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Hiding Under the Sun:

Health, Access, and Discourses of Representation in Undocumented Communities

by

Jaime Shamado Robb

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy Department of Communication College of Arts and Science University of South Florida

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Keywords: undocumented immigrants, health disparities, structural limitations, people without papers, culture-centered approach, rhetoric, identification, solidarity, subaltern

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#### **Abstract**

This project examines how undocumented immigrants in the United States communicate health and illness, specifically focusing on health narratives of undocumented immigrants in the South Florida region. In order to do this, I conducted 27 field interviews with undocumented immigrants living in South Florida to gain understanding of how this group meets health and wellness needs. Conversations revolved around prominent themes that highlighted the role of communication that produce stigma towards this group; the complexity of a costly bureaucratic health system, and the fears participants experience that stems from the possibility of deportation. Additionally, participants detailed the role of their cultural community in helping them survive in the U.S. and meet their health needs. I use a culture-centered (CCA) approach to draw attention to how these marginalized individuals are forced to navigate the U.S. health system through resistive ways due to the restrictions associated with access (Dutta 2004, p.534). The CCA approach was productive for this project due to its theoretical focus on highlighting participants as the voice of authority and truth with regards to their marginalized position. Along with CCA, reflexivity as a theory and method was foundational for attempting to build solidarity between researcher and participants, which is a central aim of the culture-centered approach (Basu & Dutta, 2011). Given a lack of narrative-driven research in this context, along with the historic and contemporary imbalance of the U.S. health system, there is a need for a humanist approach to understanding and documenting the experiences of undocumented immigrants and the way they make decisions when faced with health-related choices.

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#### **Chapter 1: Introduction**

When I was 16, practicing with my high school baseball team, a curveball hit me right above the eye. When I saw the trickle of blood, I was too terrified to feel physical pain. Terrified of the dreaded ambulance, a call guaranteed to be made once the school trainer saw blood. My grandmother had long warned me about getting into ambulances: "If you not dying and you can talk do not let anyone call an ambulance for you."

When the trainer arrived, he was already on the phone with emergency responders, I quickly stood up to inform him that was unnecessary, I did not need to go to the hospital. He replied that my face would need stiches and I probably had a concussion, plus it was school policy to call an ambulance in cases of severe injury. In that moment I could only lie- I informed him that my aunt was a nurse who worked at a hospital, so she would do the stitches, and we could not afford to pay for an ambulance ride (truth). Once he called and informed my aunt of the situation, she was able to convince him to cancel the ambulance. He later cleaned up and butterfly stitched the large cut situated on a mass lump above my right eye. That was the only medical treatment I received for that injury. I was sure I had gotten a concussion because I did not remember much of the car ride home. What I do remember was my aunt crying, telling me how brave I was for turning down the ambulance. Even at 15, mildly concussed, with a bloody face, I knew what would be at stake if I was to be processed by the ambulance that evening - my future. Not only my future but my three aunts and grandmother that I lived with who all shared my status during that time. I had been living in the U.S. for almost 5 years then- undocumented, so it was not my first time facing a situation where I had to lie to cover my identity, but it was the first time I had to make such a decision with concern for my own health.

When you are living in the United States as an undocumented immigrant, you regularly face what seems to be impossible odds, that require practical solutions. There are a cascade of unknowns that require impromptu reactions even in the most mundane of situations. The structures that one encounters daily are designed to remind you that you do not belong. For example, to play high school sports a student needed to supply proof of insurance from their parents (which my family did not have) or buy the school sponsored insurance which required \$100 upfront and \$10 a month during the sports season. The catch was the insurance company needed a social security number, which I did not have. I played baseball, soccer, and ran cross-country during high school but that was only possible because I was willing to defraud the system without my grandmothers' consent. I made up a social security number with the hopes that it would not be checked. It never was. At that time, I did not consider the potential consequences of my choices, I just wanted to be able to do the things my peers were doing but that was only achievable by circumventing the system.

This dissertation project details the health experiences of individuals like my former self, those living or who have lived in the United States as undocumented immigrants. It draws on critical theories that help bring to light the complex negotiations many marginalized groups have to resort to in their daily lives. This study uses theoretical approaches that trouble increasingly dominant conceptualizations of health communication which shape public attitudes about the management of health. The goal then, is to show how undocumented immigrants, who are considered at-risk for negative health outcomes due to inadequate access to health care, navigate the communicative environment surrounding health and illness in the United States. I use a

critical health communication perspective to explore how a rhetoric of "undocumented/illegal" influences the way this group of immigrants -with limited access- navigates the U.S. healthcare system. Specifically I adopt the culture-centered approach-CCA- (Dutta, 2004) to document how undocumented immigrants navigate the U.S. health system in creative and resistive ways due to the fears/stigmas associated with their precarious status/label. The CCA is a theoretical frame that forges entry points for listening to the voices of undocumented immigrants as they script their localized vocabularies on health and survival in the U.S (Basu & Dutta, 2007).

#### **Rationale and Significance**

The flu is a common illness that affects a substantial portion of the American population annually. Traditionally, when an individual feels flu-like symptoms they can treat the virus with over-the-counter medications. Yet, at times, the manageable virus lingers or mutates into a more complex health issue like bronchitis or pneumonia, then requiring professional intervention. For most Americans, a trip to their local doctors' office can solve this problem, where they can be prescribed antibiotics or gain further medical treatment to solve the problem. Typically, the emergency room can be avoided for flu-related complications. While this route seems logical for most Americans, for those individuals living in the United States with a "illegal/ undocumented" status, the decision to seek out medical services becomes a fraught process.

As I write this dissertation project, the world struggles to find a solution to the fast spreading Coronavirus that has infected over 100 thousand people and killed almost 3 thousand globally (CDC, 2020). The outbreak that was first officially reported in China on December 31<sub>st</sub>, 2019, has now reached 25 different countries including the United States (WHO, 2020). The World Health Organization has issued a warning that once the disease reaches low income and health vulnerable populations with limited health access, the rate of infections could possibly

double (WHO, 2020). This would suggest that the nearly 11 million people living in the United States with limited access to health service are not only at serious risk of contracting the virus but are also more likely to be a source for transmitting the virus.

According to the U.S Census (2016), over 11 million individuals live in the United States as undocumented immigrants. An added 9 million immigrants travel back and forth to the United States under some type of visa. This includes women, children and elderly individuals who make up over 60% of this population (Census, 2016). For those living in the United States as undocumented immigrants, access to the health care marketplace is limited, and sometimes unavailable. Government programs like Medicaid and Medicare do not cover those without a social security number. In many ways, a costly trip to the emergency room is the only possibility available to undocumented immigrants when faced with health-related issues. Given the impediments and fears associated with even receiving medical care in emergency rooms because of their precarious undocumented status, it is not surprising that millions of undocumented immigrants fail to seek out the health services they need (Wallace & Rodriguez, 2013). Hence, an infectious disease like the Coronavirus would present tremendous challenges to this population and in effect to the dominant American public.

Current political and media conversations about immigrants who lack official identifying information tend to refer to this group as either "undocumented" or "illegal." One's political alliance usually determines which term is used to represent this group as outsiders. Liberal sources favor a language of "undocumented," considering it a more "ethical" description than "illegal," the term often used by conservatives' to situate this group (Hitner, 2017). No one is left to account for how both terminologies affect the daily lives of the individuals who must make

important decisions under such labels. Each term carries rhetorical weight for individuals situated in the United States who lack the type of access most citizens are afforded.

Language operates as an organized system of symbols used by humans to share and categorize experiences as they occur situationally (Burke, 1945). Communication Studies positions language as frames people use for understanding how to act together in collectives (Goffman, 1972). Mutual ways of interpreting symbols and signs shape how a group "makes sense" of a given environment and constructs a reality together (Bateson, 1989). The rhetoric of "undocumented" and "illegal" used in media and political circles positions this group as an inherent collective of outsiders, which also portrays them as voiceless bodies criminally occupying space. Such labels create rhetorical situations, whereby undocumented immigrants are forced to find creative avenues to navigate access to what are seemingly basic human rights (Bitzer, 1980). Specifically, when undocumented immigrants living the U.S. need to access medical services, they must first confront the stigmas and fears that accompany these rhetorical labels before engaging with a costly bureaucratic system.

Identity labels such as "illegal" and "undocumented" function as a type of identification rhetoric that situates the boundaries for inclusion/exclusion in a nationalistic context (Burke, 1950; Quigley, 2009). Critical Communication scholars suggest that "discourse simultaneously selects and foregrounds certain meaning configurations just as it omits and backgrounds other meaning configurations" (Dutta, 2008, p.31). "Undocumented" and "illegal" as rhetorical terms foreground the immigrant's outsider status while omitting the critical importance of over eleven million people living in the United States without adequate access to vital public services such as health care. Kreps and Sparks (2008) suggest that effective health communication is central to supporting a general public that is free of diseases and illness. This would suggest that labels

which mark immigrants as outside the public serve to create health disparities for this group due to a breakdown in communication. They are unable/unwilling to identify with health messages designed for those who can access the system without limitations. In effect, undocumented immigrants must forge their own salient networks of communication such that they can support their health while existing beyond the margins of a medically-advanced society.

Communication scholarship about how undocumented immigrants negotiate and make sense of access to health is rare. Investigating the rhetorical influence that the labels "undocumented" and "illegal" have on how these individuals make decisions about their health is currently missing. Research on this topic is typically found in public health, nursing, and medical journals which primarily focus on naming barriers to good health (Passel & Cohn, 2011). Such studies are largely quantitative in nature, relying on survey and statistical data to support claims. These approaches tend to mute the local experiences of those individuals who are left to manage the day-to-day decision making that comes with an undocumented status. Hence, there is a need for a humanist approach in documenting and interpreting the experiences of undocumented immigrants, and how they negotiate their health-related choices in a hostile rhetorical environment. This dissertation project begins to fill this gap in scholarship by engaging with localized health narratives of undocumented immigrants from the South Florida region. It interrogates how rhetoric, power, representation, marginalization, stigma, and resistance impact undocumented immigrants' communication about health and well-being.

In the following chapter, "Undocumented Immigration and Critical Health Communication," I place this study within existing literature that makes note of the history of undocumented immigration in the U.S. and the policies that have shaped the discourses surrounding this group. I also focus on how adopting a combination of rhetorical approaches and

critical health communication approaches such as Burke's (1950) theory of rhetorical identification and the culture-centered approach can address limitations found in the current literature. I end the chapter by offering the general broad research questions that guide this study. The second chapter, titled "A Culture-Centered Reflexivity as Methodology" illuminates the ethnographic and reflexive approaches that I drew on to tackle the study's research questions. It also offers details about my choices to focus on reflexivity as a theory and method in Communication to guide my interpretation and analysis of the data.

Chapters 3 through 6 describe the results of this study by focusing on specific aspects of study participants' perceptions and experiences regarding health care while living in the United States with an undocumented status. In chapter three, "The Representation of Inside and outside: "Undocumented" and "Illegal" as Rhetorical Markers of Marginalized Exclusion," participants describe the labels "undocumented" and "illegal" operate as communication that produces stigma and the effects of such stigmas on participants' attitudes towards dominant health spaces. In chapter 4,"A Clash of Culture and Structure: Considering Barriers to Access for People Without Papers" I describe the various features of the U.S. health system that participants deemed as important obstacles that limit their willingness to interact with official medical spaces. The fifth chapter, "Nightmares of a Beautiful Dreamer: Fear as a Barrier to Health Access for People Without Papers," explores the role of fear in shaping undocumented immigrants' willingness to engage with dominant medical spaces such as hospitals. Chapter six, "Community: A Silent Network of Resistance," focuses on the co-constructed solutions participants draw on in order to survive and maintain their health and wellness in the United States.

In the final chapter, "Conclusions and Implications," I return to the research question that directed this research study and provide a theoretical overview of how the present findings contribute to current issues surrounding undocumented immigrants' access to health care in the U.S. I attempt to show the overlap between theory and the lived experiences of participants, and the implications of creating a society where a large part of the population lacks reasonable access to health care. I end by engaging with this topic reflexivity, once again, in an attempt to show the limitations of (re)presenting marginalized groups in dominant spaces. I also present implications for future research along with a few suggestions that participants offered regarding the potential approaches that could be taken to reduce the in-access they face.

#### **Chapter 2: Literature Review and Culture-Centered Reflexivity as Methodology**

In this chapter, I locate this research within existing literature on history of undocumented immigration in the U.S, the role of rhetoric in situating closures for marginalized groups, and critical health communication as concerned with listening from the ground up. In addition, I offer an overview of the study's theoretical underpinnings by discussing Burke's notion of rhetorical identification and the central tenets of the CCA. I start, in the next section, by briefly overviewing the history of undocumented immigration in the United States.

#### **Immigration as U.S. History**

Immigration is typically defined as the movement of people from one country to another. Scholars have historically tracked and connected the movement of people to economics, meaning that when people cross borders, economies are affected (Massey,1995). In the early 1900s, the United States gained the metaphoric distinction of being a "melting pot" due to the diverse range of cultural groups who immigrated to this country in pursuit of economic security. Critical scholars such as Bonilla Silva (1980), have troubled the distinction between both frames suggesting that it creates a sense of cultural diffusion for some, while presenting assimilation as the goal for other immigrant groups. While the United States is the self-proclaimed nation of immigrants -- from the British settlers of the early 18th century, to the eastern Europeans decades ago, to the Southeast Asians of recent years -- the need to manage outsiders has been central to the cultural landscape of this "melting pot" (Passel, 1986).

Historically, humans have migrated to new places for various reasons, but those reasons typically can be categorized on three levels; a search for economic opportunity, to flee political/religious persecution, or the prospects of better educational opportunity for children (Passel,1986). Today, this standard holds true for immigration in the United States, where the "pursuit of happiness" cradled in a rhetoric of freedom has suggested to groups from across the world that America welcomes all immigrants. According to Passel (1986) and Massey (1995), each era of newcomers has been met with concern for the outsider by the so-called natives, who once were immigrants (or descendants of) themselves. The way groups are created and sustained is typically through the management of its boundaries, as in who can enter and influence the social construction of group identity is important for maintaining the group as such (Eriksen, 2006). Even as a self-professed nation of immigrants, the United States through its laws and policies, has shown an ambivalence towards new immigrants over the past two centuries (Johansen, 2013). The challenge of maintaining a stable American ideology, while incorporating the ideologies brought in by diverse cultural groups has been a fraught process (Bolemraad, 2008). This in turn has created the conditions needed to push certain newcomers outside of the margins of social welfare (Pal, 2008).

#### **Undocumented Immigration in the United States**

Scholars have long discussed the merits and value of citizenship in a globalized society. Who is entitled to the status of citizen is usually one of the major points of contention. Historically, citizenship has been defined by one's place of birth or one's parental origins (Baubock 2001, Bloemraad 2006). In the past century, residents who could not access citizenship via birth, as is the case with most immigrants, had to acquire such status through a process of naturalization (Bolemraad, 2008). Though the act of naturalization differs by nation, it typically

requires a time of legal residency and an ability to demonstrate an understanding of the country and its dominant language (Marshall, 1950).

Until 1906, the naturalization process limited certain groups, such as Blacks and Asians from obtaining citizenship. This made it difficult for those groups of immigrants to establish themselves in the states (Ichioka, 1988). I argue that Blacks and Asian immigrants of early America dealt with struggles similar to that of the current undocumented individuals. According to Massey (1995), the need to manage which types of immigrants are allowed in, and subsequently which ones are to remain outsiders is in large part due to the fears of the populous that immigrants will in some way change social norms and the cultural landscape of the United States. As such, given the current political agendas related to immigration which are geared towards "controlling unwanted immigration," one must question which types of immigrants are afforded entry into the United States (Cornelius, 2005).

When considering the reasons why people leave their home country to immigrate to a new space, the management of outsiders via policy becomes fraught due to the impossibility of controlling who can cross borders. According to Passel (1986), humans have always crossed borders as they moved and migrated across space for survival, but the management of who can cross borders is a modernist concept. When this idea is considered vis-a-vis contemporary conversations of the "undocumented alien" illegally occupying space within a territory, it becomes clear that the management of outsiders operates with the political intent of maintaining certain ideological standards. "The belief that immigration flows can be controlled through legislation stems from misreading of US history" (Massey, 1995, p.644). The creation of legislation with the intent of policing access into the U.S. has generated the type of structural conditions which have made it difficult for certain immigrant groups to gain entry to the U.S.

through a visa process. Undocumented immigrants tend be those who were already marginalized in their previous setting, who migrated to "pursue happiness" and opportunity in an advanced society (Sliva, 1980).

Contemporary political rhetoric around undocumented immigrants have typically positioned this group as competing with citizens for resources. This has the effect of presenting to the public an image of the immigrant as having the same types of access as citizens, which is certainly not the case. According to Passel (2005) of the Pew Research Center, "Undocumented immigrants are those who entered the country without 'valid' documents, and those who entered the country with a valid visa but overstayed the time allocated via the visa" (Passel, 2005). This means that most undocumented individuals lack the symbolic resources (typically a social security number) needed in order to compete with citizens for resources. Additionally, by framing undocumented individuals as competing with citizens, media and political messages position this group as a political weapon for creating agendas that further limits the social support systems available to noncitizens.

Newton (2009) does a critical analysis of how immigration policies function as text that informs the social construction of illegal immigrants in the American public. Newton (2009) compares two moments when Congressional policies shifted our understanding of immigration in the United States. The 1986 Immigration Reform and Control Act (IRCA) provided amnesty for thousands of immigrants that were illegally living in the United States at the time (Newton, 2009). Though the policy provided an avenue for individuals to gain legal status, it also created increased border enforcement to deter future illegal immigration. This act aimed to increase the American labor force by offering immigrants a path to inclusion if they were willing to work long enough to "earn" it. According to Newton (2009), the IRCA of 1986 created the conditions

needed for the emergence of the Illegal Immigration Reform and Immigrant Responsibility Act (IIRAIRA), which was enacted in 1996. This official text introduces the category of the "illegal" characterized as "usurpers of government munificence, undeserving recipients of public benefits, and in need of regulation and restriction" (Newton, 2009, p.23). The language of both acts created the conditions for presenting undocumented immigrants as plunderers in American communities, hence unworthy of public resources.

#### Undocumented Immigrants and the U.S Health System

According of Passel (2005) there are currently over 11 million undocumented immigrants living in the United States. This amounts to 30 percent of the 36 million foreign-born residents in the U.S., which is more than 3 percent of the total population (Passel 2005). Excluding this significant portion of the population from the benefits of social welfare will eventually lead to a society where static friction creates to an overheated space (Ericksen, 1998). Meaning, tension will arise regarding spaces between undocumented immigrants with limited resources and access, and the population that has access but is largely unaware of this inequity. Unfortunately, those who lack access to resources tend to suffer the challenges and limitations of an overheated space (Ericksen, 1998). For undocumented immigrants, navigating an environment where access is limited and resources are few tends to be the norm (Ortega & Fang, 2007). For example, when it comes to health services, emergency rooms are one of the only avenues for care that undocumented immigrants have, and there are still risks involved when visiting an emergency room without proper documentation. If one considers the logic of proper healthcare as a "universal" human right (Lupton, 2012 & Zoller & Kline 2008), it would behoove policy makers to avoid creating the types of policies that closures to access for marginalized populations.

Government programs like Medicaid and Medicare fail to cover those, such as undocumented immigrants, without a social security number (Cheong, 2007). A costly trip to the emergency room may be the only option available to undocumented immigrants when faced with health-related issues (Lee & Ottati, 2001). Carrasquillo and Olveen (1998) estimate between 69% and 85% of undocumented immigrants living in southern California at the time were uninsured. "State policies have tried to make public coverage less available to immigrants, thereby forcing them to depend on the private sector for health coverage" (Carrasquillo and Olveen, 1998, p.922). More recently, California lawmakers have shifted from policies limiting undocumented immigrants' access to health care, towards new policies that would allow this group to seek health service without restrictions (McConville & Hill, 2015). This is because such policies did not work in forcing immigrants to self deport, instead it just created further health disparities for those already living in the state of California.

There are numerous factors that complicates undocumented immigrants' lack of access to health services. These factors range from limited knowledge about the health system, bureaucratic obstacles, general confusion about rules and restrictions, and fears of discrimination (Karp & Rhee, 2007). Official policies like the Affordable Care Act explicitly exclude undocumented immigrants from obtaining health insurance while presenting as "universal" health reform programs (Biswas, 2012). As such, upon reviewing previous research regarding undocumented immigrants' access to the U.S. health system, three main challenges emerge as barriers to this group (Cheong, 2007). The first barrier operates at the policy level, where official government mandates, such as the Affordable Care Act, limit the avenues that undocumented individuals have when it comes to health-related services. Additionally, the structure of the health system itself functions to limit the types of access immigrants are afforded given the

bureaucratic design of the system. Lastly, the rhetorical framing and representation of undocumented immigrants creates personal challenges for individuals regarding fears of being in health-related spaces.

#### Policy as Barrier

Across national contexts, research about undocumented immigrants' barriers to health care cites national policies as the most frequently occurring barrier to access (Hacker &Anies, 2015). According to Edward (2014), the exclusion of undocumented immigrants from the health care system occurs at multiple levels, mostly occurring through laws limiting the group's access to health insurance. Due to the exorbitant cost of medical services in the United States, insurance is typically needed for affordable care and sometimes even required as a precursor to service (Edward, 2014, p.6). Further, requiring personal identification prior to service operates as another policy related obstacle for undocumented immigrants (Hacker &Anies, 2015). Policies such as the "Patient Protection and Affordable Care Act (PPACA) and the Deficit Reduction Act" passed in 2006 required government agencies to gain proof of citizenship for access to health programs like Medicaid (Edward, 2014). This policy shift effectively created a structure that made it extremely challenging for undocumented immigrants to obtain the services they needed during medical emergencies.

