the UR population of North Carolina, fear of deportation had peaks and troughs in recent years, correlating to shifts in public opinion on illegal immigration and political crackdowns on URs. According to the Health Director, “there are periods- there are times when they’ve even detained people near the Health Department. There are many examples like this.” The high-level hospital administrator spoke to the fact that some North Carolinians are opposed to any services being provided to URs: “sometimes we’re even careful about how much we talk about these things, because of” the political opposition (personal communication, March 26, 2015).
Both experts also reported that in their experience, URs in North Carolina trust health care professionals in general. According to the Health Director of the Latino outreach organization, the fear of deportation and mistrust is more directed towards law enforcement. Despite this trust of health care professionals, there is significant fear that accessing health care can lead to discovery and detainment by law enforcement. This fear, as detailed by both experts, was encapsulated in a small number of powerful anecdotes that they shared, describing situations where using health care services had led to consequences for URs. For example, the Health Director told a story of some residents who avoided medical attention due to fear of deportation:

But the simple fact of not being able to drive freely in some counties makes it so some people don’t even dare to seek medical care, if it is very far. I remember about two or three years back some construction workers that had been driving their work van and had an accident, and didn’t wait for the police, or an ambulance, or anything. They arrived [to our office] cut up and bruised, and one of them had lost consciousness. And the only fear that they had, because they came from [a more rural area of the state, was being caught]. They were very scared, getting out, trying to move the car, clean up the scene of the accident, so the police wouldn’t show up. They didn’t even go to the hospital. The accident had occurred early in the morning” (personal communication, March 18, 2015).

The Health Director said unwillingness to call 911 in medical emergencies was a widespread problem among URs in North Carolina. She talked about how URs knew that when police came, they could be handed over to immigration. This fear was especially prevalent in the rural areas of the state, where law enforcement was less familiar with URs (personal communication, March 18, 2015).

According to the Health Director, sometimes URs can try to remain hidden while actively seeking care in North Carolina. She talked about a recent case where “a person who had an infectious disease was going to a private doctor with another person’s name and using their health insurance” (personal communication, March 18, 2015).

As she mentioned multiple times in her interview, these issues for URs are multifaceted, and include lack of insurance, lack of health literacy, differences in culture, and fear of
deportation. One gentleman she knew “was afraid to call the ambulance because it can cost more
than $800. So, someone in his family was having a stroke, and he preferred to drive them in his
car instead of call the ambulance” (personal communication, March 18, 2015).

Sometimes bureaucratic red tape can cause issues in the care of URs, which can deter
other URs from feeling free to seek care. The high-level hospital administrator detailed a story
about one patient at her hospital that is known by the community, and can influence UR
perceptions of their access to care:

“In fact, we have…one gentleman who’s been with us for over 800 days. He’s from
Mexico, and he doesn’t have any family or friends willing to care for him here in North
Carolina or the US, and we’ve been unable to identify family willing to care for him back
at home in Mexico, and we have to have a safe discharge plan to move patients out of the
hospital setting. And we have in the past on many occasions, working with the Consulate,
identified family in Guatemala or Mexico and repatriated patients…So we have a
gentleman here, and we are trying to figure out what to do with this man” (personal
communication, March 26, 2015).

Another important theme that emerged from the interviews was the fact that approaches
to dealing with URs by health care professionals mostly come down to unwritten rules in
organizations. When asked if their hospital’s policy of not reporting URs that seek care at their
facilities was codified in any way, the hospital administrator said, “it’s an unwritten policy and
there is no legislation that I’m aware of that guides us to do it or not do it, but we choose not to
ask” (personal communication, March 26, 2015).

As mentioned previously, Emergency Medicaid is a resource that is made available to
this population. But according to the Hospital Administrator, it doesn’t always represent reliable
access to care for URs.

“I can tell you a very common example, which is dialysis. The benefit for non-qualified
aliens for dialysis is that they are entitled to Emergency Medicaid for that in this
state...For Emergency Medicaid, you have to reapply every three months. So the out-
patient dialysis units may choose to accept someone on Emergency Medicaid, but often
they're leery, because when it comes time to reapply in three months...part of it is the
patient’s responsibility, and sometimes these patients aren’t compliant with getting their
information in, and now that dialysis unit is stuck, because the Emergency Medicaid
doesn’t get renewed, and that’s care that if you stop, it is life-threatening. So many of the out-patient dialysis units may not accept Emergency Medicaid, and that their prerogative. And those patients then end up sitting in the hospital until we figure out a plan for them” (personal communication, March 26, 2015).