Negative health outcomes for undocumented immigrants can create public health challenges as this group makes up three percent of the U.S. population (Passel, 2005). Additionally, about 40% of undocumented immigrants are parents to children who are born as American citizens; often these parents fail to seek out service for their children due to an inability to provide documentation for themselves (Hilfinger & McEwen, 2015). According to The Migration Policy Institute, in 2007, at least 59% of undocumented adults lacked health

insurance, while 55% of children of undocumented individuals were uninsured (Capps, 2009; Gakarneau, 2011). National policies restricting access to healthcare creates a structure whereby undocumented immigrants are less likely to interact with the health system than U.S. citizens (Derose et al., 2009; DuBard & Massing, 2007; Goldman, Smith, & Sood, 2006).

#### U.S. Health System as Barrier

Another challenge that undocumented immigrants face when seeking out health services in the United States is their unfamiliarity with the bureaucratic structure of the health system (Hilfinger & McEwen, 2015). Due to policies that limit access, navigating a bureaucratic health system becomes a convoluted process. Wallace and Rodriguez (2013), suggest that the current health system creates various constraints for undocumented individuals, including but not limited to, cost of service, fears related to discrimination and misunderstandings related to bureaucratic procedures. Loue (1997) and Kullgren (2003) note language as an additional constraint to this group's willingness to engage with a complex health system. Communication distributed regarding the operations of the health system tends to be geared towards citizens and not immigrants (Kullgreen, 2003). For instance, health campaigns promoting the flu vaccination as a means for limiting the virus and its impact on public health fail to present avenues for those without insurance to access the vaccine. This is currently the case as the CDC promotes health information regarding how to best avoid the novel coronavirus to the U.S. population, while such messages fail to speak to the restrictions and limitations that undocumented immigrants have to navigate.

#### Barriers of Representation

The negative representation of undocumented immigrants in the American public sphere still serves as one of the major constraints for this groups' willingness to seek out health services.

This group is traditionally depicted as "criminals," who are burdensome to the U.S. support system (Lee & Ottati, 2001). Such depictions, stemming from media and political rhetoric, stigmatizes undocumented immigrants as plunderers who need to be managed. The issue of fear is compounded due to many undocumented immigrants' unfamiliarity with bureaucratic procedures (Karp & Rhee, 2007). Along with fears of deportation, research shows that a lack of knowledge about the U.S. health care system, challenges related to communication, and fears of stigmatization are also central to why undocumented populations avoid seeking service (Wallace & Rodriguez, 2013). "Undocumented immigrants reported avoiding health care and waiting until health issues were critical to seek services because of their concerns of being reported to authorities" (Hacker & Anies, 2015, p.178). The anti-immigrant rhetoric presented in political speeches, television dramas, and news media alike informs undocumented immigrants as to how they are portrayed and thus, they must navigate the social world with this in mind. Further, "these health burdens are sustained and magnified by language barriers, lack of knowledge about the US health care system, and fear of detection by immigration authorities, all of which limit undocumented immigrant's ability to effectively access health services" (Kullgreen, 2003, p.13). Such negative representations create unfriendly health conditions for undocumented immigrants, and potentially burdens health care institutions while creating a challenge for maintaining healthy communities (Dutta, 2013).

#### Health Communication and Undocumented Identity

As noted above, undocumented immigrants face major obstacles accessing health care resources (Dutta & Zoller, 2008; Hacker & Anies, 2015). Government programs at the state and federal level do not cover these individuals because they lack official information, such as a social security number, which is necessary for enrollment. In addition, undocumented

immigrants are afraid to draw attention to themselves, fearing detainment and eventual deportation. This project asks how rhetorical labels and dominant health narratives within a U.S. environment impact undocumented immigrants' willingness and ability to access to medical care.

#### **Burke's Identification**

What are the rhetorical implications of mass- produced messages on local identities? Burke's view of rhetoric(1950) offers a theory of persuasion via identification, where humans are constantly divided by their symbolic representation of individuality, hierarchy, alienation, separation, class and all other modes of division. The means by which individuals go about constructing and enacting a shared identity depends on their ability to identify with various symbolic signs (Burke,1950). It is important to note that this is a key part to Burke's analysis, as he makes it clear that labels are the things that help people to act together. Hence, they are the things that make people feel excluded.

Our identities are constantly in doubt, or at odds, until we are called upon to act on their behalf. Humans are left to account for their identities and behaviors as they attempt to move through different social situations (Bartesaghi, 2009). According to Burke (1950), for identification to work, participation is required, performance involving a shared understanding of symbols. Meaning, if one wants to participate in various group rituals and discussion they must first align themselves with the discourse used to define the collective. For example, at political rallies, notions of citizenship and belonging tend to be negotiated through conversations of American values and traditions. Without explicitly talking about what it means to be a citizen, individual actors negotiate the values of inclusion by symbolic elements that communicates one's understanding of the dominant culture. This type of talk allows for identification to occur

by highlighting areas of dis-identification (Burke, 1950). Undocumented immigrants are unable to identify with the dominant narratives of citizenship. They must create new ways of identification among themselves in order to survive as a collective of outsiders.

The inability to identify with a collective forces those at the margins and beyond to take a short cut to share "a locus of motives" with the group that supports his/her identity performance in similar situations (Burke, 1950). Meaning that immigrants must rely on other immigrants to navigate a rhetorically fraught space. Burke (1945) notes, "since identification implies division, we found rhetoric involving us in matters of socialization and fiction" (p. 45). The division Burke speaks of is clear in the language used to represent immigrants as "undocumented" or "illegal" in the United States. This symbolic division forces undocumented immigrants to see and position themselves at the margins of a dominant system; whereby these terms communicate a sense of inclusion for citizens (despite political divide) while creating a sense of exclusion for immigrants. Central to Burke's theory of identification is the idea that these types of discourse tend to involve a degree of self-persuasion. If individuals are unable to identify with the symbols of the group, they in effect will see themselves as an outsider to the collective. I argue that in such situations, ways of survival must include a high degree of creativity and resistance towards the surrounding structures. As such, undocumented immigrants must negotiate and manage their identity while positioned as counter to a society that produces health messages designed for nonmarginalized identities.

Though our conception of what makes health good or bad is culturally constructed, a globalized society has transformed local health knowledge to fit a universal ideology of health care (Dutta & Zoller, 2008). When considering immigrants who leave their native cultural environment in search of greater economic opportunity, health communication scholars must

account for the re-negotiation immigrants do, locally, in their new settings (Dutta, 2008). Current policies and structures in industrialized societies have not attended to how the labels attached to this group affects their ability to make crucial health decisions (Hacker & Anies, 2015). A culture-centered approach to health communication helps document localized health narratives and offers a suitable theoretical framework for this project. Additionally, a focus on identification rhetoric will help to illuminate the tacit connection between how this group is represented in public discourse and their willingness to engage with various health settings.

#### **The Culture-Centered Approach**

The culture-centered approach (CCA) is geared towards examining how those cultural identities that are at the margins of a profit-driven health industry navigate the uneven distribution of resources (Basu & Dutta, 2010). CCA is a theoretical approach that aligns itself with subaltern identities and recognizes the agency and creativity involved in surviving beyond the margins (Dutta, 2007)."The culture-centered approach aims to deconstruct the taken for granted attitudes and assumptions of the dominant knowledge base and tries to co-construct meanings and discursive spaces from the perspective of the cultural insider" (Dutta, 2016, p.48). This approach positions culture as an ongoing process of co-creation at the interactional level in localized spaces. This means immigrant communities are involved in a diverse kind of cultural sense-making in the U.S. that is uniquely different than that of their native communities.

The culture-centered approach to health communication is meant to centralize cultural voices in the articulation of health issues and potential solutions (Airhihenbuwa, 1995; Dutta-Bergman, 2004a, 2004b, 2005, 2007). To achieve this, Dutta (2007) notes, researchers must consider the key tenets that frame a culture-centered approach; i.e., recognize the linkages between structure and culture, agency and voice, the notion of multiple and shifting contexts, and

spaces of resistance. In the following sections, I detail the importance of illuminating these linkages in conducting research with vulnerable populations.

#### Structure and Culture

Structure deals with the formation of social systems, means of disturbing resources, and ways of controlling resources that work to sustain social inequities, while culture can be explained as webs of meanings that shape social systems (Dutta, 2007). This suggests that cultures are inevitably linked to the structures which inform their environments. Dutta (2016) suggests that structures and cultures are constantly interacting with each other, and to make note of one without the other is to miss the relational aspect of cultural meaning making. "Structures are embodied in the organization of the state, of civil society organizations, and of for-profit organizations that are embedded in a social system and are complicit in the creation of life experiences at the margins" (Airhihenbuwa, 1995; Dutta-Bergman, 2004a, 2004b, 2005, 2007). Structures are mirrors reflecting the beliefs, values, and meanings of a culture, whereby they become the very systems that limit and constrain decision making (Dutta & Basu, 2011; Hodges, 2013). The culture-centered approach creates an opportunity for illuminating the ways in which structure "constrains, limits, and defines what is available to cultural members and what is not" (Dutta, 2007, p.35). The impact of structure on culture is obvious in the context of undocumented immigrants; their lack of status, due to structural reasons, means they must renegotiate their cultural understandings of health to navigate a dominant and adverse health system.

#### Multiple-Shifting Contexts

Contexts are the interconnected local environments involved in negotiating health meanings (Dutta, 2007). Contexts set the scene for participants to play out cultural rules and

roles based on shifting structural conditions. According to Dutta (2011), the culture-centered approach takes contexts to be multiple, as continually shifting and moving based on structural constraints. Context allows for local meanings to connect to larger global understandings and provides the basis for co-constructing meaning through language. For instance, Dutta (2016) argues that structural factors play a significant role in shaping immigrants' understanding of adequate health care when they migrate to more "advanced" nations. Dutta starts by troubling the way "culture" is conceptualized in health campaigns set out to reach immigrant groups, i.e., a focus on cultural cues as areas of connection, which limits the possibility for understanding how an immigrant culturally negotiates health with regards to their new environment. This rings true for undocumented immigrants living in the U.S., whereby their previous cultural practices must be re-negotiated vis-a-vis having a limited status in a society that is rich in resources but fails to offer them the access to those resources.

Thus, undocumented immigrants must adopt uniquely local ways to navigate their environment, and researchers must take this into account when attempting to reach this population. "The culture-centered approach is committed to the notion that humans have the capacity to understand their environments, to understand the contexts within which their health is enacted, and to act within and with these contexts to create and recreate their health experiences" (Dutta, 2016, p.48). This ability to understand, articulate, and engage with one's culture and surrounding structures is what is termed as agency in the culture-centered approach.

#### Agency and Voice

Agency refers to a cultural group's ability to react and respond to shifting stimuli in their social environments (Basu & Dutta, 2011). To be an agent is to participate in everyday acts in a manner that highlights ones' awareness of the structural elements impacting choice, and to

navigate the limitations of a structure in nuanced ways (Dutta & Basu, 2011; Dutta, 2007). When presented from a culture-centered perspective, agency operates as a marker for understanding structural inequalities and ways to potentially reduce such inequalities by listening to the experiences of those who are already involved with such tacit negotiations. Meaning that, the voice of authority with regards to understanding how complex social structures negatively affect certain marginalized groups should come from within those cultural spaces.

CCA is geared towards reversing the logic that cultural members are passive receivers who can be reached by simply speaking to their characteristics (Dutta, 2007). CCA aims to amplify the voices of marginalized and subaltern groups who have been rendered voiceless due to the prevailing health messages and structures focused on a dominant mainstream target audience (Basu, 2012; Pal, 2010). This places the responsibility on researchers to be reflexive in their projects, so that they are able represent subaltern voices in agentic ways. The next section highlights the importance of incorporating a Subaltern Studies framework along with a culturecentered approach in this project.

#### **Culture-Centered Approach and Subaltern Studies**

The goal with situating this study within a culture-centered theoretical lens is to rupture the "dominant assumptions of health as a global project, demonstrating that the very construction of health care is culturally situated and therefore should be treated as such" (Dutta 2004, p.536). The culture-centered approach recognizes the conditions of subalternity as being created and maintained by health promotion efforts and aims to disrupt the dominant practices of health promotion by introducing subaltern voices into the discursive space (Dutta-Bergman, 2004a, 2004b, 2005). According to Dutta and Basu (2011), subalternity points to a position of "being under" or "being erased" from discourse making. Subaltern Studies re-examines discourses of representation that historically have been written by a dominant class (Guha, 1988). "Extended to the realm of communication, Subaltern Studies forges entry points for listening to the histories and the voices of subalterns as they script their localized vocabularies" (Basu & Dutta, 2009, 2008; Dutta-Bergman, 2004a). Spivak sees the subaltern as "persons without the lines of social mobility" (1988, p.1). Based on the various structural limitations and an inability to have a voice in their local environment, I interpret undocumented immigrants as a subaltern group (Spivak, 1988). A lack of social mobility is also central to defining a social group as subaltern, and I understand most undocumented immigrant groups in the U.S. as lacking the viable resources needed for social mobility. The goal in this project is then to challenge social patterns of representation that limit how undocumented immigrants are presented (or erased) as the cultural "other" in a U.S. health context.

The culture-centered approach, which engages with the absences and articulations of alternative understandings of health through conversations with subaltern communities, presents a compelling theoretical basis to address the overarching research question in this project:

RQ: Given the precarity of their status, how do undocumented immigrants communicate about and negotiate access to health care services in the U.S.?

#### **Culture-Centered Reflexivity as Methodology**

I adopt a qualitative research method, chiefly interviewing, to investigate how undocumented/illegal immigrants in the South Florida region make health-related decisions. In addition, I draw on reflexivity as a theory/method that privileges (re)investigating the processes used to gather and interpret participants' stories to make note of how to potentially improve future research endeavors (Steier, 1993; Dutta & Basu, 2012). In this part of the research project, I explain how I gathered and analyzed data. I also explain why the concept of reflexivity is vital to this project.

#### Data Collection

The initial group of participants for this project were identified based on my previous relationships with these individuals. Participants are part of local South Florida communities that I participated in while living in the area for over a decade. I was raised within these communities and have had relationships with members of these groups, and already had contact information for most of the participants. This includes high school friends, neighbors, former sports teammates, former work colleagues, and family members. Additional participants were identified with the help of the initial group and contacted me via telephone or text message to set-up a face to face interviews.

#### Data Gathering

I conducted 27 interviews with individuals living in communities located in the South Florida region (Miami, Broward and Palm Beach counties) who have experienced life as undocumented/illegal immigrants in the United States. Out of those 27 interviews, 25 were utilized as the main source of data for this project, as 2 interviewees did not want to be recorded. I used their comments as supplemental data.

I conducted semi-structured narrative interviews which carried the assumption that individuals understand who they are through the narratives they share with each other (Lindlof & Taylor, 2019). This process creates "an interactional event in which members draw on their cultural knowledge, including their knowledge about how members of a particular category routinely speak" (Baker, 1997). As stated above, most (25/27) interviews were recorded, and

transcribed verbatim and participant's identities were kept confidential due to the sensitivity involved with their status. Additionally, I draw on field notes I collected in a journal that I mainly wrote in after interviews were finished or when participants asked to stop the recorder. This was also used as a way to collect information from participants who did not want to be recorded. Field notes were used as supplementary data to support the information gathered via recorded interviews and I draw on them mainly in the reflexivity section of each chapter. I did not keep a specific schedule and format for journal writing. All notes were written in the journal freehand.

There were a few interviews that required translation; in such cases, two approaches were be taken to translate information. For interviews with individuals from English-speaking Caribbean countries who spoke some Patios dialect, I did the translation during the transcription process. In addition, participants who only spoke Spanish or Creole had a family member translate the conversation during the interviews.

I use semi-structured interviews, I brought in a few pre-constructed questions but made impromptu changes during the interview process in order to better connect with participants. A focus on reflexivity allowed me to explore the relationship between myself, as someone who shared similar experiences with participants, and the self who is representing an institution of power in a local setting. It is important to note that these moments of reflection between myself and participants are my attempts at taking a reflexive turn in this project. Due to my prior relationship with many of my initial participants, it was important to offer some kind of transparency with regard to how this affected the recruitment, interview, and data interpretation process.

A list of foundational ideas (provided in the appendix) guided the conversations on issues related to participants' interpretation of dominant communication practices, health related narratives, and stories of the undocumented immigrant experience: belonging, representations of belonging, and experiences engaging with the U.S. health system. The interviews lasted between 45 minutes and an hour and offered a recap session where participants asked questions related to the study, which was also recorded at the participants' request.

The foundational concerns that guided my interview protocol included:

- How do undocumented immigrants understand/construct their marginalized status?
- How do communicative practices in and surrounding the lives of undocumented immigrants construct notions marginalization?
- How does representation or lack thereof impact how undocumented immigrants negotiate access to health services?
- How do undocumented immigrants construct meanings of health and illness in general?
- How do undocumented immigrants negotiate access to health services when faced with a medical emergency?
- How do policies and social rights play out in the lives of undocumented immigrants and their ability to access medical services?

#### Data Analysis

The culture-centered approach is focused on context; as such this project draws on thematic analysis as a method to undergird how context offers central themes of meaningmaking relevant to research participants (Dutta, 2008). This process asks the researchers to go through each line of each transcript in order to locate "chunks of data on the basis of its coherent meaning" (Lindlof & Taylor, 2019). This approach aims to analyze a multitude of differing concepts to help the researcher locate a theoretical relationship between the main concepts being investigated (Strauss & Corbin, 1990). Data was analyzed regularly during the interview and analysis process to help determine which themes were recurring. Using the constant comparison technique - between interview data and emergent themes (Strauss & Corbin, 1990) -- distinct concepts were crystallized into larger order theoretical thematic categories.

This allowed for the categorization of the collected information and offered the possibility for further theoretical connections. The idea was to have individual's stories and experiences be the tool for generating critical insights into how undocumented immigrants in the U.S. communicate about and negotiate access to health care services. This fits into the framework of CCA that focuses on centralizing the voices of participants to highlight their lived experiences, while allowing me to make sense of participants' narratives and at the same time acknowledge that my positionality inevitability influenced the meanings that emerged from the research process.

Thematic analysis calls for "identifying, analyzing, and interpreting" patterns (or "themes") within qualitative data (Lindlof & Taylor, 2019). Data was coded thematically for its relevance to the research question and the recurrent thematic clusters that emerged during the interview and transcription process. This approach helped me locate a theoretical and practical relationship between the main concepts being investigated (Strauss & Corbin, 1990) and led me to conceptualize three broad themes that appeared to address the research question guiding this study. I argue that undocumented immigrants who participated in my research made sense of health in terms of: a) how they perceived they were represented in the media, b) barriers they faced in trying to access healthcare systems, c) forging and maintaining community connections as means of survival.

#### **Reflexivity as Method**

Given my previous connection with many of the participants I interviewed, I believe the concept of reflexivity is an important way to illuminate the role of power, and trust in the communicative process involved with doing qualitative research interviews. When Burke (1939) suggests that "a way of seeing is also a way of not seeing," he was in effect promoting the need to be reflexive in our research endeavors. Being reflexive is structuring communicative products so that the audience assumes the producer, process, and product are a coherent whole (Ruby, 1982). Ruby (1982) highlights the function of reflexivity as a way of directing the gaze and focus of the reader to show the messiness of the research process. This in turn shapes how an audience interprets the knowledge that gets produced. Like the work of Ruby, Lawson (1995) examines how reflexivity has played an influential role in the theories produced by many famous philosophers. She shows how important the idea of reflexivity has been to the construction of western understandings of truth and knowledge. Meaning that when researchers take the additional steps to communicate about the limitations and potential biases involved in research endeavors, they open up space for further interpretations and inquiry through transparency. The hope is that this bending back practice operates as meta-commentary that helps spawn new ways of interpreting the research presented (Dutta & Basu, 2013).

Steier's (1993) notion of "bending back" offered a valuable frame for engaging with individual's stories of marginalization and in access. Steier presents reflexivity as a means for methodological engagements that foster the type of research setting that goes beyond the limitations of a traditional research design. "Reflexivity, or a turning back onto a self, is a way in which circularity and self-reference appear in inquiry, as we contextually recognize the various mutual relationships in which our knowing activities are embedded" (Steier, 1993, p.164). He

points to the co-facilitation of knowledge that occurs in research spaces, and how valuable it is for scholars to recognize that their communication is influencing the knowledge produced. This is key for this research project, as my prior experiences as an undocumented immigrant afforded access and trust that might not have been possible if I had not had these connections prior.

The idea with taking a reflexive turn is to foster a co-learning space for solidarity in the text by using language frames that were presented by participants to direct the way I analyzed the data provided by participants (Basu, 2013). The "bending back" Steier (1993) and Ruby (1984) points to goes beyond the self as embedded in a system, but also highlights the various effects that the design structure, relationships, and language of the research project has on what is produced. This means that fostering a reflexive attitude throughout this research project allowed me to notice my limitations as a researcher, along with the advantages I was afforded due to my prior connections. This started with assessing the design and language choices used to structure each interview and how to potentially facilitate more productive engagements by making tweaks to both language and design. For instance, after the first 3 interview it became clear that I was not offering participants enough time to reflect before I inserted a comment; this was highlighted by the time I waited between their last comment and my next one. As such, I utilized my watch as a means of making sure I offered participants at least 5 seconds from asking a question or making a comment before continuing on. I believed that created multiple opportunities where participants felt that they could share as much or as little as they wanted without feeling pressured to respond.