Both experts reported having hope for positive change in this area on the statewide level in the future. The Health Director pointed to community education as the best way to address the greater issue of URs and their access to health care. She also mentioned national policy shifts, such as the DREAM Act and the Affordable Care Act as steps in the right direction towards acceptance of immigrants in general, which could lead to decreased fear for URs in North Carolina (personal communication, March 18, 2015). The hospital administrator argued that URs need to be included in the provisions of the Affordable Care Act and allowed to buy in to their health care so that their access to care could be improved. She also expressed hope that a shift in opinion in the state might occur and decrease feelings of marginalization and fear for the UR population (personal communication, March 26, 2015).

VI. Conclusion

In order to overcome the barrier that fear of deportation represents for Latino immigrants, health care systems must acknowledge the existence of the disparity in utilization rates and the fact that it stems in part from fear and mistrust in the greater health care system (Cruz-Flores et al., 2011). After acknowledging the fact that this fear exists, health care systems can begin to address it alongside community organizations and improve the dialogue with the URs they seek to serve here in North Carolina.

The issue of undocumented immigration has been prominent on the national stage in recent years due to new legislation proposed by President Barack Obama, such as the DREAM Act, which offers hope for URs brought to this country as children. However, fear persists
among URs in North Carolina. Illegal immigration is a national issue with local implications. Within North Carolina, the current administration is less sympathetic to the plight of URs. Within our state, citizens and lawmakers do not look kindly on the presence of URs in their communities. Some health care institutions are trying to meet the needs of the UR population but significant obstacles remain. National policy changes will be necessary to significantly impact local care delivery.

It was outside the scope of this study to create an actual intervention; however, the recommendation of the principle investigator is for nurses to become well-informed and politically active so that we can better influence national, state and local policies that directly impact the health care services to URs.
VII. References


Davis, J.L., Bynum, S.A., Katz, R.V., Buchanan, K., & Green, B.L. (2012). Sociodemographic differences in fears and mistrust contributing to unwillingness to participate in cancer


Raymond-Flesch, M., Siemons, R., Pourat, N., Jacobs, K., & Brindis, C.D (2014). “There is no help out there and if there is, it's really hard to find”: a qualitative study of the health


VIII. Appendix A

Full Transcription of Interview with Health Director of Latino Outreach Organization

Gracias por reunirse conmigo. La semana que viene me voy a reunir con un [representante de un hospital grande] sobre este tema. La voy a preguntar sobre la política y la práctica del hospital con esta población. Hoy, quiero hablar consigo sobre la experiencia y los sentimientos de los inmigrantes sin documentación sobre su uso del sistema de salud. Si tienen miedo, y todo eso. ¿En cuales maneras usan el sistema de salud estos inmigrantes? ¿Tienen miedo de irse al hospital? ¿Solo usan unas maneras, como las clínicas abiertas?

Creo que depende más del área donde se les encuentran. Hemos escuchado, no tanto últimamente, pero escuchamos por ejemplo, unos años atrás, sobre todo la parte de Siler City y el condado de Alamance, {inclusiva la instanciaron de entrevistas y trabajos con la población} de como el estado inmigratorio de las personas influyan en la manera de que buscan atención médica. Tenían más que ver con el miedo de manejar porque muchas personas no tienen acceso a una licencia de conducir. Y están haciendo parados para la policía, no solamente que los detenían y los daban un ticket, sino también llamaban al inmigración. Entonces, esto crea muchísimo, muchísimo miedo de la comunidad a buscar atención médica. De algo por cien es muy difícil cuando educas a la comunidad la importancia de tener un médico de cabeza o registrarse en la clínica o hacerse un chequeo físico anual, no es algo que lo acostumbramos hacer. Las personas vienen aquí- y tiene que ver con si tengan o no tengan documentos- pero la mayoría de ellos vienen con idea de trabajar, e ir al médico implica perder donde de trabajo. Porque generalmente, hacer la cita, irse a la clínica, si queda lejos el acceso transporte es un problema o si tienes que manejar es otro problema, entonces hay muchísimas barreras las que tienen que enfrentar. Pero el simple hecho de no poder manejar libremente en algunos condados hace que
las personas no acudan a buscar atención médica. Si es muy lejos- recuerdo como los dos o tres años atrás, llegaron unos trabajadores de construcción que iban manejando en el camión y tuvieron un accidente y no esperaron ni la policía, ni ambulancia, ni nada. Llegaron dos cortados y golpeados a [la oficina] y uno de ellos había perdido conocimiento. Y el único temor que tenían, porque venían del otro lado de Raleigh, ellos estaban bien asustados, saliendo tratando de mover el carro, de limpiar la escena del accidente, para que no llega la policía. No había ni ir al hospital. El accidente ha ocurrido temprano en la mañana – entonces no chocaron con otro – no, por alguna razón, tuvieron un accidente, se salieron de la carretera, y ellos llegaron en la tarde a [la oficina]. Pero estaban los dos raspados y uno me contó que uno de ellos quedó sin conocimiento, pero en ningún momento buscaron atención médica, simplemente por el hecho de que- iban a trabajar, iban todos en una vana, con pintura, y si hay riesgo de manejar sin licencia y por el solo hecho de que sabían que si llegaban la policía a hacer el reporte o llamaban a la ambulancia, iban a pedir la licencia y no lo tenían, pues sabían que iban a llamar inmediatamente a inmigración. Eso fue unas de las cosas que nosotros vivimos. No nos vuelta a escuchar historias así en los últimos años, creo pero- yo sé que las cosas se están cambiando actualmente, ¿no? Con Obamacare, que es malo para los inmigrantes sin documentación, ¿no? Sí, no pueden buscar ayuda. Pero también, el gobierno está haciendo cosas para- Sí, hay menos temor ahora, y realmente Durham siempre ha sido un condado que no ha sido anti-inmigrante en términos generales, o sea, si hacen retenes, pero no escuchamos cosas tan malas como las que escuchamos de Raleigh- que tiene tiempo que no escuchamos, pero había una época en que por el simple hecho de hacer un retiene y no tener licencia, te llamaban inmediatamente a inmigración sin tener ningún antecedente. Ahora, lo están haciendo más con las personas que manejan bajo la influencia de alguna droga o alcohol, o por violencia doméstica. Estos son los tipos de casos que
la policía usualmente llama a inmigración. Y dependiéndose en el antecedente y todo. Esto ha cambiado un poco el concepto de la gente que no busca asistencia médica. O simplemente van a la [sala de] emergencia también, esto es otro problema. Saben que la emergencia está abierta a cualquier momento, y hay pues no importa el tiempo en que van, y los van a tener que atender. Mucha gente tiene el concepto de que mientras te sientes bien, no necesitas ir al médico, entonces pueden pasar muchísimos años sin nunca vas a ir al médico. Esta es una de las cosas que también nosotros queremos atraer de los programas que tenemos de relacionar y educar a la salud de la comunidad: la importancia de la prevención y hacer un chequeo anual. Físico para evitar, si tienes ciertos factores de riesgo, …

He escuchado que alguna gente tiene miedo de llamar a 911, porque creen que, o escucharon que en Carolina del Sur, alguien llamo a 911 y se fue deportado. ¿Tiene miedo la gente aquí de eso?

Si, si eso es otro problema que tiene la gente que muchas veces no llaman y reportan crímenes, no hacen renuncios, porque saben la policía va a llegar y pedir algún tipo de documentación o forma de identificación. Tienen mucho temor de eso. Y si por alguna razón una persona tiene una experiencia de que llaman a la policía por otra cosa y cuando entran, pongan su nombre y si parecen antecedentes o ha tenido orden de deportación, pues esta es una excusa para que la persona se queda detenida.