This approach to research is extremely valuable when working with at-risk, marginalized populations, such as undocumented immigrants. Once again, the concept of reflexivity aligns with the aims and goals of doing research within the culture-centered approach. "A culture-

centered approach contributes to the critical trend. By locating expertise within the culture instead of external actors, a culture-centered approach requires a reflexive process of inquiry on the part of the researcher" (Dutta, 2007, p.3; Beverly, 2004). Dutta (2007) & Beverly (2004) indicate that a focus on reflexivity will allow the researcher, myself, to take the step back as an expert in understanding the lived conditions of participants and instead operate as a coparticipant who is involved with facilitating the stories of those marginalized experiences. "Reflexive-ness requires subject and object, breaking the thrall of self-concern by its very drive toward self-knowledge that inevitably takes into account a surrounding world of events, people, and places" (Ruby,1984, p.6). This type of attitude toward research creates opportunities that can start to offer the possibility for solidarity (a sense of trust) between researcher and reciprocators. It further highlights the limitation of any qualitative research project and the duty of the researcher to learn from the spaces they interact with.

## Conclusion

As the United States' population grows via migration and immigration, with this rise in diverse identities, there has been increasing concern regarding disparities for undocumented immigrants living in the U.S. with limited access to the health system. Given the various constraints involving communication and social structures that undocumented immigrants face, a health communication approach is recommended as central to investigating how this group goes about navigating a dominant health system given their restricted access. Grounded in the CCA, I explore co-constructed themes that emerged through conversations with undocumented immigrants living in the United States to engage with three main research questions that guide this study. In the following chapter, titled " The representation of inside and outside: "Undocumented" and "Illegal" as rhetorical markers of marginalized exclusion," I tackle the first

research question, that asks how undocumented immigrants interpret the rhetorical labels that are used to represent them as a collective in media and political conversations, to discuss how study participants perceived the effects of identification rhetoric in influencing decision making, particularly when it comes to health related decisions.

The fourth and fifth chapters titled, "A clash of culture and structure: considering barriers to access for people without papers," and "Nightmares of a beautiful dreamer: Fear as a barrier to health access for people without papers," deals with the second research question of this project, which asks what undocumented immigrants experience as major barriers to healthcare access that they must navigate while being situated in the United States. While the fourth chapter focuses on the structural barriers participants discussed having to navigate; chapter five details the personal obstacles that operate as health vulnerabilities for this group due to their stigmatized representation. In turn, the sixth and final analytic chapter, titled, "Community: A silent network of resistance," considers the third research question of this project which asks, how does undocumented immigrants in this region support their health and wellness needs despite their lack of structural support. This final chapter offers insights into the creativity and solidarity participants rely on in order to meet their health and wellness needs in the United States.

# Chapter 3: The Representation of Inside and Outside: "Undocumented" and "Illegal" As Rhetorical Markers of Marginalized Exclusion.

I recently watched the 4<sup>th</sup> season of the CW tv show *Supergirl*. The show draws on the narratives from the DC comic book series which shares the same title. While the show has touched on controversial issues in past seasons, it took on a metaphorical approach when it focused on the United States government's approach to managing outsiders in season 4. The show is based in a fictional world, so the outsiders of concern were aliens from outer space who came to earth (U.S.) to seek refuge. Within the first few episodes of the season it becomes clear that the aliens and their search for a home were representative of current political issues involving undocumented immigrants or illegal "aliens" as they are labeled in *Supergirl*. What was clear throughout the show was that 1) aliens were being marginalized (even though they had superpowers), 2) the source of their marginalization came from the negative representation that in effect limited alien movement in the U.S., and 3) the way humans judged aliens was influenced by the political discourses used to promote various political agendas, such as the "Alien Amnesty Act."

I do not mean to suggest that a fictional TV show does the job of representing the complexities involved with immigration in the United States. According to Ono (2002), "the stories told by western media often have a generic quality; the images and language used to depict people 'elsewhere' have an uncanny resemblance to things we have already seen or heard 'at home'" (p.2). *Supergirl*'s use of metaphors to present a contemporary social issue highlights the influence that media has in shaping public perception regarding various political issues. *Supergirl* as a mediated form of communication shows how dominant cultural discourses

(policies, political labels, etc.) attempt to shape the attitudes of citizens, while in turn creating limitations for those located beyond the margins of citizenship. This type of programming in turn, reproduces the types of dominant narratives that tend to represent this group as voiceless and lacking agency. In this dissertation project, I draw on local narratives of undocumented immigrants' experiences with navigating this type of discursive environment to highlight how immigration rhetoric fosters a sense of dis-identification among this group. Dis-identification practices allow for this group to be strategic in the way they survive beyond the margins of citizenship (Burke, 1950). The aim is to understand how dominant discourses work to frame the larger issue of this project, which deals with the health disparities faced by undocumented individuals living in the United States under dominant communicative structures (Dutta, 2008). This project demonstrates how "undocumented" and "illegal" function as rhetorical terms of identification that frame governmental policies, which together symbolizes this group's marginalized status and reduces their willingness to interact with "official" medical spaces.

This chapter will focus on the first research question of this dissertation project that speaks to the representation of undocumented immigrants in the political and media landscape. The focus will be on how the language used to represent this group creates certain stigmas regarding how people with such labels are judged in public, particularly in medical spaces. To do this, a rhetorical approach is taken to first investigate the way these terms are operationalized in media and political spaces. From there the focus will turn to the reception of these terms by local individuals who are classified as such, to better understand how these labels influence the movement of undocumented individuals. This leads to themes generated from the interview data that connect with the notion that identification rhetoric shapes a stigmatized understanding of this group by dominant standards.

# **Rhetorical Citizenship**

As a part of the social negotiation of roles, various membership discourses offer humans the tools to easily locate how to situate him/herself in a particular situational doing (Baker, 1997). Citizen is one historic membership category operating rhetorically in everyday talk. Membership discourse is used to help individuals negotiate a sense of identity derived from the social/national context (Baker, 1997). If we consider Burke's (1950) notion of language categories as means of identification that help us "act together," then we must consider the ramifications of creating divisive categories such as "illegal" and "undocumented" when discussing (non)immigrants. Both terms emerge as sub-categories for framing the (non)immigrant as either a threat or a potential laboring body (Newton, 2008). Each term also symbolizes a population which operates below the authorized categories of citizenship. To be framed as illegal or undocumented clearly highlights one's inability to belong in the American social order. The way these labels are represented in American politics and media creates a stigmatized idea of who undocumented immigrants are and their role in American society. Such terms foster internalized restrictions and limitations for this group based on its use, which makes it challenging for them to move freely as subaltern bodies in a dominant space. This means that navigating a dominant cultural space from a marginalized position requires agents to be knowledgeable about their surrounding structures and strategic in the way they use communication to interact with said structures.

In this section of this chapter, I draw on Burke's (1950) concept of identification to make note of how identity labels function rhetorically to represent certain identities as lacking the

<sup>&</sup>lt;sup>1</sup> Subalternity points to a position of "being under" or "being erased" from discourse making (Dutta & Basu, 2011).

capacity to belong. Identification, theoretically, speaks to the need to survive through disidentification practices when a group lacks the symbolic resources to participate as an insider (Ratcliffe, 2005). I do this to begin responding to the study's primary research question as to the impact of the communicative environment on undocumented immigrant's decision making regarding health care services. I start by interrogating the labels themselves (undocumented/illegal) as political markers used (by media and politicians) to structure and influence how citizens make judgements about immigrants and immigration policy. I then turn to narratives from undocumented immigrants to show this group's relationship with these identity markers and their presumed rhetorical effect. Finally, I make note of the ways that undocumented immigrants navigate and maneuver around these labels through a process of disidentification that allows individuals to enact agency from their marginalized positions.

Ultimately, it is imperative to make note of the irony involved with using the same labels to discuss this group as I levee a critique of them; this not only shows the reach of dominant discourses in all areas of communication, but the responsibilities of the researcher of (re)presenting these subaltern positionalities from the ground up. I end this section by turning to reflexivity as a method/theory for discussing the complexities involved with the use of both terms (undocumented and illegal) and the importance of interrogating such labels when (re)presenting a vulnerable population such as people who lack official immigration status. As such, this chapter is organized in three parts to help capture the relationship between political and media representations and the reception of these terms by individuals living under such labels. The next section will discuss how these terms are used as political rhetoric that help shapes party lines, which will be followed by discussing the role media plays in prolificating the stigmas

attached to these labels rhetorical function. Finally, the media and political use of these terms will be juxtaposed to the way participants internalize and interpret said labels.

#### Trickle down Rhetoric: Political Representation of (Non)immigrants

The anti-immigrant rhetoric presented in political speeches, television dramas, and news media alike informs undocumented immigrants as to how they are portrayed and how they should navigate the social world with this stigma in mind (Ono, 2002). This in turn limits the avenues that immigrants might see as possibilities for accessing services due to an internalization of stigmas attached to these rhetorical labels. While it is important to focus on the taken-for-granted effects of these terms everyday use, it is also important to consider how there use in political documents creates long-term structural ramifications. Let us first take a look at how these terms have been used to drive political agendas and then make note of the political divisiveness involved with their use.

On Friday, July 6<sup>th</sup>, 2018, Vice President Mike Pence made an appearance at the U.S. Immigration and Customs Enforcement (ICE) headquarters. During his visit, the vice president made a 23-minute speech to members of the organization which focused on praising ICE employees for their role in carrying out the tasks outlined in President Trumps executive order on "Enhancing Public Safety in the Interior of the United States." The order, which was issued on January 25, 2017, offered ICE additional powers with regards to the removal of (non)immigrants currently residing in the U.S. In the weeks leading up to Pence's speech, Democratic party members proposed the abolition of ICE due to the extreme measures taken by agents in their attempts to carry-out the presidential order. This speech was meant to challenge that democratic proposal. During the speech, Pence praised ICE employees for their role in making American communities safer through the removal of thousands of immigrants who lacked legal status. He assured the audience that their work was being recognized by the president and the American people. "The President sent me here today with a very simple message; while I stand before you today at a time when some people are actually calling for the abolition of ICE, in this White House, let me be clear: We are with you 100 percent" (Whitehouse.gov, 2019). The vice president reassured the support of the White House, while identifying the dangers involved with protecting American communities from illegal outsiders. The vice president's message speaks to the different political attitudes involved with the management of (non)immigrants. He makes it clear that the management of outsiders is a politically divisive issue. The former republican governor went on to detail the success of the ICE agency, stating:

every day, men and women of ICE also confront criminal illegal immigrants who endanger our communities and prey on our most vulnerable. Our ICE agents are busy every day taking them off the streets. You've fought vicious gangs like MS-13. You've stopped human smugglers, child traffickers, and destructive drug cartels that are poisoning our youth and stealing lives of promise. You've apprehended terrorists who've come into our country to challenge our way of life and harm our people (WhiteHouse.gov, 2019).

We should note that while detailing the successes of the ICE agency, he refers to the "criminal illegal immigrants" that are responsible for making American communities unsafe. The former republican governor invites his listeners to dis-identify with those immigrants who are "illegal" and thus criminal in their actions. He goes on to draw subtle connections between illegal immigrants and criminal activities such as human trafficking and gang activity. The use of the

adjective "illegal" followed by a list of crimes ICE has been involved with preventing creates an association between the outsiders and crime in general. This rhetorical composition frames "illegal" immigrants of all make-ups as lacking the civility needed to be included in the United States social environment. He ends by suggesting that terrorists also fall into the category of illegal immigrant, which communicates the importance of managing this group. The frame that is employed by Pence is an example of the way political rhetoric about immigration in the U.S. tends to draw on language that identifies within party lines (Lakoff, 2004). This polarized political discourse in turn communicates to undocumented immigrants that they are indeed enemies of the state (Ono, 2002). It further communicates that the current administration considers this group to be in the same category as terrorists.

On the other hand, on June 26<sup>th</sup>, 2018, the Huffington Post published a story detailing Democratic Senator Elizabeth Warren's visit to an immigration detention center. The article stems from a Facebook post made by the senator a month before, where she gave detailed information about her visit to the McAllen Customs and Border Protection center in Texas. The senator's post reflected on what she saw as the "inhumane" treatment of detained (non)immigrants, and thus the increasing need for policy that changed how ICE functions as an agency. The second paragraph of her post details the facilities and its overall functions, she writes:

I went straight from the airport to the McAllen Customs and Border Protection (CBP) processing center that is the epicenter of Donald Trump's so-called "zero-tolerance" policy. This is where border patrol brings undocumented migrants for intake before they are either released, deported, turned over to Immigration and Customs Enforcement

(ICE), or, in the case of unaccompanied or separated children, placed in the custody of Health and Human Services.

Warren offers a political description (by framing it as 'the epicenter of Donald Trump's so-called "zero-tolerance" policy) of the detention center; while doing so she invites the audience to take a political stance with regards to immigration and the president's policies. The senator operationalizes the adjective "undocumented" to identify with a more democratic audience, as opposed to the word choice of Vice President Pence. Warren's use of the term "undocumented" functions as a frame by which to speak with a more sympathetic audience of citizens. Once more, both politicians draw on polarizing discourse as a rhetorical strategy for emotionally reaching their audiences.

The moral frame that is erected by Warren's use of "undocumented" is one that exists in a symmetrical relationship when juxtaposed against Pence's use of "illegal" (Lundberg, 2013). Rhetorically, "undocumented" helps Democratic Party audiences situate their political pathos on the topic of immigration in much the same way "illegal" operates from a conservative standpoint. Her comments point to a population that is vulnerable to exploitation and lacks any legal recourse. She communicates this group's lack of belonging through a more moral lens, unlike Pence, as she focuses on the "unaccompanied or separated children" as the symbolic identity of this group. This allows a liberal audience to be sympathetic to the outsiders while reinforcing the notion that they do not belong. This is to say, rhetoric as an area of study is concerned with the local, daily participation of language in civic and political life (Ono, 2002). What is clear from both politicians' messages is that the (non)immigrant body is a contested political battle ground; hence the language used to represent this group reinforces a dominant discourse aimed at connecting with a voting population (Chavez, 2013). Further, while both

terms communicate a different emotional attitude, they actively symbolize this group as not belonging, as non-agentic individuals needing to be managed and surveilled.

Both frames (illegal/undocumented) activate political stances, which communicates an idea of how Americans should go about managing the (non)immigrant outsider (aggressively or sympathetically). This also has the added effect of helping citizens make (politicized) judgments about the individuals living under these labels. This means that judgements and expectations of doctors, nurses, and healthcare workers are shaped by such mediated understandings. What is clear from the use of the terms "illegal" and "undocumented" is that such labels are meant to connect with citizens and not those individuals who currently exist in the United States with a (non)immigrant status. When considering Burke's (1950) argument that identification language operates rhetorically to situate boundaries within groups and societies, it becomes clear that the media and political (which eventually becomes part of the local lexicon, and policy language) use of these terms influences the way undocumented immigrants maneuver within/around the (border of) U.S. health structure. "Rhetoric shapes understandings of how the border functions; taken further, rhetoric at times even determines where, and what, the border is" (Ono, 2002, p.5). "Undocumented" and "illegal" as political labels operationalize a symbolic border through language that communicates a sense of how this group should be judged according to one's political leanings as a citizen. This in turn makes it difficult for this group to make positive health decisions as they must navigate the internalized stigma attached to such labels.

#### Media Representation of (Non)immigrants

Burke's theories of symbolic action argue that humans are largely distinguished by their symbol-using behavior (Burke, 1945). People have the ability to create, use, and misuse the symbols which work to help them act in unison (Burke, 1950). Because humans use symbols to

name things, situations, and people, they often abuse the way these symbols work to present reality (Cialdini, 2008). The reality we perceive as humans is filtered through some kind of symbolic filter, what Burke calls "a terministic screen" (Burke 1935). Both the imagined and physical worlds are symbolically filtered according to Burke. As people search for the need to be social and coordinate their actions, the symbolic pieces we call language becomes the vehicle by which individual attitudes are shaped. In contemporary society, the media plays a significant role in shaping how symbols are used in everyday political conversations (Ono, 2002).

The New York Times published an article on March 10th, 2017, titled "Illegal, Undocumented, Unauthorized: The Terms for Immigration Reporting." The article was published for an online audience and was written by Stephen Hiltner. The front page of the article features a young woman who is half embracing an older woman. The caption at the bottom of the picture informs the reader that "Teresa Reyes left Honduras last year to be with her husband, who lives in North Carolina." The article articulates the challenges with trying to publish works that capture the situation of immigration in America while not isolating certain political groups (which is the common practice). According to Hiltner, "Illegal immigrant," "Unauthorized immigrant," "Undocumented immigrant," "Illegal alien," "Migrant," and "Noncitizen" have been used in The New York Times to describe a person who has entered, lived in or worked in the United States without proper authorization — and each has been met with criticism (Hiltner, 2017). The author indicates that audiences are primed to discuss the issue of (non)immigrants in certain ways, using certain discourses which are familiar to them (identification). The point Hiltner makes here is that current journalistic practices are concerned with using the type of language that successfully frames the issue for the publication's majority

audience, who are citizens, which in turn ignores the effect such framing has on marginalized groups' sense making.

The article suggests that the various terminologies have been met with criticism from different political audiences. Other media companies (such as MSNBC and Fox) have explicitly utilized one term over the next when talking about (non)immigrants. Hiltner makes the claim that there are political implications based on which word is used to talk about noncitizens. This point becomes obvious when analyzing the words of Vice President Pence and Senator Warren. Hiltner details the type of identification rhetoric that marks a political stance for readers, whereby word choice erects certain frames and boundaries. Similar to Pence's speech and Warren's post, the media's use of both terms carries an intent of situating a political stance with regards to citizenship and immigration.

Hiltner (2017) goes on to note the standard style reference manual for how to organize such terms (368 pages), but the style book fails to identify when to use each label based on context. Hiltner suggests:

'Unauthorized' and 'undocumented' are also listed as acceptable descriptions, though each is presented with caveats. "Undocumented is the term preferred by many immigrants and their advocates, but it has a flavor of euphemism and should be used with caution outside quotation," the guide states. And "unauthorized," it warns, has a "bureaucratic tone. Off the table entirely are "illegal," when used as a noun, and the sinister-sounding "alien"

This indicates that there are no clear standards within media and political circles for which term is most appropriate. He suggests that 'undocumented' is the term preferred by immigrants while also suggesting that such a term carries "a flavor of euphemism." This creates the impression that

the term used by the Times is one that is founded on moral grounds by stating that it "is the term preferred by many immigrants." Once again, a rhetorical move is made by associating "undocumented" with immigrant preference, which is counter to the idea that the majority of Times readers are citizens. Hiltner tacitly gives authority to the Times use of the term "undocumented" over "illegal" by citing the reference style book as the proper source for determining which term is most sustainable to represent immigrants. This shows that such labeling tactics is directed from the top down, with the style book being the source of authority (Lundberg, 2013).

While he suggests that undocumented is preferred by immigrants, Hiltner offers no cited information from immigrants to support his claims. This shows how a dominant discourse likely gets authorized and reproduced by media practices. Yet, based on the way most media companies employ one term over the next indicates that each term frames the conversation of immigration in differing ways, and that the style book is an influential guide. What is clear is that the (non)immigrant lacks a voice in this conversation regarding how they are represented. Historically conservative media outlets like Fox News have largely relied on "illegal immigrant" as the terminology for representing non-immigrants, much like Vice President Pence. On the other hand, liberal news outlets like MSNBC regularly employ the term "undocumented" to represent (non)immigrants, like that of Senator Warren. It is worth noting that government organizations such as USCIS (United States Citizenship and Immigration Services) uses both terms on their websites and applications.

Hiltner's (2017) article offers a clear illustration to how identification rhetoric is designed to connect with certain individuals as a way to interpret and respond to political situations. Identification discourse of this type allows citizens to locate themselves within a larger political

conversation (Burke, 1950). The media does the work of authorizing the way these terms get used and how to operationalize them in everyday conversations. "Illegal and Undocumented" become political markers that help citizens negotiate their expectations for who should be allowed to participate in the American public. According to Garfunkel and Sacks (1970), "persons possess practical linguistic and interactional competencies through which the observable, accountable, orderly features of everyday reality produce – 'members' whose activities constitutes social order" (p.15). Communication operates as the primary material for building and reinforcing dominant structures that position certain individuals as lacking the means to belong (Lupton, 2012). Thus, the way groups are talked about influences what they see as possibilities when attempting to make decisions.

The NYT piece helps us locate these terms as membership discourses that citizens use to participate in a political structure that draws on a historical conversation of how to manage outsiders. What the article fails to offer is a sense of how these terms affect those who are occupying them currently. What effect do these labels have on the individuals who are forced to navigate dominant cultural spaces under such politicized labels? What are the nonobvious rhetorical effects of these labels on individuals who currently reside in the U.S. with a (non)immigrant status? Ultimately, for this dissertation project, I ask how rhetorical labels impact this groups' ability and willingness to engage with official health spaces. In the next section of this chapter, I turn to the local experiences of my research participants - undocumented immigrants living in the South Florida region - to better understand how they interpret such labels.

## **Identification Discourse as Symbolic Exclusion**

To gauge the effect of politicized labels discussed above on undocumented individuals, I asked each participant about their relationship with each term. At some point during each interview, I asked: "What do you think or feel when you hear the word undocumented immigrant used to describe your situation?" and "What do you think or feel when you hear the term illegal used to describe your status?" While each question garnered different responses, and while some favored one term over the next, the majority of participants believed that both terms were ill-suited for representing them and their situation. This section of the chapter deals with representation as an overarching theme that shapes this group's willingness to interact with spaces dominated by citizens. In each instance, participants made it clear that neither term was created with them in mind, so they must accept it. At the same time, there were a few individuals who saw the labels as inconsequential and were indifferent to their use because material in-access was a more pressing issue for them. What was clear however, was this group's awareness of the effect these labels have on presenting them as those outside the norm.