En mis investigaciones, leí que es mucho peor en California…

Hay épocas, hay temporadas de que- inclusiva han hechos retenes aquí cerca del departamento de salud. Que más ejemplos de esos, [porque] saben [la policía] que esta es un lugar en esta vía. O lo han hecho también cerca de la escuela de ciencias, donde hay vecindarios latinos. Hay temporadas en que lo hacen en áreas donde la mayoría son de la comunidad latina.
¿Usted tiene esperanza para lo que está haciendo el gobierno con el cambio de política?

Es una buena opción, porque resuelve muchas barreras en términos de… la personas pueden ir con más tranquilidad a la clínica. Pero también es… el que las personas entiendan cómo funciona el sistema de salud y que lo usan es más tarea de educación, de crear programas o seguir trabajando en la parte de educación de la comunidad. Porque hay muchas personas que vienen de lugares bien remotos a buscar servicio de atención médica, y no tienen acceso a eso. Y realmente no saben cómo sale el sistema de salud. El sistema de salud aquí es muy complicado y más de que es muy costoso. Entonces, he escuchado un ejemplo de un señor que le dio medio a llamar a la ambulancia porque la ambulancia cuesta más que 800 dólares. Entonces, alguien en su familia estaba sufriendo un derrame cerebral y prefirió llevarlo en su carro en vez de esperar a la ambulancia. Así que el tratamiento sea completamente diferente. Y no es porque no sepa llamar a la ambulancia en caso de derrame cerebral, es simplemente porque dijo “No, es porque es 800 dólares.” Es una de las barreras para las personas a usar el sistema de salud. El transporte es un problema bastante serio, el uso de transporte público toma mucho tiempo. No es muy eficiente.

¿Los inmigrantes sin documentación a veces usan otras maneras de mantener la salud, como hierbas o cosas así?

Hay muchas tiendas mexicanas que venden medicamentos o muchas personas van a traer sus medicamentos de sus países. Siempre escucho de eso. Porque la distribución de medicamentos en nuestros países es muy diferente. O sea, el farmacista [SIC] es como el médico de la familia. La gente a veces ni siquiera va al doctor, sino que van a la farmacia y dice “oh toma esto para el dolor. Toma esto…” Es como el medico de ellos. Ellos, si tienen algo crónico, traen sus medicamentos de allá o se pueden mandar. Y sí, hay personas que hacen lo que es la medicina de, como curanderos. Como las personas que soban, quiroprácticos. La misma cosa [de aquí]
pero sin educación formal en una universidad, ni nada. Y también, hay lugares que vendan hierbas y dan consejos.

*Tambiién en mis investigaciones, he escuchado de personas sin documentación que usan otro nombre en el hospital, como el nombre de un amigo o pariente que tiene documentación. ¿Ha escuchado de eso aquí en Durham?*

Sí, sí. Hace poco había una persona que tenía una enfermedad infecciosa y estaba yendo a un médico privado con el nombre de otro persona y usando su seguro médico.

¿*Es raro, o no?*

No es tan frecuente, pero no me sorprende que esté pasando. He escuchado de eso anteriormente, sí.

*Gracias de nuevo por reunirse conmigo. Fue muy útil hablar consigo, entonces gracias!*
IX. Appendix B

Full Transcription of Interview with High-Level Administrator in a Tertiary Teaching Hospital

*Does your organization have any written policy regarding reporting undocumented residents when they present for health care treatment? Is this policy, or lack thereof, guided by legislation or local or federal governmental policy?*

When you say that, meaning capturing those who are undocumented- is that the question you’re asking?

*Yes, in other words, is there any policy on the books, whether it’s enforced or not, regarding if you discover that a patient is undocumented, would you pass that along?*

Not at all, not at all. In fact, we don’t ask. Often it becomes apparent when perhaps a patient has an admission and then they lack a discharge disposition. And the case managers try to access a public benefit for them, to help them, whether it be Medicaid or food stamps or anything like that, that’s when it becomes apparent. Because, yeah we don’t ask. That is not- it’s an unwritten policy and there is no legislation that I’m aware of that guides us to do it or not do it, but we choose not to ask.

One of the reasons why I asked you [before the interview started] if you’re interviewing other hospitals is because we might have a slight bias because we are the state’s safety net hospital. And part of our mission is to treat all North Carolinians regardless of socioeconomic, racial, ethnic- so it would be inconsistent with our mission if we were to start asking and reporting.

*I could see how, possibly people with different perspectives or beliefs would say that resources spent on undocumented residents detract from resources available to “legitimate” North Carolinians. But that was all good to know; very interesting. If there is no written policy, is there*
a general philosophy or plan- you just answered this actually- for situations involving patient immigration status? In general, how are these cases addressed?

They’re really one by one; it depends on the magnitude of the case. In fact, we have two right now that we’re working on, we have one gentleman who’s been with us for over 800 days. He’s from Mexico, and he doesn’t have any family or friends willing to care for him here in North Carolina or the US, and we’ve been unable to identify family willing to care for him back at home in Mexico, and you know, we have to have a safe discharge plan to move patients out of the hospital setting. And we have in the past on many occasions, working with the Consulate, identified family in Guatemala or Mexico and repatriated patients. But we need to make sure there’s someone on the other side who’s willing to accept and care for them. I personally have signed checks to pay for hospital beds that we have shipped to homes in Mexico and to make sure that they have supplies and things that they need. So we have a gentleman here, and we are trying to figure out what to do with this man. We have another woman here from Nigeria, actually in a similar situation. We have identified- there is family involved, but they can’t afford a nursing home here in the States. We just got an email this morning- we’re about to spend quite a bit of money putting her on a medical flight to send her back home to her family, but- you know, it’s the humane thing to do, but quite candidly, it’s very expensive upfront, but the alternative is they remain with us indefinitely which is a more expensive proposition. So, we have to look at each case individually, and see in totality, what’s best for the patient, family, and the organization.

I have some amazing case managers here that- there is no defined approach to these situations. You have to just figure out where all your resources are and tap into them. I had never imagined- I picked up case management and I’ve had it for probably 9-10 years now. I did not anticipate
getting to know people at the Consulate and to go in myself in Raleigh, but to be able to navigate this and figure out how to best manage it, you’ve got to know where your resources are and a couple of us have even participated in the NC Latino Health Coalition, which was another way to get to know people and resources across the state. And that process culminated in a trip to Mexico to learn more about what their health system is like and what’s available.

*Do issues related to immigration status impact the patient’s care? If so, how?*

They do, they do. There’s no question about it, they do, because they’re denied access. We do our best, here anyway, because if you show up in our emergency room, we take all comers. But for example, if you want to have something elective done and you don’t insurance and you’re not eligible for Medicaid, it presents a challenge for them. They would have to come up with- and obviously we discount that service, but they would have to come up with the out-of-pocket and initial deposit, which often- I’ll think of an example. You’ve had problems with your back, and you really need to get surgery done, but it’s not life-threatening. But it’s debilitating and it’s impacting your work. There’s an example where, unless you can afford to pay for the care, you won’t have access to that. Now if they show up in the emergency room, that’s a completely different story, because by law, we are required to care for patients who come through the ED, if it’s something emergent or life-threatening. I also think it impacts access- I can tell you a very common example, which is dialysis. The benefit for non-qualified aliens for dialysis is that they are entitled to Emergency Medicaid for that in this state. It varies state by state. In this state currently, I wouldn’t be surprised if it changes, but currently they’re eligible for Emergency Medicaid. For Emergency Medicaid, you have to reapply every three months. So the out-patient dialysis units may choose to accept someone on Emergency Medicaid, but often they’re leery, because they- when it comes time to reapply in three months, part of that is the responsibility of
the dialysis unit, but part of it is the patient’s responsibility, and sometimes these patients aren’t compliant with getting their information in, and now that dialysis unit is stuck, because the Emergency Medicaid doesn’t get renewed, and that’s care that if you stop, it is life-threatening. So many of the out-patient dialysis units may not accept Emergency Medicaid, and that is their prerogative. And those patients then end up sitting in the hospital until we figure out a plan for them. So to answer your question directly, it absolutely does impact care.

One thing that’s come up in my research, is that sometimes undocumented residents may use the name of a family member or friend who is documented or may have some form of health insurance while they’re in the hospital. Have you heard reports of that?