#### **Identifying at the Margins**

The way (non) immigrants are represented in media and political spaces plays a significant role in shaping the narratives surrounding this group. Too often these narratives tend to fit a trope like that of *Supergirl*, which depicts (non)immigrants as either refugees or criminals, in both cases needing to be carefully managed, politically. Such depictions create generalized stigmas about this group which they internalize because they often consume the same media as citizens. For Luke, the negative framing of undocumented immigrants is something that is constant and expected. He states, "I mean think about it, when was the last time you saw an illegal immigrant or undocumented immigrant being presented as doing something

good on tv?" As a young adult who has lived most of his life in the U.S., Luke is acutely aware of the way his status frames him to citizens based on how (non)immigrants are represented on television. His statement/question is an insightful critique of the way dominant communicative structures use the marginalized "other" to support its own narrative (Said, 1972). Troy shares a similar theory. He says, "I think that umm, immigrants are definitely stereotyped, you know, a lot of who they are calling illegal immigrants is an effort to further create a negative image of these people who want a great future and are willing to work hard to get it." For many undocumented immigrants like Luke and Troy, they understand the value of positive representation and communication when it comes to shaping the general public's attitude towards this group. Troy's comments highlight the subaltern subjectivity involved with decision making from stigmatized positions.

Several research participants suggested that the terms used to describe them as a group (undocumented, illegal) framed them in a negative light. They indicated that the mainstream media's use of these terms, along with their rhetorical function in political conversations cast them as plunderers and criminals. Nancy, said she feels "fear" and "sadness" when she hears the word "undocumented" used to describe her situation. "It brings fear, lots of fear, you are not comfortable, that word does not allow you to feel comfortable," she said. Her neighbor, Maxine, also noted that using such terms to describe their situation creates a false sense of who they are and what they are trying to do in this country. She mentioned that being "undocumented," does not allow her to feel human. "When you hear it, you feel bad, it does not make you sound welcome, I wish they could have another name, you know, find a more decent term to use because we are all humans," she said. When asked about the term "illegal" Nancy added, "oh my goodness, that's way worse, lots and lots of fear, that one really causes you to think about looking over your shoulder every time you leave the house." Both Nancy and Maxine have lived in the U.S. for over a decade now, and both suggested that the stigma towards undocumented immigrants had worsened over the years. Their comments show the emotional baggage that these terms carry for individuals who must navigate the current political environment under such labels. These terms that are used for political identification vis-a-vis citizens, create a disidentification effect for undocumented immigrants who are currently living in the U.S.

Research participants like Nancy and Maxine are aware of the labels that are ascribed to them and the marginalization that follows. While Hitlner (2017) suggests that "undocumented" is the more favored term for immigrants, it is clear from Nancy and Maxine's comments that neither term allows this group to feel at ease. Troy claims, "sometimes you wonder if the two terms are synonymous you know, undocumented and illegal, what do they actually mean, right?" Troy's awareness of this politized representation deeply affects' this belief that he can seek out services without potential ramifications. When considering that nearly 11 million undocumented immigrants currently live in the United States, a sizable portion of the population is left vulnerable to exploitation due to stigmas associated with labels like "illegal." Serina expressed her feelings regarding stereotypes and the stigma such stereotypes has on the lives of those who must survive under such labels:

Those words, it, it makes you feel like, as if you are not counted. If you are undocumented there is not accountability for you, so it is easier for things to happen outside of your control. It is hard for you to report if something goes wrong with you, because there is just so much fear. Things are so much harder for you, your circumstances are harder, you do not know where to turn to for help at times. You never know what you can get into, because you are undocumented the fear that you have makes

you wonder if someone might instigate something with you just because you look or sound a certain way, you don't want to get in anything that can prevent you from moving forward, so in a lot of ways you really become stuck.

Serena suggests that undocumented immigrants live beyond the margins of those in civil society who get to be counted, which Spivak (1988) classified as subaltern populations. Not being counted by the politico-civil system means that it is easy for this group to be exploited. Serena's dis-identification with mainstream discourse, her not being a legal resident of this country, marks her body as outside of the realm of public consideration. She recognizes the labels as contributing to her feelings of marginalization based on the stigmas attached to them. Serena also indicates that her marginalized position ultimately results in a type of paranoia, whereby she is constantly left to worry and account for her own well-being.

Serena's words, like those of Maxine, Troy and others highlight the subaltern position of undocumented immigrants and their awareness about this subaltern subjectivity (Spivak, 1988). What is most striking is participants attention to the role such representation plays in structuring their marginalized status. Pat explains that, "as an undocumented person, you don't have much rights, as a documented person, so you can't do anything basically, you're stuck, and being stuck is not a nice feeling, you can't do much, jobs, health care, or even making a simple grocery run, you are constantly on edge because you are undocumented, it's dreadful." She articulates a clear dis-identification with the dominant population due to these terms when she states, "you're stuck, basically." Her comments show how structurally aware participants are from their subaltern position and that decisions are made with this understanding in mind. Kim remembers that , "at one point, I heard they were taking people off the streets because they were undocumented, and I stayed in the house for weeks, like I wouldn't even go to the front porch, it

was rough." Taken together, these comments show a clear understanding of how communication plays a significant role in structuring an inclusive environment for people in marginalized positions (Lupton, 2012). The way Pat, Kim and Serina are represented as a member of this subaltern group limits their choices and at times even their agency.

In addition, participants are also aware of the rhetorical function that these labels carry for citizens and the way they make judgments about noncitizens. Serina states that, "based off my interactions, I have friends who have said why couldn't you come here the 'right way,' to just apply for visa, then apply for green card but Americans don't understand the circumstances that happen between... they think it's just a straight forward process, you apply and they say yes." She speaks to the expectations that citizens tend to carry about this group that tends to immolate the communication patterns derived from mediated representations. The way undocumented immigrants are talked and written about shapes expectations that citizens will make judgements about them according to those negative frames. Marlene thinks that, "stigma works for U.S. citizens, but I want to say there is bit of stigma from us as well. Sometimes you are assuming that someone else is thinking this way about you when you don't know, so I think it affects both." Marlene's comments show why trust becomes impossible for undocumented immigrants, as they are forced to navigate the same communicative environment that positions their identity as a political battle ground. Such language games sustain stigmas related to this group and the way they do sense making, which in turn reduces their willingness to interact with official spaces, such as hospitals. When asked how the political arguments surrounding undocumented immigrants affects individuals, Maxine suggest that, "it affects them bad, most go to bed wondering what's going to happen next, things are changing so fast that you have to constantly ask what is happening. People don't even want to go to work anymore because they

are undocumented, even employers are afraid to hire us these days." Maxine describes the trickle down effect of politized rhetoric that reinforce stigmas about this population which in turn limits their movement. This leads to varying health vulnerabilities, as individuals are unwilling to risk being exposed to seek out the medical service they might need. Something as routine as the flu could lead to a more complex issue such as pneumonia due to an undocumented individual not being able to overcome the stigmas attached to their labels and the marginalization that follows. When we consider a novel virus like COVID 19, which has created a public health threat

## **Internalized Stigma**

Research participants pointed to how policy language validates the stigmas that accompanies being undocumented, which in turn sustains fear-inducing and alienating structures that limit the ways in which individuals in these groups can access resources and living conditions available to the nation's citizens. Troy, from Miami, talks about the negative impact of Trump's executive order 13768 for the protection of the interior of the United States. He saw the policy as a powerful moment that "changed the daily rituals of many undocumented immigrants." Nancy too subscribes to this narrative on how policy discourses have affected dayto-day decision making for members of this group. She has lived and worked in Miami since she moved to the U.S. 13 years ago, and she recalls the deep sadness and fear she felt when Trump announced his plans. She said, "If Mr. Trump stop, if Trump stop saying what he is saying that will help, that alone is killing people, yes." She makes the point that Trump's rhetoric is just as damaging to undocumented immigrants as the policies that he puts forth. According to her, Trump's continuous tweets and speeches about this group are as influential to this group as the policies he writes into law. Maxine also supports this claim that, "if Trump leaves the white house things will get better because he talks too much, always stirring the pot." She makes it

clear that dominant political discourses are actively involved in shaping the lives of individuals in this group. For both Nancy and Maxine, top down political communication plays a vital role in shaping the temperature and tone of their local environment.

The negative representation of undocumented immigrants in policies and political rhetoric sustains fear as a central locus in the lives of these individuals. Shelly sees Trump's rhetoric and policies as a critical barrier to undocumented immigrants' leading meaningful lives. She says,

Well that's, that policy strikes fears into all immigrants hearts, undocumented or not, I have a co-worker, and I didn't even know that they could do this, she told me that when she showed up to work there were people there asking them umm for paperwork, showing that they citizens or green card holders, so people would show up to your actual job, and ask for your paperwork, and she was like her husband was a citizen, so he had paper work, but for other people they didn't show up to work, they called their friends, and family to tell them not to show up to work, so before that Trump Ice agreement there was still fear, but I want to say the threat has become very real, the policy that Trump has put into place it is not a matter of if, but a matter of when, they are going to come.

As I explain later, the increased fears that undocumented immigrants have experienced since President Trump took office have further limited this group's ability to try and access any medical services. It is not only Trump's policies that have had effect; many past presidents have used anti-immigration policies for political gain. However, it is also the persistent discourse surrounding this group as a problem needing to be fixed that is critical. Angela claims that, "it's always negative, I don't think I've ever heard the president say anything nice and positive about

immigrants who aren't his wife." These comments reinforce the fear that stems from such dominant discourses, and the way immigrants are forced to readjust their habits and rituals in order to survive. Shelly's final three lines paints a picture of how policy discourse manifests in material ways for this group, whereby language fosters structural limitations that further restricts the avenues of access available to undocumented immigrants.

Sandra explains the obvious effects of these terms when she states, "but of course they do, when you hear the big politicians talking about this stuff with these kinds of words it really makes you tighten up a bit, so yes they have to have a big effect." She expresses her awareness that these labels have political force and that they in effect shape emotional attitude of immigrants such as herself when it comes to decision making in a dominant society. She makes note of the role communication plays in shaping her material reality and the pathos attached to certain words when uttered in a political context. Shelly explains the complexity of this negotiation when she says,

Well some media, and some political leaders in these latter days, they have associated undocumented and illegal immigrants with rapists, killers, people with no skills who are coming to take, (with) no real experiences that can benefit American or American industry and economy, so I think lately, these ideas have gained more negative connotations, negative representation, which is hardly true, and that makes people without papers feel not wanted, not welcomed in America, and some people will even go as far as to say go back to where you came from when they realize that you are undocumented, not knowing that most undocumented people aren't a threat to their jobs or way of life.

Once more, she notes the attention to language paid by this group as it is necessary to stay vigilant when making decisions from subaltern positions. Shelly reinforces Serina's point that undocumented immigrants must internalized the stigmas attached to these labels to protect themselves and their families from exposure. To the point that some individuals are willing to self deport due to their inability to overcome the shame and stigma that shape their experience in the U.S.

Karen shares Sandra and Shelly's sentiment as to what she feels when she hears the term "illegal" used in a political context, "ohh, that, uhh, that makes you feel, hahaha, that you are something, someone who is not worth awhile, you are umm, you are an intruder, you know." Karen's comment shows the identification function of such labels and the secondary effect whereby boundaries are created, and outsiders are forced to make sense of their outsider status. Her use of the term "intruder" to describe her reaction to this term ties back into the way Pence used the term "illegal immigrants" when addressing ICE employees. It shows that undocumented immigrants like Karen have internalized the meanings attached to these terms and must negotiate the potential ramifications of being seen as an intruder. Maxine sees illegal as, "discriminating, yea illegal, it's discriminating," which often makes her feel like a target.

In addition to Karen and Sandra, Beverly, shares how the term illegal carries moral implications about one's identity,

I think the words illegal immigrant make you sound like a criminal, illegal like, you know, you carry an illegal weapon, you know, there is strong consequences for that so when you they use the words illegal immigrant, it makes you feel like a criminal, when you really not, you are just trying to make a better life for you and your family.

Beverly's reaction to being asked about the term "illegal" functions as a critical response to the rhetorical use of the term by Vice President Pence when addressing ICE agents. Her comments speak to the implications that are attached to such labels and the individuals who live under them. It is clear from Beverly's comments that she understands the rhetorical implications of "illegal" in the same way as Karen, and both have internalized the symbolic boundaries that such language carries. Peter states that these terms "makes you feel inferior to the American citizen." This kind of violent symbolic boundary makes identification impossible for groups at the lowest end of a hierarchy (Burke, 1950). It forces this group to create different communicative strategies for interaction and foster ways of surviving that are unique to those situated below the dominant order. The stigmatization that flows from immigration rhetoric communicates an environment that is hostile to this group, one that needs to be navigated with the awareness that one is operating from a subaltern position.

Beverly sees "illegal" as related to violence and crime; she also understands the term "undocumented" as carrying a certain emotional baggage. When asked if "undocumented" is a better term, she states, "seems like you have a limit to everything that you do, and you have to constantly be looking over your back all the time, you are not free to go get a job because you know it's not right, you are afraid to go to school, you can't open an account with your right name, so when I hear that I think that I cannot really do things by the book." To Beverly, both terms communicate a limitation of her being and belonging and she must make sense of her inability to engage with mainstream spaces due to this limitation. For her, both terms symbolize the same idea, which is that she is an outsider in this context. They both mark her as someone who lacks the merits of inclusion (citizenship), and thus she is forced to make sense of her position by dis-identifying with the ideas and structures that such terms reinforce in order to

maintain a livelihood in this country. She makes it clear that she cannot always do things "by the book," because the book was not written with her in mind. When considering the effect of both terms Jack says they conjure up the same feeling, "like I am a fugitive and realizing you can get caught and go to jail at anytime, not doing anything, but you end up in a cell, detained." These comments show that the stigmas attached to these labels are symbolic resources that help this group see the forest for the trees, meaning that they must also recognize themselves as outsiders in order to navigate a dominant environment without being detected. This limits this group's willingness to engage with structures and spaces that might expose their marginalized status, such as a hospital.

#### **Rationalizing the Subaltern Experience**

Even though many American journalists and scholars tend to position the term undocumented as being more sensitive to the (non)immigrant situation, it is clear from comments made by research participants in this study that both terms have the same exclusionary effect. Participants said that they had to take such representation of themselves seriously because it showed how they would be judged and later ill-treated by U.S. citizens/systems. According to Kim, " you always have to think many many steps ahead because that's the only way not to get caught because you never know who is who." She suggests that she had to learn to cover certain parts of her identity to navigate spaces dominated by citizens. For Kim and members of her community, this is important because it allows them to limit their trust to (mostly) only fellow immigrants. Beverly explains that "it's not easy, because you have to be around people (citizens) and observe them for a while before you think about trusting them, you can't just tell any American friend your business because they won't understand." In effect, (non) immigrants are limited by this lack of trust towards citizens because it inherently reduces their willingness to

engage with official spaces like hospitals. The way these labels are represented becomes a source of information for how/if this group should engage with the dominant structures through disidentification practices. Put it simply, a healthy amount of distrust is important for this group to navigate dominant structures from their subaltern position.

Pat shares her disdain for the term "undocumented." "I think it is such an ugly label, like undocumented, like everybody looks at you sideways, people who are undocumented, like it's a stigma almost, like no one wants to be undocumented but it is what it is, so you just have to learn to deal and to get over it, do whatever you have to do to change that and become documented," she says. Pat shares a powerful message by suggesting that "no one wants to be undocumented," showing her awareness of how dominant hierarchies forces certain groups into subaltern positions through discourse. Meaning that the way certain groups have been talked about and represented, historically, positions them as inferior compared to others who have benefited from over representation. It also speaks to the fact that many migrants move to the U.S. without understanding the formal process of citizenship, so the enter the country expecting that they would be able to stay.

This not only counters their subaltern status of being voiceless but also shows the awareness group members have with regards to the stigmatization involved with politized representations. Pat reinforces Beverly and Karen's earlier sentiment that undocumented immigrants are forced to internalize the representation that are attached to these words. When Pat states that "you just have to learn to deal and get over it," she clearly understands that one must first work through the stigmatization that accompanies the labels in order to survive in the U.S. Pat's comments show how communication/representation functions as a structural limitation for

marginalized groups and how such groups are likely forced to navigate dominant communicative structures in resistive ways (Dutta, 2008).

Pat, along with other participants' use of the term stigma to talk about the influence of this label shows how pervasive these ideas have become in the dominant discourse. As rhetorical scholars, we have a duty to look beyond the mainstream use of terms to understand the multiple ways influence unfolds from within and through discursive practices. Journalist like Hitner and politicians like Warren tend to stress the importance and morality involved with choosing to use undocumented over illegal to represent this group, but both terms have similar effects for those who are forced to navigate them. "Yes, stigma works, I wanna say it comes from the media," according to Serina. The stigmas that emerge from the use of these terms make it challenging to envision being accepted in any capacity for this group. For Steve, trusting citizens seems irrational based on past experiences. "Oh yeah, it's hard, so many times, when people here the accent they call me all kinds of words, and all kinds of stuff, banana boat man, money island man, ganja man, everything," he says. For him, such experiences align with the representation that he notices in his surroundings. Though he has relationships with citizens, he is aware of the frame from which they make judgements about those who fit under such labels when he states, "some of them look down on you, you know, some treat you right too, but some treat you as if you a real alien, you know." He has to try and cover as much as possible to avoid detection, but that becomes challenging, he notes, due to his accent. His only solution is to limit himself to spaces that will welcome his non-American accent.

Undocumented immigrants dis-identification with the dominant communicative environment leads to an awareness of their subaltern position, which helps them navigate a complex surround in creative ways. This awareness, however, creates health disparities and

negative outcomes for this population due to a combination of communicative factors. Namely, this group's skepticism towards spaces and information dictated by citizens, along with their perceived stigmatized identity formulates a lack of willingness among this population when it comes to seeking out the services they might need particularly in health-related situations as will be discussed later on in this project. Francis shares how he feels about the semantics involved with describing his situation,

I feel like it doesn't really matter (what they call us) because they are going to call us something, and we don't get to choose what they call us, no, that comes from the top so, I never feel no way about it because I call myself illegal all the time, and you know when you having a chat and a reason with your friends that is the word we use sometime to talk about the situation, especially if Americans are around because that is the only way they really can understand the situation.

For Francis, he must first rationalize the discourse use to describe his situation because that is the only way that citizens make sense of his position. In his own way, he takes authority over the words stigmatizing force to reduce the effect it has on him. Ricardo shares a similar sentiment when he claims that, "he don't really feel anyway about it, some people are here legally and some people aren't, it's just for politics." By reducing the terms to just that, terms, Francis and Ricardo both accept their lack of control regarding the communication used to describe their status, and instead are focused on how to move forward with this limitation in mind. They rationalize this stigmatized identity as a product of Americans not understanding their collective struggle as people without citizenship paperwork. By avoiding the use of these stigma laden terms to discuss people lacking official documentation, citizens and officials can start to repair the lack of trust that undocumented immigrants experience. This can open up opportunities for

dialogue to begin to emerge between these populations, health care providers, and campaign managers. While the undocumented immigrant population is not a homogenous one, the stigmatized representation that is currently attached to their identity through these labels forces them to suffer disproportionally high health burdens when compared to U.S. citizens (Derose, Escarce, & Lurie, 2007). The chapters that follow deals with health vulnerabilities and disparities specifically to highlight how dominant discourses/beliefs limits the type of access this group is afforded.

#### **Reflections and Reflexivity**

The media and political use of discourses such as "illegal" and "undocumented" functions as a type of identification rhetoric that is used to represent a symbolic boundary of citizenship. What is at stake is an understanding of the power involved with shaping representation of identities (immigrants) and dominant truths (Ono, 2002). By looking at how dominant rhetorical practices affect decision making among those that are marginalized, we can start to make note of the rhetorical agency needed to survive beyond the margins. Struggles over representation function as the type of political action needed to affect change in technological and postindustrial societies where political struggles take place in representation (Gary, 1995). The language used to represent (non) immigrants trickles down to politicize day to day conversations, which works to enhance the citizens' sense of membership while symbolizing a sense of exclusion for the undocumented immigrant (Baker, 1997). This tends to limit this group's willingness to interact with official medical spaces.

The goal with situating this research project as concerned with reflexivity is to tackle the taken-for-granted attitudes which tend to accompany academic research. It is important to recognize the responsibility we have as researchers to foster co-learning relationships with those

individuals we look to engage. Meaning to best represent this group and avoid potential negative consequences for community members, I continually interrogated my motives, goals, methods, and relationship with this research topic. This started with interrogating my use of labels such as illegal immigrants and undocumented immigrants as a means of representation. This happened for two distinct reasons, the first being that the word "undocumented" has been co-opted by western media and political figures as a way to derive bio-power from this group's current struggle (Foucault, 1965). The political polarization that "illegal" and "undocumented" has fostered over the years is often felt most by people without papers, as such it is a representative practice that I wanted to avoid. Moreover, participants interpreted these as labels that communicates a sense of inferiority in relation to citizens. Second, reading the Hitlner New York Times article that referenced the style manual as the authority on these naming practices was eye opening because it showed how dominant media institutions use their authority to frame subjective truth as objective ones. At one point in the article, Hitlner states that "undocumented" is the term preferred by immigrants, which felt like a slap to the face. By juxtaposing "undocumented" to "illegal" he creates a rhetorical shift that suggests one term is preferred over the next. By limiting the way we reference this population, we limit the avenues of understanding that are possible with regards to how to communicate about this group outside of the political rhetoric.

The contemporary approach to human research has been one focused on dissecting the whole into separate parts to better understand the entity (Eisenberg, 1999). Ironic, I know. We have, as researchers, positioned ourselves as agents of knowledge, while re-positioning others as subjects needing their knowledge interrupted (Sarangi, 2003). This scientific approach to human research has created a distance between the "researcher" and "participant," which in turn has

produced the type of knowledge that presents one group as more knowing than another. A reflexive turn on human research forces us to bend back into noticing the co-production of knowledge in research engagements (Steier, 1993; Dutta, 2010, Basu 2020). Given the sensitive nature of the research project, being reflexive was vital for understanding and questioning my taken for granted assumptions about this population, and my limitations in attempting to represent the complex situation this group finds themselves in.