I’m not aware of [individuals] using other people’s health information, and nowadays it would certainly create all sorts of problems, if they’ve already been seen here or, now that EMRs are integrated, if that individual were a patient at Duke or at Nuvant, we’re all on the same EMR, so it creates a significant patient safety issue, because EMRs are all integrated. But what we have seen here, and what causes some confusion, is that many of these patients have a working name and a legal name, so when they come to register, the names don’t always match. It’s a cultural thing, and our registration staff- they’ve gotten better, but when someone has three last names, which one do you put in the system? But I’m more aware of that then of [individuals] intentionally using another family member’s identification. But there are American citizens who do that, too.

Does your organization have policies or practices in place to either intentionally discern patients’ immigration status, or alternately, keep their immigration status undetermined?
No. No policy, but again it’s just our practice where- because again, 98% of time, it doesn’t impact care, it’s just in some rare exceptions such as in the gentleman who’s been here for over 800 days, in those situations, it really impacts care.

How does your organization compare to peer organizations in how they deal with undocumented residents? Do you think this should or will change in the near future?

A lot of what I’m going to say is things that I’ve heard anecdotally, and would need to be validated. But I know, when we looked into the dialysis issue for this population, because it really is an issue, it’s three times a week- how do we provide this for them? We can’t be their dialysis for life. We were in a position where other states were beginning to send- because in other states this is no Emergency Medicaid for dialysis, hospitals and physicians were saying “well in North Carolina, they have Emergency Medicaid.” So unqualified aliens were beginning to come to North Carolina, and since this is the state’s hospital, they would land here, and it was creating challenges for us. And I’m aware that we did some research to find out, in states like Texas, where the population is even greater, how are the hospitals in Texas managing this? And we found out that an unqualified alien needing dialysis, if they showed up in the morning in the ED, they were told “Ok, we can manage two today, the rest of you have to go home.” And the next day: “we can take three today.” Or “we can take one, the rest of you have to go home.” And they were rationing it, but I can understand it to some extent, because you can’t- it’s cost-prohibitive to be able to provide it to everyone indefinitely. I can also tell you here, again a lot of it has to do with our mission, but we’ve invested heavily in interpreters, we have a primary care clinic where the providers all speak Spanish, the administrators all speak Spanish, and it’s really geared toward the Latino population that we serve. So we have put in some specific measures, we try really hard, not just with the Latino population, to be culturally sensitive and even now,
we’re beginning to work with the staff to address transgender issues. It’s consistent with being a state hospital, you probably wouldn’t find that in a private community hospital.

*How do you think undocumented residents perceive your organization? How does this compare to similar organization and is this perception founded? In other words, does this perception have basis in reality? Do you have a sense that patients delay or avoid care because they fear detection and deportation?*

I wonder what the community’s perception of us is. I don’t believe we’ve ever surveyed- there’s a lot we do to make Latinos feel welcome, but I don’t really know how those efforts are perceived.

I don’t think you’re going to find providers or hospitals who are interested in getting into that [catching undocumented residents and having them deported]. The only thing is when it comes time for payment- we don’t want to report people, we don’t want to get involved. And I think most of my colleagues at other hospitals feel the same way. We’re just trying to get the care paid for. That’s really what we’re trying to figure out. How do you give good care and get it paid for?

*If you were able to dictate state and/or federal policy, what would you like to see changed in regard to health care agencies’ treatment of undocumented residents?*

I wish they were eligible under the Obamacare plan, giving them an opportunity to pay for it. Perhaps at a reduced rate, but allow them to engage in the exchanges and pay for it. Because I do think many of the patients we see here are very hardworking, and if it was a reasonable amount of money, I think many of them would buy in and pay for insurance. So it’s disappointing that they’re denied that opportunity. I can understand Medicaid being a state and federally-sponsored program for not truly residents, but if they were willing to go out and pay for it on the exchange, you know.
Are there aspects of this issue about which I haven’t asked but are important to consider?

No, but I do think with every election we have at the national level- I wonder when a Latino Republican candidate comes up, I think it’s going to take somebody like that to get more of the population ready to make some changes. Because until then, in a conservative state like North Carolina, sometimes we’re even careful about how much we talk about things we do like this, because we have a very conservative legislature.