# Localized Labels

It became clear after the first few interviews that individuals were aware of the rhetorical function of these labels in terms of shaping how they were represented. Individuals offered insightful and well-thought out critiques of the complex political issue of immigration, which showed how well-versed they were in dissecting the structures around them. It quickly became obvious that my main job as a researcher was to listen to the knowledge participants had acquired. They discussed the labels used to represent them as having material effect and shaping their engagement with surrounding structures. They saw such labels as strategic communication meant to induce fears and limit their ability to make sound decisions. While they did not talk about these words as rhetorical, they none the less interpreted these terms as having influence in a negative capacity. For participants, the words, the meanings, and the ideas attached to them are passed from the top down, so immigrants have historically had little influence over the way they are represented in contemporary society.

While participants did not offer up a term or label that they saw as most appropriate for representing their situations, multiple participants chose to talk about their lack of legal residency as "not having papers, or people without papers." To keep with the culture-centered goal of aiming towards solidarity, I will utilize the phrase "people without papers" (PWP) henceforth to

discuss undocumented immigrants for the rest of this dissertation project. I am not claiming that this phrase is more ethical or appropriate than "undocumented" or "illegal," but it is the metaphor that was most used by this group to represent themselves. I adopt this phrase to introduce this localized expression to the dominant discursive space. This is to say I want to bring in the language and frame used by my participants into this discussion, I want to do so without the baggage of a polarizing discourse. By moving away from "undocumented" and "illegal" I hope to bring my reader away from the political stigmas attached to this group and instead think about them as people living in this country with restricted access.

I believe that by using this type of language, scholars can start to draw on the type of language that this group would be willing to identify with. People without papers (PWP), offers a familiar lexicon for this group that would remove the institutional frame that is attached to the previous labels. Kim offers a sophisticated critique of the origins of these labels: "I think they hear us talk about having no papers, and then they go and Americanize it with undocumented to make it sound proper." She suggests that their labels are not good enough for Americans, so they were rebranded in a sense to offer more rhetorical force. This type of rhetorical maneuvering allows dominant hierarchies to speak for subaltern populations without listening to said populations. Language games of this sort only widens the distrust PWP have towards dominant institutions and citizens in general.

#### Reestablishing Trust

One of the obvious challenges with this particular study involved establishing trust with a vulnerable population. As a researcher who is employed by a dominant institution like a university, I knew that my body represented the types of institutions that this group typically found untrustworthy. In my first couple of interviews, it was obvious that my communication

and word choice made individuals respond to me as if I was an institutional body. Simply because the first four participants I interviewed were people I knew for most of my life, I was extremely sensitive to the way their pattern of communication changed once I started recording. The formal structure of an interview created an unforeseen distance that showed itself in mundane conversations. For example, choosing to use the word "undocumented" to engage with Francis, a neighbor who I worked with throughout high school and college, hinted to me that my presentation was communicating institutional body in their eyes. When I asked Angelia, a close family friend, "how do you think Americans judge undocumented immigrants?" She responded: "do you mean people without papers?" This suggested to me that maybe my language choice was not as favorable and grounded as I hoped it would be. As Angelia is someone that I had a prior relationship with before conducting this interview, I interpreted her response as a powerful communicative moment that showed the separation between institutional discourse and local language. It also forced me to reflect on my role as an institutional body that was being afforded trust by this vulnerable population. Additionally, the interview as a communicative event creates a certain level of formal structuring that made it impossible to ignore the institutional distance between myself and my participants.

The struggle for me as a researcher situated in the field of Communication Studies is that I am constantly attending to communication styles and patterns, along with the nonverbals that accompany a message. So when Francis, someone who I worked closely with for years as a teenager, says "she didn't even know that when I came to work with people like you and Mikey that you all didn't have papers either, most of the people I took to lawn bush weren't straight," I interpreted this exchange as more authentic than other responses during the interview. While this was not the case for participants that I met for the first time, I could not help but consider how

the frame "interview" that included a recording device influenced participants responses. Simply put, participants I had prior relationships with were much more formal when answering questions as opposed to when talking after or before the recorder came into the fold. This inherently speaks to the relationship between communication and structures.

I believe that I was able to gain this understanding for two reasons, first of which was me having prior relationships with the first four individuals I interviewed. This allowed me to reengage individuals after I interviewed them to ask about their perception towards me as an interviewer as opposed to a family or friend. The most reoccurring feedback I received following the first set of interviews was to not use so many "big words." This indicated that my communication style and tone were influencing how participants responded. Angelia suggested that I she did not understand some of the words I used, "that's why I kept asking you to repeat things." Meaning that because I was asking questions in a way that was more formal than they were used to when talking to me, I had to assume that my communication patterns to fit the interview frame, as I was also doing. I think what was most telling of this is the nine times during all 27 interviews that a participant asked the simple question, "am I allowed to say that?" I believe this question made it clear that both parties were communicating with a sense of institutional oversight.

Second, having been someone who lived in the U.S. for some time without papers also afforded me a certain degree of trust because I realized after the first set of interviews that talking about my own experiences would help to re-establish some level of comfort. Talking about my time in high school as a student athlete without papers was important for helping Luke "understand what he was allowed to share." By sharing of my own experience, in my opinion, it

helped participants feel a bit safer communicating about their struggles in this formal way. While this by no means guaranteed me participants' full trust, I believe it reassured them that I would protect their stories as I was also implicated.

It became clear by the sixth interview, when I interviewed someone, I had no prior relationship with for the first time, that PWP are very attentive to patterns of communication. This indicated to me that I was viewing this group as limited in their agency and awareness; I was in effect using a dominant institutional frame to make sense of this group's seeming lack of attention to their communicative environments. I brought a limited perception of this group as I assumed that only students of Communication are attentive to local and global communicative practices. I had to reflect on my own biases to understand that participants also see communication as a signal as to how they will potentially be judged, which indicates if a situation is favorable or not. I do not mean to suggest that having shared in similar experiences afforded me complete trust because it did not, I was still a citizen who brought in prior mediated assumptions to the research space, which showed how removed I was from this space.

What my experiences afforded me was a willingness to investigate my own language practices in order to be sensitive towards this group awareness of their own structural limitations. The discourse mattered. For example, when asking participants about their work life, framing questions as "how do you find work under the table," as opposed to " where do you work," shows that I am attentive to the complexity of their situation (which is completely normal for them). Meaning, this group does not feel comfortable explaining the details and complexity of their situation to those who are seemingly ignorant towards their ways of knowing. Trust and willingness are things that go hand in hand for this population, whereby some level of trust is needed for this group to be willing to engage with dominant spaces and individuals. This is

certainly the case for hospital and medical institutions, as PWP tend to view these spaces with the same critical lens that they take to political conversations. The first step towards reducing the health disparities faced by this group is to supply medical professionals with the communicative resources that would show sensitivity towards this group and their structural limitations. In the following chapter, I will discuss the relationship between the medical structures and the shifting cultural ideologies that must be navigated by PWP when they decide to seek out service. The tension between the U.S. medical structure and PWP's cultural understanding of medical spaces is critical to this relationship.

# Conclusion

In review, this chapter started with a rhetorical approach that identified the mainstream terms for representing people without papers ("illegal" and "undocumented") as communication designed to exclude this group from public consideration. By juxtaposing the way these terms are used in political and media discourses, with how participants interpret these terms in their day-to-day lives, this chapter showed the rhetorical impact of these labels in (re)producing a certain level of stigma towards this population. Participants discussed how such labels represented them as inferior and unworthy of the resources available to those with legal status. They also spoke about having to internalize the stigmas attached to their politicized labels in order to better understand and navigate the structural limitations they face. These terms limit the trust that people without papers afford to dominant institutions such as hospitals, which in turn leads to avoidance and further health vulnerabilities among this population. In response to this study's second research question, the following chapter examines the structural elements that operate as barriers to the health access for this group when combined with the personal anxieties produced by having to navigate a dominant space with stigmatized identity labels

# Chapter 4: A Clash of Culture and Structure: Considering Barriers to Access for People Without Papers

Having described the way communication structures and reinforces the stigmas associated with people without papers (PWP), and how that affects this group's willingness to engage with spaces dominated by citizens, this chapter will turn to examine how the healthrelated structures limit the avenues of access PWP tend to see as possible. Structures, as mentioned earlier, deal with the formation of social systems, means of disturbing resources, and ways of controlling resources that work to sustain social inequities (Dutta, 2007). Keeping with the culture-centered approach (CCA), attention to structures necessitates a focus on the relationship between structures and culture. Culture can be explained as webs of communicative meanings that shape social systems (Dutta, 2007). Drawing on the thematic approach that was used to analyze the data, the results presented in this chapter proceed from a culture-centered theoretical perspective typical to interpreting locally-produced knowledge that manifests at the intersections of culture and structures. Specifically, I pay close attention to participants' accounts of a shifting structural/cultural environment in relation to health and wellness to identify prominent recurrent themes that cut across their shared accounts. I will focus on three main themes: a shifting cultural understanding of health, the perception of the U.S. health system as a bureaucratic business and internalizing the capitalistic logic of money first. Taken together, these themes highlight the complex negotiation to access that PWP face when deciding if medical intervention is the best course of action. PWP must navigate their contextual health needs, the constraints of their non-citizen status, the stigmas they face, a complex and unfamiliar health

system, and diminished access to native cultural strategies of managing health. The next section engages with each theme in more detail.

## **Shifting Cultural Understandings of Health**

Lupton (2012) questions how dominant health structures and discourses mute certain cultural considerations by presenting health approaches as singular. The intermingled nature of culture and health practices becomes deceptive in dominant mediated messages as the two are often presented as separate entities (Dutta-Bergman, 2005; Lupton 1994). This is to say, a critical cultural approach to communication interprets culture to be dynamic and maintained in discourse by those within a given cultural space. Lupton (1994) explains that "the term culture need not be limited to the traditional anthropological definition but rather should be understood both as a way of life including ideas, beliefs, language, institutions, and structures of power and as a range of practices, encompassing artistic forms, architecture, mass-produced commodities, everyday activities, eating habits and media products" (Lupton 2012, p.57). For PWP, culture has to be viewed as dynamic, as groups' cultural practices are (re)shaped by a lack of status, change in cultural environment, and limited access to available resources.

The first theme that emerged from participants' discussion of managing their health in the U.S. was how different the surrounding environment was when compared to their native country. All 27 participants noted that the U.S. health environment was drastically different from what they had experienced back home. While the majority of participants stated that the U.S. health system was more technologically-advanced and delivered better results than the system in their home country, they nonetheless saw the U.S. health system as more selective with regards to who is afforded the best care. Moreover, many of the PWP that were interviewed believed that U.S. health culture is designed for when things go wrong without much concern for promoting

wellness practices that could help people avoid medical intervention in the first place. They suggested that many of the local remedies that they relied on in their home countries were not available in the U.S. or that they were much more expensive to purchase. Along with a lack of cultural remedies available in the U.S., participants also stated that a shift in lifestyle contributed to their negative health experiences.

## Shifting Diet

Many of the participants I interviewed mentioned how important it was for immigrants to pay attention to the way habits and lifestyle change when one enters a new country. While the idea of attending to health and wellness is a familiar concept, the way they went about managing both had to shift based on their current location. Notably, participants talked about how consumption practices must be taken into consideration when living in the U.S. Steve sees immigrants as suffering from the dramatic shift in consumption practices, especially for immigrants from poorer regions. He states, "some people come here and they try and eat as much as they can because they didn't get that type of regular eating back home, food wasn't available like that back home, you come here and see so many choices that are cheap, so you just end up eating and eating and before you know it you lose control and suddenly you're sick." He notes how the availability of various food options in the U.S. makes for poor eating habits that run counter to what they were used to in their home country. Steve speaks to the "cheap food" that is readily available in the U.S. and how immigrants tend to fail to recognize the negative health consequences of such dietary change. Angela also supports this idea that a shift in consumption practice tends to create negative health situations for immigrants. She says:

oh my god, that can affect your health in a very poor way, yes, because we eat these bad things but when I was growing up back home, we use to have organic foods at our

fingertips, and we didn't have to pay a lot of money for it. Now, here, you can't afford organic foods, so we end up buying what we can afford to buy to survive.

She highlights how this shift away from cultural patterns of consumption can be attributed to a U.S. system that promotes less healthy food options. She sees this as an unanticipated consequence of migrating to an economically-powerful country like the U.S., where she has more access to food but less resources to obtain the "right kinds of foods." Maxine supports this point when she states, "yeah, I grew up with organic everything, chicken, cows, goats, they only ate the straw and grass we grew, but here they put all kinds of antibiotics and chemical in the animals, so you never know what you are eating, and these are the things that help you get sick." Having lived in the U.S. for over a decade, Maxine has had to learn to navigate the complex food environment in order to try and avoid medical intervention. She suggests that such understanding starts when PWP recognize just how different the U.S. structural environment is as opposed to their home country.

Poor consumption practices lead to health issues that become hard to detect and manage without regular medical intervention. Francis shares a narrative that details how his change in eating habits since moving to the U.S. negatively affected his health:

when I came here I use to eat all the fast foods, and the cheap things that taste good, but after a couple years I put on a whole lot of weight, and I started to add things up and see that it was all that junk crap that I was eating. I would work all day and get home late so I would just grab a McDonalds for lunch and dinner for cheap, so I felt like I was saving a lot of money, but you have to figure out that it's no good, because no one is telling you that these nice tasting cheap things will kill you. I never had high blood pressure before moving here, and it's because of all them McDonalds. Francis' story illuminates the struggle that immigrants like him face, where they must negotiate the plethora of food choices available while trying to find the most cost-friendly options. He argues that his fast food-diet contributed to his eventual hypertension because he failed to realize how drastically different fast food is in America versus in his home country. For Francis and others, it takes time to make sense of the food landscape in the United States because of how differently it operates versus back home. Marlene understands that, "McDonalds doesn't use any good oil, they don't use coconut or olive oil to fry their chicken or fries, no they use the cheapest one they can find, and poor people just eat it up. I never had no McDonalds growing up, there wasn't that terrible food to buy." This shift in eating habits is not only due to cost but also due to the work-life balance (or lack thereof) that PWP must negotiate as part of their new cultural environment. Like Angela said previously, they are no longer in an environment where organic foods are available for cheap or where they can grow it themselves; she recognizes the hierarchy involved with how food is consumed in the U.S. but lack the resources to take part in healthy ways.

What is most damaging about PWP shift in consumption practices is the immediate lack of awareness about how food practices differ in the U.S. vis-à-vis those back home. The tacit relationship between the food and health industry in the U.S. is something that PWP fail to take into consideration when migrating (Lupton, 2012). Immigrants tend to carry the expectations they had back home to the states, and when it comes to food, the expectations are that organizations like McDonalds would not knowingly sell people food that would eventually make them sick. This is an understandable oversight when considering that most of these individuals grew up in an environment where they had some form of relationship with the food they ate, where something like fast food was not readily available. Angela makes note of this tension

between cultural consumption practices and being able to afford to eat healthy in the U.S. "My grandmother use to boil the coconut oil herself, and now they say coconut oil is one of the best oils. But we can't afford it here, you see it in the supermarket and you turn away it's so expensive." Along with the high cost, Angela's 10-hour work days does not afford her time to boil her own coconut oil anymore. She no longer has a yard that has multiple coconut trees that she can use as a resource; instead she is limited to what is available on grocery store shelves. This cultural shift makes it hard for Angela to maintain her health the way she did back home. She is left to manage her health in the way citizens do, which typically involves regular doctors' visits for checkups, but she lacks the access needed for routine health maintenance practices.

PWP migrate with the expectation that people in the U.S. see food as a vital part of maintaining health as they did in their home country. Ricardo's comments speak to this point, when he states,

you just come here and you do what you see everyone around you doing, you see what everyone else is eating but you don't think where is that coming from, what are they putting in it or anything like that, until one day you might hear it on the news or from a friend that they don't use real meat, then you are like oh wait. At the same time, you are new here, so you want to try everything, especially with all that's on TV, and you just go with the flow.

Ricardo speaks to the way communication structures ritualistic expectations, even when it comes to food. He states that by engaging with the discursive environment, immigrants learn to reimagine what is acceptable food consumption. This connects to the earlier theme of representation that discussed the dangers of PWP consuming the same media content as citizens without the same available resources. Having to ask questions like "where is that from" or "what

is in it" is a new negotiation people like Ricardo must make when they migrate. For participants, this awareness takes time to develop, which often happens long after one has developed diseases from their new eating habits. This tends to be a reoccurring trope for PWP, where they are having to make sacrifices to their health in order to offset high living costs and low paying jobs. *Shifting Lifestyle* 

Along with a shift in consumption practices that leads to negative health outcomes, PWP must also negotiate a shift in ritualistic behaviors that previously helped to support their health. Most of the participants I interviewed spoke about how the fast-paced American lifestyle runs counter to what they experienced growing up. For Ricardo, "it's different here because back there you were healthier because you would walk or run to most places, even to get a taxi was a walk, so those things were built in exercise. You don't drive everywhere like here, there wasn't bus down the street every 15 minutes." Such subtle ritualistic shifts impact this group's ability to be agentic about managing their health in the U.S. This adds to the complex negotiations that PWP already have to make when attempting to manage their health in the U.S. Beverly solidifies Ricardo's insight by saying,

That's why people go in shock when they come here...your mom teach you how to break the coconut, how to grate it and cook it... when you come to the states you realize everything comes in a tin, you just pour out the coconut, pour out the peas... so it takes us a while to realize that everything is like this now, it affects us, it takes time to get used to it and realize that health is not only about the physical, because eating is completely different because not many of us grew up where we could just go to the store and buy a burger, no, before you went to school your mom would make you whatever she had, even

if it was just some tea from the backyard, but here you realize that kids will drink juice and eat sweets for breakfast...so it takes some time because things are so different.

Beverly's comments shed light on the adjustments that immigrants have to consider when they move to the U.S. The lifestyle changes they experience due to the change in environment and surrounding structures limits the control that PWP have with regards to maintaining their own health and wellness. Participants talked about how they walked less, had less conversations with neighbors, ate more unhealthy foods, slept less, worked harder, and generally experienced more stress than they did before immigrating to the U.S. For someone like Beverly, these environmental changes have dramatic health consequences because immigrants tend to fail to recognize that such habitual changes negatively affect their health. For Beverly, "you become lazy here, that's the culture, so now you have to think about going to the gym to stay in shape, back home we had no gyms, we just lived, and I was very very very skinny back there, and once I came here I just blow up and it happened before I realized." She sees this oversight as something that affects PWP even more so than traditional immigrants for two reasons: PWP tend to originate from already impoverished locations where food can be scarce, and they are unable to eat and behave in the same ways that helped them maintain their wellness back home. This highlights the dynamic feature of a culture, Beverly's comments show how immigrants are forced to evolve their cultural practices due to the structural shifts they experience when they immigrate to the U.S. (Dutta, 2007). "Structures are embodied in the organization of the state, of civil society organizations, and of for-profit organizations that are embedded in a social system and are complicit in the creation of life experiences at the margins. Cultures are intrinsically linked to the social structures that surround them because the way resources are allocated and controlled significantly influences how meanings are created in the context of the life

experiences of cultural participants" (Dutta, 2007). Given the shift in structure she experiences, Beverly indicates that such structural changes affect the cultural rituals that immigrants in her position are able to draw on to deal with health issues when situated in the United States (Basu & Dutta, 2011). This central tenet of CCA, speaks to the relational dynamics of structure and culture, whereby shifting structures tend to negatively affect those cultures bodies situated in marginalized positions.

As will be discussed later, the challenge of having to work long stressful hours in order to overcome low wages, along with their obvious lack of access to governmental resources makes the health consequences of these lifestyle changes dramatic for PWP. Kreps and Sparks (2008) suggest that it is important to examine the cultural backgrounds and orientations of at-risk populations, such as immigrants, along with their current limitations before distributing health-related messages. They note that cultural groups listen and respond in different ways as their environments shift. "Understanding a group's beliefs, values and attitudes offers more nuanced possibilities for reaching and educating various at-risk immigrant communities, while reducing the fears that certain cultural identities will be in questioned in medical situations" (p.326). Beverly's message incorporates a sense of adaptation that is needed for immigrants to survive and be well in the U.S., but such adaptation becomes nearly impossible for PWP due to a lack of material and symbolic resources that they no longer have access to in this context.

Beverly's comments demonstrate the constant overlap that exists between the medical industry and larger surrounding cultural beliefs and ideology in the U.S. Shelly comments on the cultural differences she has noticed since living in the U.S., "managing yourself in America is mostly you going to get check-ups and preventative care, but back home you only go to the doctor based on emergency or need, a last resort. In America it's kind of first resort, in America

you get a couch you go see a doctor, back home you get a cough you drink some tea or get some chest rub ointment or something." Shelly's statement speaks to the different set of expectations PWP face when it comes to medical decisions in the U.S., and how those expectations tend to run counter to the cultural practices they are used to. This complicates what PWP see as potential solution to a problem like a cough, as they lack the means to create remedies like they would back home, along with the lacking the access and resources needed to receive professional care in non-emergencies. Participants believed that because of the design of the U.S medical system, which incorporates insurances and governmental programs to offset cost, Americans are more willing to engage in risky health behaviors because they can turn to their doctors anytime. Participants like Beverly saw this as a major struggle because while PWP are able to engage with other economic markets (such as garments and electronics) in the same way Americans do, but they are unable to have the same protection citizens have when it comes to healthcare which creates an unforeseen trapdoor for this group.

### **U.S. Bureaucratic Health System**

In addition to a drastic shift in environment and lifestyle that PWP must navigate in order to maintain their health in the U.S., they must also figure out how to interact with a complex U.S. health system when they are most in need of service. Regardless of what country participants originated from, they saw the U.S. health system as overly complicated and confusing. This is juxtaposed against the perception that most participants carried in relation to the U.S. health system being more effective due to its technological advancements. This, in turn, creates a clash between reality and expectations for this group, as they have to learn how to obtain the benefits of an advanced health system while lacking the resources needed to qualify for such services. Participants discussed three structural features of the bureaucratic U.S. health system, which they

identified as reasons to avoid dominant medical spaces (such as hospitals) altogether.

Participants saw the need to provide identifying information before service as a communicative process done by the health system that signaled their exclusion. In addition, the need to supply proof of insurance before obtaining medical service was also a major deterrent for PWP. This led to a lack of trust in a health system that they argue values capital over care. While participants trust that U.S. medical professionals would provide advance and adequate service, they did not trust that they could be honest about their situation, as they expected to be judged and/or stigmatized for their lack of resources and individual knowledge/information.

## Bureaucratic Identification

Health meanings are negotiated and shared based on living contexts (Dutta, 2007). Contexts, according to Dutta, comprise interconnected local environments that are involved with the negotiation of health meanings. It sets the scene for participants to enact culture based on the shifting material factors present. For PWP, being in the U.S. without official documentation creates a unique health context that has to be approached strategically due to a variety of restrictions. One of the main reasons participants gave as to why they avoided medical situations such as private clinics and emergency rooms was that most medical contexts required "official" identification in order to offer service. If participants were unable to provide such information, they assumed that they would be denied service or be inadequately looked after. Nancy understands the quality of service to be superior in the U.S. but does not welcome the need to constantly provide documentation. She says,

First thing, in my country you hardly get (health) service, service is last minute, it starts because back home we ate healthy, the foods were natural and you ate things from the earth, so I think it was harder to get sick back home, but if you did end up getting really

sick, there are clinics, small health clinics you could go to and you get looked after without being asked for ID, insurance, money up front or having to fill out lots of forms and questionnaires.

Nancy's comments shed light on the recurring theme that participants brought up regarding the difference between their health system back home and the U.S. system. While most participants praised the efficiency of the U.S. health system, they recognize their less advanced, often limited, health system as being more accessible to all, including foreigners. Nancy talked about how shocking it was to experience the overly bureaucratized U.S. health system, where she thought "an advanced nation like America would be more open to treating" all those who resided inside its borders. Much like Nancy, participants discussed how they were unaware of how bureaucratic the health system was in the U.S. before they migrated. Karen supports Nancy's argument when she states, "you just don't know what you are leaving behind, it's the grass is greener on the other side thing, yes it (health care) is better here but what's the use if you can't get it." She understands the need to provide identification as a major limitation that communicates to her that the less advanced health system back home was more functional for her. Because PWP tend to migrate for economic reasons, they tend to not consider the health limitations they will face in the U.S. as they carry the expectation that an advanced health system would be more accessible than their own. In many instances, participants mentioned how they thought the U.S. system would be similar to that of Europe or Canada, which offers universal health care for all. This speaks to the unique set of limitations and challenges immigrants face when they migrate to the U.S. as opposed to Europe or Canada.

According to American medical law journals, it is completely ethical for doctors to refuse treatment to a patient who lacks proper documentation in non-emergency situations

(Fruth, 2015). This means that PWP run a risk when they attempt to seek services without having what is consider official identification. Older participants talked about how in the past, pre-9/11, they would be able to use their native passports and drivers' licenses as a means to provide identification. This is no longer the case as most hospitals and clinics require some form of government issued identification, which has reduced willingness on the part of PWP to engage with such medical spaces. Andrew proclaims,

There is too much questioning at the hospital, they are asking for all sort of things, calling for your ID, and I don't know the full, but I know you have to show some sort of ID, so no, I don't want to deal with any of that more than anything, you don't want your information to go into the system, once it hits that computer they could do anything with it, you never know when your information could come back to hurt you.

He sees the bureaucratic process of collecting patient information as a potential trap door for PWP, as the issue of trust once again arises. Andrew's comments indicate that he is not completely familiar with process of the U.S. health system but based on what he has gathered it is a situation that could end up hurting him in the long run. Due to this, he has avoided official medical spaces like hospitals and clinics since he immigrated to the U.S. back in 2004. He shows an acute understanding of how bureaucratic systems tend to morph and transform over time, where the rules and regulations are constantly evolving with the introduction of new policies. Shelly rehashes this point by saying "you are unwilling to give your name and any kind of background information about yourself because that information can be used against you at some point when government administrations change, when new senators, house and senate switch powers, when policies change." For Andrew and others, the computer represents the dominant system of power which they aim to avoid, one that is more permanent than government

administrations. He is aware of the role of surveillance in how western societies tend to go about regulating influence over a population. Andrew's example highlights how technology in advanced medical systems tends to operate as a type of structural violence against those who lack meaningful resources (Farmer, 1996). Farmer's (2003) concept of "structural violence" draws the readers' attention to the type of suffering and in access that are embedded in the everyday, taken-for-granted rituals that stabilizes the structures around us. The culture-centered approach (CCA) aims to explore the ways by which structure impacts the health choices of marginalized cultural members (Dutta, 2010). Dutta (2008) contends that structures are communicative in advanced societies and they tend to "constrain, limit, and define what is available to cultural members and what is not." What Andrew's comments show is that a task that is mundane and routine for a citizen, such as giving information to a connected system, becomes a source of anxiety and misery for those who lack sufficient resources.

Andrew's experience is consistent with that of most participants, where they were not exactly sure what could be done with their information once given to a hospital and hence, they tended to avoid such risks. Shelly sees this insight as shared knowledge that is communicated among immigrants that help them protect themselves from potential backlash. "Some people are saying that the moment that you give your information and it goes inside a computer they don't know what happens with that information and it could end up working against them, so that is what stops most people from doing regular visits." The process of requiring government issued ID in order to gain service operates as a symbolic boundary of exclusion that PWP have come to recognize as needing to be navigated in order to avoid detection. This communicative process, where governmental identification communicates a sense of inclusion, operating as the

literal/material process of Burke's identification that was discussed in chapter 3, which works to manifest exclusionary boundaries, symbolically. While there might be HIPPA laws in place to protect patient information in medical situations, participants are aware of the notion that these laws might only protect the information of citizens. Moreover, participants saw the request for IDs as one half of the bureaucratic coin as they also discussed the need to supply insurance information as a major deterrent.

# *Insurance as boundary*

Along with discussions of the symbolic message requiring an ID communicates, participants also talked about insurance operating in a similar fashion. They saw the need to provide insurance as a major deterrent for those who lacked the means to obtain such services. As noted earlier, government programs like Medicaid and Medicare fail to cover those who do not have a social security number to put on file (Cheong, 2007). Further, it is extremely challenging for an immigrant to purchase any kind of private health insurance without a social security number. "Undocumented immigrants are also limited in their ability to access care by a lack of both health insurance and sufficient financial resources to pay for services," which is central to obtaining service (Loue, 1997; Kullgren, 2003). Sandra proclaims that, "they are not going to take care of you, you go there and the first question they ask you is if you have insurance, instead of asking your name and what's wrong, they ask 'what insurance do you have,' and that's a no right there, that means you won't get cared for unless it's extreme." Such bureaucratic requirements signal to Sandra that health service spaces are not designed for her as she lacks the symbolic resources needed to qualify as a patient. The request for insurance operates symbolically to demarcate the dominant from the marginalized. It's important to note that participants suggested that in the U.S., you are not a patient until after you supply

identification and proof of insurance, which speaks to the systematic erasure of subaltern identities who lack the capacities of being a patient in dominant health-related spaces.

As will be discussed later, the cost of service in the U.S. when it comes to health care tends to be so high that most working-class individuals cannot afford to cover basic services without the support of insurance. When it comes to PWP, this issue is even more dire as many of the participants I spoke to talked about working low wage jobs, which did not offer any insurance support. Nancy highlights the tension she experiences navigating this situation, saying, "if you are not healthy and you get sick, you will never be able to go get the help you need, you will never pay the bills, it's so costly, so costly, because you need health insurance, and when you are undocumented like myself, you can't get health insurance, therefore you can't even go to see a doctor because it will cost way too much." Nancy has come to recognize the interconnection between insurance and medical services as dictating the way health services are delivered in the U.S. She goes on to say, "you know how many years now I was supposed to go back to the doctor but I haven't gone, no way, too much." For her, the two are so intricately linked that she must avoid one because she lacks the other. Her comments shed light on the U.S. medical system as one that features extremely high service cost because insurance operates as a complimentary economic system to health services. For participants like Nancy, a lack of insurance makes it nearly impossible to afford any sort of care due to the limited range of employment her status affords her.

While programs like the Affordable Health Care Act (Obamacare) provided support for working class citizens and residents who were previously uninsured, it did not offer any lenience for PWP. Even programs like the Deferred Action for Childhood Arrivals (DACA) that offered protection for children without papers failed to create any avenues for coverage for these

individuals. Luke, a DACA recipient, shares a powerful story about his experience as a high school athlete who lacked medical insurance. Luke states,

I mean certain situation could really come about where you really must have insurance to stay healthy, for example someone could find out that they have cancer and if they don't have insurance you know, then what does that mean for them, it is possibly death, suffering you know. In my case, my personal experience, I had this happen to me in high school, I didn't have insurance and ahh, I tore my ACL, and because I didn't have health insurance I could not afford to get it fixed at the time, and that ended up meaning that my sports career was over, done, gone in an instant... the surgery was almost 25k which my family couldn't afford, I had a friend who had the same surgery and it cost him like a thousand dollars because he had insurance.

For Luke, the consequences for not having medical insurance in the U.S. can be demoralizing and extremely limiting. His story shows the range of bodies being affected by this bureaucratic structure which allows insurance to dictate the type of service an individual is afforded. His narrative sheds light on how PWP see the two industries as tied together and how they interpret their lack of ability to obtain medical insurance as a signal that they will not be afforded adequate health care. Luke's story also details the frustrations he experienced as he was forced to engage in a communicative environment where having insurance is a normative practice. It is challenging enough not being able to afford the care needed but he also has to navigate the communication about why he does not do things the "right way" like his friend. His anecdote highlights how health meanings are understood relationally and shaped through daily communicative interactions. Yet, PWP like Luke have to negotiate different health understandings than their citizen counterparts who tend to communicate more freely about their

relationship with the system. Talking about their structural limitations is a fraught process for immigrants like Luke because he must provide rationales for non-normative behavior to insulate himself from the potential stigmas attached to his identity, as you see in the next paragraph.

The feeling that not having proof of insurance would result in reduced quality of care was common among participants. In some cases, participants believed that their bodies would be judged by medical professionals if they were unable to provide insurance. "If you don't have insurance, you are probably poor," says Tim, as he believes this is how medical professionals tend to prescribe their judgements. Steve offers a more critical take based on his prior experiences, "because I am black, and I am an immigrant, I couldn't provide proof of insurance, all those things make me suspect." He sees multiple aspects of his identity as shaping the stigma he experienced, whereby a lack of insurance confirms his subaltern identity in the medical space. His experience is tied to multiple misdiagnosis of a blood-clot that emergency room physicians classified as acid-reflux. "Both of them (hospitals) never really checked me out, they saw that I didn't have insurance and looked at me and sent me away," said Steve. It was not until a friend recommended a particular hospital doctor that he got a full work up "and they tell me I have blood clot in my lungs, so the previous hospitals never did any of those tests." For Steve, his marginalized body coupled with his lack of insurance rendered him limited in the dominant hospital space. Steve's comments show how his lack of access to legal services also limits him from having a voice in these types of medical spaces. His misdiagnosis is not something he is willing to challenge (legally) due to his lack immigration status, which highlights how dominant (health) systems tend to silence those who lack essential resources. Steve's example connects to Spivak's (1998) notion of how subaltern groups tend to be muted due to structures that are designed to ignore the concerns of those who lack necessary resources.

Steve's experience ties into the last barrier of complexity that PWP identified within the U.S. health system which deals with trust and the belief that medical professionals are more concerned with the patients' ability to cover services as opposed to their health needs. Many participants believe that because the U.S. health system is so driven by capital, those who lack insurance or financial resources will not receive optimum care. Steve explains,

Well, if you don't have papers you are going to feel it in all areas, even in medical places, you can't get any Medicare, no Obama care, none of that so how do you survive, everything in medicine is high, and never get a discount or go on sale or nothing, you got a job and you probably get paid under the table so you can't get insurance, and you probably aren't making that much money anyways, that's why many of us are just here and get sick until we die.

Steve shares how challenging the situation is for PWP, as he has to navigate high stress, low wages, and a lack of social support while having to decide if a health problem is dire enough to risk interacting with medical institutions. The way this group understands their position in relation to citizens makes it impossible for them not to interpret the need to provide proof of insurance as a means of gate keeping. Steve went as far as to say some people die from this restriction because he also talked about his friend, who was also undocumented, that died just a few weeks before our interview due to an infection he developed. For Steve, he believes his friend would still be alive if he had insurance or financial coverage, as he was turned away from two different emergency rooms in the days leading up to his death. Alice shares a similar tale of death, "recently, a friend of mine died, practically because he did not have the money or insurance and he died. He went to the emergency room and they told the cop to take him out of the hospital and he went home and he died." Alice and Steve's stories shed light on how the

health disparities faced by this group tends to be pushed aside due to their lack of status. Their stories speak to the way subaltern histories and experiences tend to be erased or not registered by dominant groups, as both of their friend's death was marked as a failure to have resources (Dutta, 2007). Due to the complexity of the system and the various means of gate keeping involved, many immigrants do not consider the ambulance as a choice in dire situations. Peter suggests that, "the truth is some know but they are scared because they don't have an ID, for instance, back in the day when you went to the emergency room you didn't have to show ID, but now, you need an ID to be seen, unless the ambulance takes you." Peter suggests that calling an ambulance is a way to gain service without having to provide proof of insurance, but participants believed that the long-term consequences of utilizing such services would be damaging due to high cost. Steve and Alice's friends did not consider the ambulance as an option because they were already rejected and shamed by multiple emergency rooms, which culturally symbolizes a rejection by the entire medical system. This makes trust a challenge for this group, as they are constantly navigating the U.S. health system from a precarious position.

# Trust as Limitation

While the need to provide identification and proof of insurance functions as a major deterrent for PWP, these requirements also further communicated to participants a sense of disillusionment regarding medical ethics in the U.S. As will be discussed later, participants believed that because the U.S. health system is so economically driven, they found it difficult to afford trust in medical situations due to their lack of resources. Maxine says that if one visits the emergency room "you aren't going to get fully looked at, they will check your vital signs and tell you go to your primary doctor, which you can't do because you don't have money or insurance." While individuals discussed health as a human right that should operate outside the realm of

political rhetoric and posturing, they did not believe that this was the case in the United States. For them, because the medical system tends to be structured and designed like a bureaucratic business, participants interpreted the health industry as willing to ignore the human health needs in favor of profit. Marlene comments that "because the pharmacy have 10-15 brands of the same pills, the doctor is going to give the patient the pill that gets him the most money." Marlene saw the overlapping relationships of the medical system as greatly contributing to the high cost of service. Participants discussed how the American health industry is designed to over prescribe medication, recommend unwarranted consults, ignore home remedies and holistic treatment options to promote the business of continued pharmaceutical medication.

Being outside the dominant structure creates opportunities for this group to see beyond the ideological limitations that tends to govern the lives of citizens. This speaks to the critical lens that the subalterns need in order to navigate the boundaries of a powerful yet limiting system. For Angela, trust in the medical system tends to be a class-based issue, as the coupling of lack of insurance and low capital leads to limited care. She states, "you can't go to the doctor and get the help you should get, they look at you, you know, they may see you for a few minutes but the long term treatment you may need, you are not going to get that because you don't have the money." For her, because medical systems are so interconnected, just going to see the doctor does not provide much relief alone, so a patient has to be prepared for the additional costs and follow ups that may be needed to resolve their issues. In most cases, the PWP that I interviewed interpret referrals as a sign that things are not dire and that follow-ups are just as another expense they could potentially avoid. Kim argues that, "everything here is a pill, everything, even a little cold they push pill, so it's hard to trust them all the time." She mentions her distrust in the

medical trend that sees doctors support various pharmaceutical products to gain kickbacks and improve profit margins.

While participants stated that they believed they would be judged in medical situations due to their lack of resources, they also suggested that their mistrust in the American medical system is tied to the way doctors and medical professionals tend to overprescribe medication. Marlene articulates that "most of them are getting some kind of kickback for what they prescribe. A lot of these doctors have stakes in these (pharmaceutical) companies so they are basically marketing their own product to you the patient." Because Marlene grew up in a culture where home remedies were the norm for treating common illnesses such as colds, migraines, stomach aches, etc..., she interprets things like the flu shot and other medicines prescribed for these illnesses as concerned with profit and not health. Angela offers some insight on this point, "I know that going to the doctor and getting two pills is not the priority, it's not the first thing I think of, but because you are unable to get the help like you did back home, you are unable to get that sort of health treatment so you have to go with what they do here." For her, the cultural remedies she utilized back home are just as effective and they come without the baggage of a bureaucratic health system that carries heavy cost and potential backlash. Maxine supports her when she states,

sometimes these drugs is just, you know, money making, the heap of drugs they put in your system is just money making, you just go along because you're not the doctor, they are the doctors and you do what they say, but it's all a money making thing, the doctors, the pharmacist, the pharmaceutical companies, everybody.

Once more, the subaltern awareness is present in Maxine's comment as she speaks to the limited power she has as the patient. While she understands the traps and limitations of the system, she is

still subject to it because of her limited medical knowledge. For both Maxine and Angela, the trust that they afford in medical settings is due to the lack of cultural resources that they could turn to in order to maintain their health. In the next section, I will move on to discuss how cost and finances dictate how the PWP I interviewed tend to interact with the medical system. The notion of trust in the medical space is one that is connected to the capitalistic structure of the U.S. medical structure. One participant, Andrew, went as far as to say, "how can you trust a business that doesn't even let you see how much something cost before you decide." Such critical insights mark Andrew's awareness regarding the limitations of what is considered the world's most advanced medical system (Lupton, 2010). These narratives presented above show how the communicative structure of the U.S. medical system tends to operate rhetorically to frame a sense of inclusivity that is void of class-based assumptions. In turn, participants argue that while their status and lack of identifying information operated as a major barrier to seeking service, they would easily have been able to overcome those obstacles if money was no option. According to Angela, "Health care, everybody should have health care, and shouldn't have to pay so much for health care. Health care should not be just for the rich and famous, but it should be for everyone."

#### **C.R.E.A.M** (Cost Rules Everything Around Medicine)

While participants discussed the limitations and restrictions put forth by a bureaucratic health system as major barriers to them accessing health services, they argued that the high cost of care in the U.S. made seeking out service impractical. Because the PWP that I interviewed migrated to the U.S. for economic reasons, having enough money to cover routine medical procedures without insurance was a constant challenge. They saw the price system in the U.S. health industry as the most salient barrier to migrants gaining medical service. Francis went as far as to say that "all poor people suffer from this medical system, citizens, immigrant, everybody." He suggests that this is a class-based system and as such it is designed to offer the best and most complete service to those who can prove that they can afford such services. When asked to describe the health system in the U.S., Angela comments that "it's money, it's all about money," marking the capitalistic ideology that dominates western health practices. Such structural setups tend to render subaltern groups defenseless against the uncertainty of diseases and illnesses in the modern world. The limited resources that PWP have to navigate and the critical negotiations involved in maintaining their health needs is a testament to the creativity needed to survive beyond the margins in the United States.

## *High Cost* =*Work*>*Health*

When it comes to health needs, the PWP that were interviewed spoke about avoiding medical services altogether, either because of cost, or because of mistrust in the medical system, or the need to prioritize work, or due to a combination of two or more of these factors. Many migrants end up sacrificing their health needs because they are forced to put money first, and in some cases their health needs would drastically cut into their already low wages. Nancy agrees. She explained that she knew of someone "right now, right at this moment," who is not healthy; "they are diabetic and the doctor said they must try not to work too hard, to take time off, how is he supposed to do that, how does he pay his rent?" Evident in her narrative is a structural double-bind. As Nancy argues, to maintain his health, her friend needs to take time off work; but he cannot afford not to work if he wants to take care of his health. Being "kicked out on the street" is a constant worry, notes Nancy, unlike the "supportive" community back "home," who are more loving, caring and are willing to look out for their neighbors. As I explain later, solidarity plays a crucial role in the health and survival of undocumented immigrants I interviewed.

The need to prioritize work over health is a common trope among participants, as the precarity of many of their occupations makes it challenging to gain the time needed to address their health needs. Troy states, "it does not guarantee you anything, you coming here will not always work out for the best, trying to make a future, it does not mean you are going to make it because you do things at the risk and expense of your health." Due to their limited status, finding work is one of the biggest challenges faced by people without papers, which makes job security vital for this group. Andrew explains that, "when you are illegal here, you have to find a way to have a roof over your head, you have to work, because you can't just come here and live, you have to find some way to find work." As most participants migrate for economic reasons, their main focus upon entering the U.S. is to earn enough money to support themselves and family both here and aboard. Andrew continues by saying, "because you don't have papers, you are not paid for the value of your work, you are often underpaid, you work as a dog because even though that job under pays you, if you lose it, you don't know when you will get another one." The fear of losing one's job for any reason, even health related ones, makes it necessary for migrants to push their health concerns to the side at times. Angela shares a similar story to Nancy's that highlights the structural double-bind PWP tend to find themselves in,

I had a friend, she had high blood pressure very bad, and she was working and she didn't want to stop from work to go to the doctor and because of her lack of papers, she couldn't afford to lose her pay, so she didn't go to the doctor, she was thinking, oh, I have to pay so much so she didn't go and she end up having a big stroke, now she can't work... So it's real when you don't have insurance, when you have to work to get paid, you don't get days off with pay, and you can't stop because you have your kids and family back (home)

to maintain, so you just keep working, working, and in the end you end up hurting yourself.

Angela's story is just one of many that marks the health sacrifice that participants routinely make in order to survive in a capitalistic structure. As a member of this society Angela's friend has to put money first in order to maintain a footing in a resource-rich environment. Part of the cultural shift that many PWP face when they migrate to the U.S. is having to stay employed to maintain a livelihood. Nancy and Angela's stories detail how a lack of employment opportunity for PWP leads to continued health vulnerabilities that are similar to what they faced in their improvised home environment. The inequalities of access to employment and resources that participants face, often results in higher rates of morbidity among marginalized groups (Dutta & Kreps, 2013). For a few of the research participants like Nancy and Troy, the cost of accessing healthcare is intertwined with the precarity of their job situations. With their "illegal" label, undocumented immigrants, according to both Nancy and Troy, find it imperative to keep the jobs they have, because getting new jobs is close to impossible due to their inability to produce required identification documentation. For example, Tory said..." of course, because when you are illegal here, you have to find a way to have a roof over your head, and for you to have a roof over your head, you have to work hard..." He added:

You have to wake up early, come home late at night, the money is not enough, and you now if you miss one day of work you could lose the job, and you miss one month's rent and you are out on your own, so, if you feel sick, or if you are at your best, you still have to work. Because I see people who are out there going to work sick as a dog, and you have to keep going because you will lose that job, and you don't know if you will get another one, so that ends up being a lot of stress. You don't get time to just relax or to recoup.

In addition to direct and indirect cost-related structural barriers they face, several research participants said that visiting medical facilities was not their first choice when they became ill; the fear of being questioned in those spaces made it impossible to think of accessing such facilities as a first option. Many individuals, like Troy, shared similar stories of having to work through their sickness, and that due to the precarity of their occupation it was easy to prioritize income over their health.

Tim talks about how the type of work that PWP are able to get at times comes with health risks that are unavoidable. "Immigrants do all the high risk jobs, because you can be an electrician without papers, you can be a plumber or roofer, so you do a lot of labor, but something could happen at any time where your hand gets messed up or something, and then how do you pay such a big bill without insurance." Tim details the vulnerabilities of work that PWP face and how their risky occupations leave immigrants vulnerable to potential health crisis that they are often unable to afford. Francis shares a similar story of a time his occupation lead to an injury that could have been catastrophic:

When I first come up here, probably like a year or so after, I got this job working construction on the 95 highway, and we would work late at night. One night I was walking across a beam that goes over this ditch we made to store things, and I was really tired and it had been raining before, so when I tried to walk across the beam I slipped and fell, landed right on my back, bum my head and split my elbow open... the supervisor wanted to call the ambulance but I said I didn't want that, and they bandage me up and I went back to work.

Francis describes his construction job that featured plenty of health risks and the ease by which he chose to return to work versus seeking medical treatment. While this occurred quite some

time ago, it still highlights some of the risky jobs that people in his situation are forced to work without insurance. Francis, as a father of 2 children who were living "back home" at the time, was more concerned with getting a weekly paycheck to support his family than the damage done by his fall. Sandra makes a similar claim when she states, "before I had a child I never really thought about health like that, I was focused on making enough money to survive here." For Sandra, she "didn't have enough time" to think about managing her health as she needed to make enough money to afford a place of her own. The bootstrapping mentality that Francis and Sandra allude to show how these individuals are being shaped by the cultural ideology of the American environment despite their limited resources and restricted access.

The bootstrapping narrative communicates to immigrants like Francis and Sandra that they can overcome their current limitations if they are willing to work hard enough and make sacrifices, even to their health, as such metaphors are meant to capture the defining quality of American life. Serena talks about how her early days in the U.S. and how difficult her negotiations were as a young adult who came to the U.S on a student visa that expired before she finished her program. She explains,

I had to pursue a life so, the school part stopped because I couldn't pay anymore, so then I had to get employment, I'm going to say backdoor for lack of a better term, so you get your money, but that money you need to live, you need food, you need cloths, and incase you get sick you have to have money in pocket, so whatever it is that's going on with you, you have to manage. At the time I developed eczema, so I was here, I had to pay to see a private doctor, to pay for medication, so by the time you realize you spend all your time focused on trying to get money to keep up, so I never even got the time to think about going back to school.

Serena's narrative coupled with Francis' and Angela's are meant to highlight how limited employment opportunities leads to continued health vulnerabilities for this group. The high cost of medical service, coupled with risky jobs that provide no insurance, situates health as a vulnerability that is unique to PWP because they are situated in a communicative environment that markets healthcare as a business, not a human right. This connects to the American capitalistic logic that sees healthcare as a market that anyone can buy into if they have enough capital. In the next section of this chapter, I will discuss the cost of service as a disparity in general and touch on how the cost of service creates fears that leads to avoidance.

## *High Cost =Avoidance*

In addition to fears related to deportation, participants discussed the high cost of medical service in the U.S. as one of the main reasons why they avoided medical situations like emergency rooms. As discussed in the previous section, individuals spoke about working risky low wage jobs that did not provide insurance, so any medical cost they incurred would come from their pay checks. Pat reminded me that she "doesn't get to save money and prepare for emergencies like that," she just hopes and prays for the best. Nancy shares a similar response when asked if she had enough saved in case of medical emergencies, "wow, let me tell you something about how I feel, I honestly pray to god every day, I have to, I beg god to keep the city, I can't even imagine what I would do, I try not to think about it to be honest, I have to beg god to watch over me." She communicates a lack of control towards her health situation, whereby prayer is her only solace. For Nancy and Pat, their jobs do not allow them to save enough to cover already pricey medical services. Their limited capital resources means that they are left to hope that a medical emergency does not arise, as they would be unable to cover such costs. Nancy and Pat see medical services as a luxury that they cannot afford and hence, avoid.

Each participant talked about their experience and relationship with a pricey medical system as being a root cause for their avoidance. Karen claims that, "the cost needs work, I think we can do much better in terms of cost, like based on cost alone people will be less afraid to seek out a doctor for help, they will have the resources to stay healthy." She argues that a change in cost would greatly reduce the disparities faced by people in situations similar to her own. Peter offers support for Karen's premise as he states, "even if you do not have insurance, you should be able to go and get service without being afraid." As Karen goes on to explain, high cost comes with fear for her because medical situations tend to be unpredictable, so she is never sure if she has enough to cover what she needs. She comments, "yes, because fear is like, it means you try to stay away from going to get help because you know that the cost is going to be so much and it could be more, you don't know, if you cannot afford it, and in the end it could get you in some trouble." The only thing Karen can be certain of when entering a medical space is that the price of service will be relatively expensive, but she is unable gauge the cost of service before obtaining treatment. This makes it challenging for her to feel comfortable making decisions in this type of environment, as the fear of potentially receiving service that she is unable to afford makes avoidance the safest choice. The theme of fear will be discussed in more detail in the following chapter to highlight how high medical cost is incorporated in the fears that leads to avoidance.

Many of the PWP that I spoke with noted that cost and fear went hand in hand. The two are integral concepts for immigrants to consider before deciding to enter a medical space. Serena talks about this duo as having great influence over her decision making,

Yes, it's cost, the cost, even if you overcome your fear of being deported and detained, and you try and seek out medical attention, you won't be able to afford it, so it's almost

as if it would be better if you sat home and died of whatever illnesses, because my father is here in Florida and he can't see out of his right eye, but it's the cost, we cannot afford to get him the surgery for one eye (without insurance), if we lived in New York he could get the surgery on that eye for really cheap, that state offers subsidies for that surgery... but we can't just go to New York, it's not easy, we don't have that kind of access, so it is fear and cost.

Noteworthy in Serena's anecdote are the structural inconsistencies that tend to shape medical practices throughout the United States. While the cost of her father's eye surgery is extremely high in Florida, that same procedure gets subsidized by the state of New York. So while she lacks the capital to fix her father's eye in Florida, the fear of travelling hundreds of miles without papers creates a different type of obstacle in her situation. Her limited status, in this case, traps her into only exorbitant cost options, which has led to the avoidance of medical treatment all together. Serena's story is one that exemplifies the complex negotiations PWP tend to have to make when attempting to find affordable medical service in the U.S.

Kim goes on to explain how she is forced to view the medical situation in the U.S. through a capitalistic lens, whereby the amount of money she has available communicates to others her level of agency. She states that, "naturally, money makes you have opportunities that other people wouldn't have anywhere else in the world, because I don't think the health system will turn you away because you are not a citizen, they will treat you but the type of treatment you get will vary depending on the payment that you can afford." Kim explains that lacking status is not the actual danger in medical settings, it's what a lack of status communicates to medical professionals, which is a lack of capital. This ties back into the earlier discussion of how PWP tend to not trust that they would receive the best service due to what their status symbolized. Kim

sees herself as inherently marked in medical settings due to a lack of insurance and identification, but her restrictions and limitations are associated with her inability to pay for services. Shelly shares a narrative that supports Kim's point:

Well, money is big, money plays a big part, the fact that you could pay for something plays a big role in the decisions that an undocumented immigrant will make when it comes to health care, it really doesn't matter if you have documentation or not to get seen, you will get seen in the end, it's just how are you going to pay for it, so if you know that you don't have the money to pay for it then obviously you are not going to go there because you can't afford the treatments and medications long term, they might give you a temporary fix but nothing long term, you won't be cared for because you can't afford it. For instance, my dad had an eye issue, glaucoma or whatever, and if we had the money the issue would have been fixed already, but it is still not fixed today because we can't afford to do the surgery because he has no insurance because he doesn't have paper work yet, so money is a big part of it.

Shelly explains that her status only limits her to the extent that her money does. She has bought into the capitalist ideology that presents money as the solution to any and all social ills. While her status marks her as an outsider, having enough capital becomes the symbolic resource for overcoming such exclusion. Her narrative marks an important moment for future discussions about PWP that speaks to the intersection of class and status. While a lack of status places someone like Shelly in a subaltern position, in a society driven by capital, she theoretically could move beyond her subaltern status if she had resources in excess. Angela supports the idea that class factors into the access PWP are afforded in medical settings; she states, "I'm sure, President Trump's in-laws, they recently received full status. I'm sure if and when they were

undocumented they were privileged to go to any doctor they wanted because they have the money to pay for it versus someone who doesn't have the money." Angela communicates her frustration regarding the instrumental role class plays in shaping who is afforded access to medical services. America is unique because class is largely dictated by capital, so in theory anyone can elevate in class status (bootstrapping), as there are no innately elevated class of people like in a monarchy or like caste systems.

For participants like Ricardo, he does not believe that a country as powerful and diverse as the United States should reduce access to those with resources. Ricardo thinks that a country "as big" as the U.S. should do more in terms of creating equal health access. He cites "other countries like Canada, their health care system is wonderful, I feel like the U.S. can do so much better in health care, people should be able to go to the doctor and shouldn't be afraid to call the ambulance because it is going to cost them all this money." For Ricardo, America as a country has the resources and technology needed to offer the same kind of care as systems in socialist countries like Canada or the U.K. The freedom of health access he mentions could create possibilities for treatment for individuals like Steve, who recently suffered a blood clot in his lungs and have been dealing with the ramifications of a prolonged recovery. Steve says, "you know that blood clot I mentioned earlier that is something I am still having to deal with." A problem which has led him to incur hefty medical costs that he struggles to pay as doctors recommended him to avoid any strenuous work, which is a challenge for someone who has worked in construction for over 5 years. When asked how he makes sense of his situation, Steve explains, "well, it really cost so much and because of that I can't save any money and it makes everything have so much more pressure. Sometimes I gotta beg for donation to help out with medication from the church, friends, family members and anyone who is willing to help with a

small amount because it all adds up." In Ricardo's version of America, Steve does not have to resort to begging in order to support the continued care he needs for his recovery. Even as an immigrant without status, in countries like Canada and the U.K., Steve would have much greater access to the medicine he needs. This highlights the unique experience that PWP face when they reside in the United States, as they must navigate greater obstacles to health access due to the market logic that shapes the culture within American medical institutions. In the next chapter, where I discuss fear as an additional disparity faced by this group, I will revisit the theme of cost as it ties into some of the fears that participants discussed as leading to avoidance.

## **Reflections and Reflexivity**

Migrating is a challenging process that involves making sacrifices to be able to gain economic sustainability. One of the major sacrifices many immigrants make when they move from a less developed country to a global powerhouse is in regard to their health. For instance, individuals migrating to the United States might be unaware of the importance of buying health insurance towards "good" health (Dutta, 2004). While many developing countries might not have the same technological advancements as the U.S., they nevertheless offer health services without the need for insurance. According to Jun (2016), information about health connects with immigrants at a different rate when compared to citizens. As migrants, they bring their own beliefs, and normative practices about health with them, which at times clashes with dominant health beliefs and practices in the U.S. I notice and point to the disconnect that immigrants face when negotiating health in a dominant, unfamiliar health systems, such as the one in the United States. My research participants discuss their disconnect with the health system as being influenced by issues related to a shifting cultural environment, a complex bureaucratic system, and high service cost. Taken together, these factors help shape the way decisions are made by

people without papers with regards to engaging with the health service industry. In this reflections section, I focus on the challenge of finding the language to represent this group as a collective, additionally I offer an entry from my journal to highlight some of the connections between culture and structure I made during the interview process.

## Collective Ambiguity

One of the biggest challenges with representing a population as complex and diverse as people without papers is to classify them as a group. This was a struggle during the interview process and even more so during the data transcription process. The reason being that all the individuals I interviewed were not culturally from the same group. While they offered similar stories of struggle and creative survival, they nonetheless had different and varying cultural networks that were usually tied to their home country. During the transcription process it became clear that parsing out and highlighting how participants from different cultural backgrounds made sense of their situation could be a future direction for this project. Of the 25 participants I interviewed and recorded, 15 were from a Caribbean island (Jamaica, Haiti, Barbados, Dominican Republic); 8 were from South American countries (Brazil, Honduras, Peru, Colombia); 1 individual was from Africa (Egypt) and 1 individual came from Europe (Ireland). The multitude of cultural understandings and beliefs that makes up the research pool creates a limitation in terms of how to represent this population to an American audience. I felt this tension as individuals discussed their relationship with health and health systems in their home country. It became clear during the coding process that participants relied on their national cultural identity to make connections with others to help circumvent a dominant system. Even more importantly, participants talked about how they felt more comfortable communicating in their native tongue/accent which I interpreted as a symbol of trust.

With this in mind, I still believed that discussing this diverse group of cultural bodies as one group was important for two reasons. The first being the fear of over/underrepresenting certain cultural identities. As certain nationalities had more participants that others, it was essential to try not to position certain groups as the face of agitation or protest. I feared that any type of dissent or criticism made by this group towards the current administration could potentially lead to harm for this population. Secondly, it was extremely important to frame this group as subaltern, because they are conditionally erased and silenced in contemporary America, which meant that I had to present the collective as one in order to show how the process of being a PWP limits choices for people living without an immigration status. Despite their diverse cultural background, the similarities in experiences among participants reassured me that framing this collective as a group was the appropriate choice at this point in this research endeavor. I do not believe I would have been successful with generating themes if I did not consider this collective as a group as it would have limited the possible connections that emerged due to their shared status.

#### Considering Health Culturally

I see one overheating metaphor that explains how we can start to reconsider how humans are going about negotiating differences in what Eriksen calls a post-tradition society (Eriksen, 1998). Post-tradition suggests that as peoples' local traditions shift due to the rapid changes in their environment, they create ways to protect and sustain traditions (at times) through the management of outsiders. His idea of overheating is useful with regards to the complex challenges that are involved with immigration in the United States (Eriksen, 1998). Eriksen (2016) uses the metaphor of "overheating" to talk about globalization as accelerating social environmental changes. He highlights the friction that results between cultural groups as our social environments rapidly change due to things like immigration, mobile connectedness, and a drive towards technological advancements. Eriksen (2016) is concerned with the divide that emerges between the local and the global due to this fast change in environment, whereby, globalization has created the conditions that challenge local traditions and ways of being together. The questions then are: *What role does the health industry play with regards to overheated spaces? Do global health systems and practices operate as combative with local/traditional understandings about health? Do local meanings/understandings of health get erased due to a conceptualization of western health practices as the universal standard?* 

And more important, what does it mean to be in good health? The answer tends to be qualified by the location in which one looks to determine the meaning of "good" and "health." Culturally, we identify different symbolic markers as indicating whether something is good or bad, whether something is healthy or unhealthy. The historic practices and rituals that form a cultural understanding of what makes good health is embedded in the language used by a group to make sense of their surround (Burke, 1945). This is changing due to the accelerated changes to our environment and by extension to our cultural beliefs and practices. What it means to have good health in an industrial city; whereby pollution, poor air quality, large population areas that bring risk of contamination are factors that must be negotiated and managed in order to practice "good" health in such settings? If we juxtapose an industrial city with a farming community in the mountains, where air quality is great, pollution is low, but instances of physical harm are high, it becomes clear how locally-situated health meanings have traditionally emerged. So, what happens when the farmer who spent most of his life breathing quality air, living in small pockets which limits the spread of disease, and drinking water that has not been chemically altered,

migrates to an industrial city? How does such an individual negotiate good health given the drastic change in setting?

We live in a world where science is the driving rationale behind how we make decisions, and because of this some cultures have been willing to discard their old traditions in the name of scientific progress. I think health ideas were some of the first major globalizing projects that presented this idea of the "universal." In effect, many cultures were willing to give up on their cultural traditions regarding health care because scientific rationales of medicine were able to solve particular health-related issues. For example, in Jamaica in the 1980's, one of leading causes of death had to do with issues related to hypertension (Payne-Jackson & Alleyne, 2000). This problem affected mostly urban areas, but those were the most populous areas; so the problem was treated as a widespread cultural issue. Thus, when the government decided to subsidize the cost of hypertension medication to offer more affordable treatment options to urban residents; rural groups who were able to manage and stave off hypertension due to diets that were rich in foods that naturally combat high blood pressure such as beets, ackee and sour soap, accompanied by an active lifestyle, eventually moved away from these dietary practices as it conflicted with hypertension medications (Leavitt, 1998). In effect, rural individuals started to suffer from extremely low blow pressure levels, so the medical recommendation was to change their diets to incorporate a more balanced nutritional intake according to the food pyramid at the time.

The example I offered above is productive for understanding how the global and local become intermingled. When it comes to the context of health, I think this rings even more true, given the superior authority we have placed in a scientific understanding of health care. Universalization leads to simplification, and that is what is being offered through a universal

rationale of health (Lupton, 2001). Health as a practice is much more sophisticated and varied than any system can potentially achieve; it is a tradition from my understanding, which is intermingled with ways of producing culture. In fact, much of the current standards in the scientific view of health come from local traditions and practices, whereby this universal health understanding borrows from indigenous cultures and rebrands it in a way that fits a global audience.

Reflexivity becomes central to these questions because of how globalized practices have created the conditions for hybridity. Meaning that cultural mixing is a central component to a connected globe and as such our participation in creating hybrid cultural doings are not necessarily optional, it is a given. I mean, just take McDonalds as an example of cultural hybridity, where distant cultures all over the world have mixed with this American tradition due to connected global markets. McDonald's has in effect become imparted in cultures all across the globe, which in effect has created a mixture of American with whatever other culture (Eriksen, 1998). Reflexivity as a discursive move allows for paradoxes to emerge as part of how humans create knowledge and ways of knowing. I believe the immigrant's position within a globalized society that is dominated by accelerated change is paradoxical. The very systems that are put in place to control the inward flow of cultural knowledge and practices are also utilized to rapidly export our own American cultural beliefs; this in turn frames western societies as the epicenter of knowledge and commerce. For many immigrants out of status, movement is related to survival, and not being left behind; so legal status pales in comparison to economic viability.

I am very much of the stance that groups only exist due to border/boundaries, how they go about monitoring and maintaining those borders/ boundaries in a globalized society designed for rapid change is still a question of major concern. This idea aims to make note of how

globalization has impacted local cultural environments. One rationale put forth by Eriksen (2016) deals with the increase in immigration due to globalized structures, and how the movement of people has affected cultural environments, as well as group customs and traditions. He suggests that the mashing of local cultures with outside global structures in effect reshapes the cultural environment for all groups. Given the contemporary rationale of continued progress, it would be wise to argue that as a society we are moving towards greater rates of immigration and potentially increased national tensions with regards to who is allowed to enter, and influence a given cultural environment. The point Eriksen (2016) makes is that due to the globalized structures that dictate global economies, immigration and border crossings will only increase over time. In essence, how can advanced western societies reshape their traditional structures in order to better incorporate those diverse cultural bodies that are bound to enter the national space, and in effect participate in reshaping said space, if not we will continue to experience the frictions that exist culturally, politically and socially due to what Eriksen sees as a clash of new cultures and old structures leading to overheated spaces.

### Conclusion

This chapter focused on second research question of this dissertation project which asks what PWP experience as major barriers to accessing health services. The findings of this section highlighted the structural violence that certain subaltern groups experience due to their limited access to foundational systems in their environment (Farmer, 2003). Research participants made note of how a shifting cultural and structural environment influenced and shaped the way they made health related decisions. Due to a health structure that participants determined to be largely unfamiliar, overly bureaucratic, and designed to police who's afforded access, they argue that avoidance was an important strategy when interacting with the U.S. health system. Because

participants associated their ability to remain in the U.S. as important to maintaining their health and well-being, avoiding potentially threatening health structures was a way participants' discussed managing their health needs. Additionally, this chapter illuminated the structural limitations people without papers face due to the high cost of health care in the U.S. High health care cost, and low wages in a capitalistic economic system was something that participants identified as influential in their health decision making because they constantly had to negotiate sacrificing their health needs to meet their monetary needs. The following chapter details how high health cost contributes to the fears participants experience due to the stigma associated with their status, and their larger overarching fear related to deportation.

# Chapter 5: Nightmares of a Beautiful Dreamer: Fear as a Barrier to Health Access for People Without Papers

A few days before I started writing this chapter, I watched the 19th episode of the 14th season of the ABC popular television series Grey's Anatomy. The show is a medical drama situated in a Seattle teaching hospital that deals with contemporary medical issues while aiming to capture the inner workings of how doctors train to become surgeons. In this episode titled "Beautiful Dreamer," the issue of immigration runs as the focal point. The episode opens with an ICE agent requesting to speak with one of the surgical interns at Grey-Sloan Memorial hospital. The camera then pans to the group of 7 surgical interns, focusing on the two brown bodies in the group; Roy, who is a brown skin Indian looking individual and Qadri, another brown individual who wears a hijab. This sets the stage for the audience to create a stereotypical association of which surgical interns fit the mold of outsider, as the close-up of the brown bodies is followed by an intermission for the show's opening intro. While this is not a media studies project, I thought it would be productive to make note of the way people without papers tend to be portrayed in popular media, especially one situated in the medical setting.

The next scene sees supervisor Meredith Grey taking one of the surgical interns, Bello, into a private room to talk. Bello, who is of a very fair complexion, starts by explaining that she made a mistake in her treatment of a patient, as she thought this was the reason for the conversation. Grey proclaims that they do not have much time and that she needs to listen carefully and stay calm. Once Grey explains that ICE is looking for her, Bello's face shifts drastically. She says no 10 times, to which the chief of surgery (who had entered the room) asks with a grimace, "what is this about, are you undocumented?" Bello yells passionately, "no, I am a dreamer!" "I'm here under DACA, I am protected." Grey goes on to ask if she has kept everything up to date, and maybe they are just here to check her papers. Bello then shares a story of a friend who experienced a comparable situation and was later deported after speaking with an ICE agent. She tells them she must run and hide, to which Grey and Bailey (the chief) responds by telling her that running would make her "look like the criminal they think you are." We later find out that Bello immigrated to the U.S. from El Salvador when she was a one year old and has never been back since. She received DACA protection as a student but because she recently ran a red light after working late, ICE found her to be in violation of her DACA agreement. Grey is shocked because she "runs a red light once a month," so Bello's situation makes no sense to her.

While the surgical staff try to help Bello figure out a solution by distracting the ICE agent with medical exams, the audience is able to see her emotions while she panics about her next move. The episode ends with Grey securing another surgical position for Bello in Switzerland to work with one of Grey's friend. In effect, Bello voluntarily leaves the country by securing a visa for elsewhere. She acts on the fear brought forth by the ICE agent. I draw on this example of media's portrayal of people without papers because the pathos of the episode was steeped in Bello's fear of deportation, which is the focus of this chapter. While fear is a major component in how the participants I interviewed navigated their surroundings, the idea of voluntarily leaving the U.S. was not an idea that most of them entertained. The show tried to offer a critical argument against current immigration policies and while it was successful in certain areas, it ended up re-establishing fear as successful tacit for getting PWP to leave the country. This ties back into the earlier discussion about representation and the message such representative anecdotes communicate to citizens and individuals who are out of status. Bello's proclamation that she is not undocumented but instead is a dreamer conveys a prosocial message that portrays

the dreamer as being morally-grounded as opposed to the immigrant who lacks government authorization. The labels matter. Bello's fear does not reside with her dreamer status, it is the idea that running a red light made her lose her dreamer status and in effect become someone who is out of status in the eyes of the state.

Grey's Anatomy, in effect uses Entertainment-Education as a campaign strategy to promote the "good" immigrant and show the failure of the system to protect those good ones. Singhal and Rogers (1999), defines Entertainment-Education as media messages that were purposely designed to both entertain and to educate audiences about current issues or to create favorable attitudes towards a certain issue. While I cannot say for certain that this episode was designed to educate, it was rather easy to interpret an educational message operating along with the entertainment. According to Singhal and Rogers (1999), these texts are usually created to "improve cultural climate to become more conductive to the desired behavior" (p. 289). Taken this way, the audience can see how the show aimed to reduce stereotypes surrounding dreamers by juxtaposing them to immigrants without papers. In effect, the message presented in the show repositions those situated outside of a dreamer status as the true culprits of immigration law, who spoil it for those who are seeking to immigrate the proper way. Bello's willingness to leave the country on her own after violating her dreamer status shows that she is indeed one of the "good" ones that is willing to work within the system, even at the cost of her career. These types of media narratives about people without papers reinforce the stigmas surrounding this group as being a population of lawbreakers.

In this chapter, I will discuss the larger theme of fear among PWP as three sub-themes that connect with fear and how it affects health decisions among the people I interviewed. These sub-themes relate to navigating a culture of fear in the U.S., fear as health disparities, and fear as

a road to creative resistance. Additionally, I will end this chapter by setting up a discussion for the following chapter that deals with the board theme of community that connects to how participants enact agency to survive in the U.S. despite the restrictions and limitations they face.

## The American Dream as an Immigrant Nightmare

Narratives about fear often involved discussions about the American dream and how buying into that dream allows for individuals to move forward with a sense of hope. This idea that an individual can work their way up from nothing is something that many participants saw as a driving force when they initially arrived in the U.S. As discussed in chapter 4, the idea of the American dream can have dire consequences as participants discussed how often they would sacrifice their health needs to protect their source of income. Pat suggests that, "this is why we have a lot of prostitutes because some of us end up having to sell ourselves for money, because when you don't have any money, you don't have choices, and you can't get a job so the next best thing is prostitution." Pat highlights how the restrictions of work for people in her situation forces them into seeing sex work as their only option. She sees this as a reason why sex trafficking is so high in the U.S. because being here without papers forces individuals into very vulnerable positions.

For many participants that dream turned to disappointment quickly once they started to realize just how restricted they are in the U.S. due to their status. Participants' sense of disappointment stemmed from the realization that not having papers meant that their hard work and sacrifices could easily be undone. Their fear is connected to the idea that people without papers can only rent the dream, they are not able to actually own it. Troy talks about his relationship with the American dream, he says:

The American Dream causes one to make decisions that they normally wouldn't make. For years, millions of immigrants have come here relinquishing their homelands to chase this supposed American dream, they get this first in their heads that this American dream is real and because of that you are willing to put aside everything to try and do this. It works out for some who share their stories and continue that idea of the dream but for most that dream is a nightmare.

Troy shares his understanding as to how this ideological trope of the American dream does two things for immigrants like himself who are living in the U.S. without papers: first it motivates them to work towards a goal of upward social mobility, which is an extremely challenging task for individuals with limited resources. Added, this focus on upward mobility creates a certain among of stress as individuals like Troy try to work harder to overcompensate for their restricted access to work and social support systems. Beverly says that she "was promised a street paved with gold, one where everybody was successful," before she immigrated to the U.S., but her reality was one that "made you feel small and unworthy." Central in Troy's story and Beverly's comment is the fear that all their sacrifices would still see them fall short of their dream. A dream that is an influential factor in how participants make decisions about their health. The fear of failing to reach this American dream is one of the reasons why participants like Troy and Beverly are willing to choose work over their health, and why they are willing to avoid medical intervention until the need is dire. Hank explains that,

We do a lot of sacrifice because to survive you are so caught up in this idea of the American dream that you do whatever you need to do to survive, even at the expense of your health, you work 3-4 jobs, you don't have time to be a good parent to your children,

and you end up sacrificing your health by the time you reach, so this pursuit of happiness is at the expense of your health.

The pursuit of upward mobility is a common trope among participants I interviewed, one where sacrifices are common and the fear that those sacrifices will end up not paying off tends to lead to a high degree of stress. Hank's statement shows how he has internalized the communicative ideology of the U.S. without being able to draw on the structural and material support available to citizens. Andrew identifies with this point when he says, "unfortunately, some of us will never be destined to make it because the system is made in a way that has many traps." He speaks to a fear that is common among this population, whereby his hard work and sacrifice could end up with him being deported and left with nothing. His hopes encapsulate the fear that even if he does achieve his dreams, such as owning a home or car, he has no recourse to keep it based on the way the system is designed for people of his status. This ties back into the earlier discussion in chapter 3 that talked about immigrants consuming the same type of communication that are meant for citizens and the potential harm that comes when "outsiders" consume the same type of communication as the dominant public. It tends to lead to a type of structural violence against those in marginalized spaces because they are unable to interact with their surrounding structures in the same way others are able to (Farmer, 1999). Participants spoke about how this narrative of the American dream starts long before they arrive in the U.S. and because of that they are blindsided once they arrive due to the stress and fear involved with trying to work their way up the social ladder. Troy offers a critical take on where this idea of the American dream stems from and its cultural impact, he says,

I think growing up as a child and having relatives and friends who lived aboard, and you know probably because of the traditional history of colonial expectations of the empire,

in your head this idea of aboard is better; it is the heritage of our colonist history and mentality, so when we come here we come here thinking that this dream is a reality only to find it to be a nightmare of your worst fears. What we expected is totally different than what we experience, but you know others who can make something out of nothing, so you keep pushing.

Troy draws on the history of his birth nation to show how deeply rooted some immigrant's attachment to this ideological concept is, and how dramatically different the narratives are from his lived reality. He suggests that many immigrants arriving from post-colonial territories have already been indoctrinated with the idea that western beliefs and practices are superior to their own. This makes it easier for participants to be willing to leave their home behind to migrate to the United States. Karen shares a similar story about her experience of arriving to the U.S.; she says,

When I came to America, you have heard the stories about going to this foreign place and you think it will be perfect, haha, that made you want to give up everything to come here to basically start over and then once you get here your expectations change. I remember my first job I worked in someone else's house taking care of their kids all week and then come home to see my children on the weekends, and I could not help but feel sad, I think why did I leave what I had to come to this kind of prison system of work, it was like war, you are way more trapped than when you are back home.

Karen shares her experience as to how blindsided she felt upon arriving based on the narratives of America she grew up hearing. She speaks to the type of sacrifices she has had to make as a mother who is working towards this dream of creating a better life for her children, where she had to be absent to her own children while supporting someone else's. Karen's metaphor of the

American system being like a prison system sheds light on the traps that Andrew referenced earlier. She describes having to continue to work to gain enough capital to survive as being like a hamster wheel that many participants find themselves stuck on. Much like Troy, Karen's narrative highlights her fear that her status as someone without legal status in the U.S. means that she will have to continue making these kinds of sacrifices to survive in this country. For her, going back is not an option because she was willing to "sell everything I had back home, including my house in order to chase this idea of a better life," Karen explained. Situations like Karen's create the condition for migrants to internalize a sense of inferiority or subalternity in relation to the dominant order, what Farmer (1999) describes as structural violence, which is connected to a sense that she is doomed for failure in a space designed for success (Dutta, 2017). The irony lies in that this metaphor of the American dream becomes a motivating factor for people without papers to remain in the U.S. despite all these fears. This ideological trope runs counter to the policies and political rhetoric that have been used to generate fear among this population, whereby the American dream includes overcoming your fears.

Kim feels a similar dissolution about this idea of the American dream that brought her to the U.S., she says, "so once you get here you realize that the American dream is not all that dreamy, or it's not really built for me. We laugh but at some point, that dream becomes more like a nightmare." The nightmare Kim speaks of stems from the multiple avenues of fear she must deal with as she tries to survive as a human in the United States. Kim, Troy, and Karen all talked about the multiple disappointments they experienced since immigrating to the U.S. and they suggest that their disillusion about their ability to succeed in the U.S. leads to stress and fears related to failure. They highlight one of the key features of the culture-centered approach, which

speaks to the way structures in advanced countries tend to limit the class movement of certain cultural groups who lack valuable resources (Dutta, 2017).

While the fear of deportation tends to be the most pertinent and the most talked about aspects of the pathos that individuals like Troy and Kim experience, the fear of making multiple sacrifices without anything to show also looms large among participants I interviewed. In addition to this, participants also talked about more immediate fears they experience in their daily lives that in some way connects back to the central fear of deportation. Marlene postulates that, "as far as I am concerned the fear over immigration is far more important than health for folks because if you get legal status then you can get all kinds of access." Fear was discussed as a major barrier that limits participants' willingness to interact with official medical spaces. In the next section, I discuss the fear participants experience as a health disparity and the limitations that stem from the personal challenge of trying to overcome one's fear to remain healthy. This is followed by a discussion relating to the fear of deportation and the effect such emotions have on decision making when it comes to seeking out medical service.

### **Fear as Health Disparity**

Participants suggested that they were fearful of going to seek service and not having enough to cover the cost without insurance; fear of being questioned about their accent; fear of not having requested documentation; fears that their medical information could later be used to track them down; fears that they would need prescriptions or a second visit that they could not afford. Even such things as taking public transportation to visit a doctor runs as a fear that creates disparities for this group. Along with the fears of deportation that people without papers face, they must also operate in fraught spaces knowing they have no means of legal protection.

In effect, PWP are aware of their lack of legal support, which makes it difficult to go against what is communicated through official channels. In addition to the structural limitations that are generated through written policies, participants must also negotiate the political rhetoric that have shaped their recent cultural environment. Nancy explained,

Oh yea, the things he says, that alone is killing people, yeah, because even the other day, these people, ummm, what is the name of these people with the large writing on them, ICE, the ones that were going around taking people off the bus, and I travel on the bus, and I realized that when it comes heated like that, Haitians who I use to travel with never travelled on the bus anymore, but after Trump, no, they were quite even when they did take the bus, silence, you couldn't tell who was from where anymore. First people use to talk in their native language and be ok, now everyone is just hiding.

Nancy's comments explain how many participants tend to react when faced with the fear caused by dominant anti-immigrant discourse. Her story indicates that hiding from these structures and avoiding them all together is one of the only avenues left available to people in her situation. In the same way that this group avoided taking public transportation after the president's policy was announced, they also became more avoidant of health spaces as well. Maxine shares why she finds medical spaces unsettling. She says,

My fear of going there (the hospital) it starts with giving information because you have to give information and when you give information because of what is going on currently in the country that information can be used against you. I mean lets say they really and truly want to get me, like I committed some crime or something, they will go into the health system, I don't care what kind of laws doctors tell you about, they can go into the health system to find

out who are the people that visited that hospital without paper work, or foreign passport or id and they will get that information.

Maxine's comments connect back to the earlier discussion in Chapter 4, which focused on how the need to supply information in medical settings operates as a deterrent for people without papers. Her comments also speaks to the issue of trust in the medical setting, where immigrants are not convinced they are protected under American laws written by and for citizens. This speaks to the way subaltern groups tend to be silenced by dominant populations through the writing of laws and policies that exclude their cultural perspective and structural limitations (Spivak, 1989; Dutta, 2008; Pal, 2013). For Maxine, she understands that there are HIPAA laws in place to protect patients' information, but she does not subscribe to the idea that those laws will protect her as someone who is out of status. The Grey's Anatomy example presented earlier, where Bello's information as a DACA recipient allowed ICE to find her due to a traffic violation, offers a representative anecdote of the lack of protection afforded to this group, even those with "protected" status. If future neuro-surgeons who are out of status are being persecuted by ICE, then no one out of status is truly safe. Maxine fears that there is no legal protection for her as someone who lacks immigrant status, which makes it hard for her to have trust in this kind of health system. Shelly supports this argument by saying,

the older set of people if they don't have papers, they don't go to the doctors, period, they don't go to the post office, they don't give you any kind of information that might lead back to them, even though it probably won't affect their status, they won't go because of the fear that any information they give to the doctor can get them deported, and I mean a regular doctor, not just hospitals.

Being situated in a neoliberal-bureaucratic system while lacking essential resources can produce significant health disparities for any group or individual (Basu & Dutta, 2011). The way groups/ individuals respond to such disparities has the potential to shed light on the limitations of a system and offer insights as to how marginalized communities interact with available structures to forge meanings and pathways to health and well-being (Dutta, 2017). According to Shelly's comments on the "older" population, they have learned to navigate this system by keeping their information close and limiting who they afford trust to. This "older" population has allowed their fears to become a guidance for avoiding potentially harmful structures and situations. We can assume that this "older" population has experienced many changes to the system to the point where they have little faith that their information will not be later used against them. It is common that many people lacking papers interpret their well-being as connected to their ability to remain in this country, especially when we consider someone like Karen who gave up all her belongings to migrate to the U.S. Thus, avoiding health institutions was one way for participants to manage their well-being, while simultaneously having to manage their own health in order to balance the equation.

When it comes to health needs, most of the people out of status that were interviewed spoke about avoiding medical services altogether, either because of fears related to having to give information that could work against them later, or fears related to cost, or fears related to taking time off from work that could lead to losing their jobs or due to a combination of these factors. Nancy's anecdote of when her son became ill sheds light on this. She says,

He got pneumonia and I didn't take him to the regular clinic, or go to the pharmacy to get medicine, so I took him to a private doctor that people told me about, and pay him, and that help, I did not want to go to the emergency room, because I have a fear of going

there, even though I am not sure that I need to be afraid, I realize that I can go there and because they can't turn you away, because it would be unethical if they did, I still don't go there, no, because I do not want them to get my information. You know once your name goes into that computer it never comes out, never.

For Nancy, the stress of going to an official medical space like the emergency room is paralyzing; she cannot overcome her fear that her information will be used to hunt her down. Even though she recognizes the ethics involved with medical treatment, she is still not comfortable taking such risks. Nancy subscribes to the logic of the "older" population that Shelly made note of earlier in that she is unwilling to trust places like hospitals with her information because it could later do her harm. She is more willing to go to a private doctor that has been approved by a friend who shares similar experiences. As will be discussed later in this chapter, participants rely heavily on close cultural networks for information about how to best navigate the health system to gain medical treatment when situations become dire. Marlene supports Nancy's stance on avoiding medical spaces as she states: "there are a lot of us out here like this, can't, won't go to the doctor, a lot of us here fearful, so yes, I couldn't imagine seeing an illegal immigrant going to the doctor, I hardly hear of such things, they sure not going to the hospital." Marlene also subscribes to the idea that official medical settings like hospitals are not for people like her who are out of status. From a Communication Studies perspective it is fascinating the way Marlene tacitly ties the role of representation into the fears she experiences, which connects to the discussions presented in Chapter 3. She references not being able to see "illegal immigrants" take this action, which she immediately follows up with by saying she "hardly hear of such things," indicating that the communication surrounding this group is one that does not represent this possibility. She shows a dramatic disidentification with the hospital scene, one

where she cannot even imagine being in that setting without it seeming odd and out of place. Her story speaks to the way structures tend to communicate closures for those who lack the viable resources to properly participate (Dutta, 2008).

What was clear among this group was that they constantly avoided medical systems due to a multitude of fears that stem from the policies and political discourse used to frame them as deviants. Participants not only described an ultimate fear of deportation, but other more immediate fears that stem from their lack of access. Maxine offers an example to illuminate this point:

I know friends who are still here who are undocumented, and they are sick, they can't get better because they can't go to the doctor, some of them are just scared to go because they don't have papers, they don't have a social security number, and the fear that the doctor might look at them or look down on them, call ICE on them, immigration on them, so some of these things just make people stay home and possibly die.

Maxine uses her friend as an example to show the effects of stigma on this population and how it limits the choices they see as possible. Maxine's friend's fears are connected to the idea that their subaltern status would see them looked down upon and possibility discriminated against in dominant medical spaces. Once again, stigma is part of the tropes of representation that we see in popular media and hear in political discourses when talking about immigrants who are out of status. Hank suggests that this administration is "just creating policies to make us afraid and that make people stress and it's not like we can get mental health treatment or nothing like that." Hank brings up a critical point about the effects of the fear he experiences and the way it creates added stressors for people like him who are without the resources needed to effectively manage stress. Pat exemplifies this point by saying,

Like my friend, she got pregnant and she didn't have papers, but she got pregnant and she said she never went to the hospital until she was 6 months pregnant, and I'm like is that safe, and she says maybe not but I don't have a choice, I have no insurance, I got no papers, so she wasn't trying to do all that, because going back home was not an option for her. So that's what she did, she put it off until she was 6 months and then she went to this doctor, thankful the baby came out ok, so it's always survival.

Pat's comments shed light on how inhumane fear mongering strategies are and the way it drives the belief that people like Pat and Maxine's friends are not welcome in dominant medical spaces such as hospitals. Meaning, the added stress of entering a potentially harmful environment tends to make avoidance the safest choice. For Pat's pregnant friend, the best way to protect herself and her baby was to remain in the U.S. which meant avoiding health situations was the most logical choice, even if that involved certain health risks. Karen, when discussing the increased use of ICE to deport immigrants, highlights the increased fears related to seeking medical treatment, she says,

Oh god, yes, it (Trump's executive order) really does affect us, because now, it is just going to be worst with fears people have and even to go to a doctor is fearful because you are afraid to take the bus there, or that something might happen while you are there so in many ways you will do whatever it takes to avoid these situations, people are turned off. Karen's statement captures the complex mix of fears that participants experience when thinking about seeking medical service. She highlights the layers involved with making these decisions and shows that even the journey to the doctors can be riddled with anxieties. As someone who has lived in the U.S. for over a decade, Karen cites Trump's executive order as a watershed moment for people out of status because of the way his policies and rhetoric has been successful

in its aim to create fear among this subaltern population. She states that, "I don't even things were this bad after 9/11." According to Steve, the biggest roadblock faced by this group is "definitely the government, all the laws and things they make is to keep us in fear. Because one time you could come here with a visa and it expires and easily find a way to get your paperwork but not anymore, because everyone knows they are out for us now." Steve shares Karen's assessment that government policies have been created to elevate the fear people like him already experience daily. Steve suggest that these strategies have cut out some of the earlier avenues he had with regards to gaining more access to services. Participants, like Steve and Karen interpret these kinds of fear mongering practices as the government trying to put pressure on them to return to their home country willingly.

Despite this, the hope of immigrants who are out of status voluntarily returning home due to these increased fears is not something that participants identified with. Shelly notes,

Most immigrants will not self deport, at least that I know of, you know, why take the trouble of being here, possibly having children here, and then self deport to what, to where, you left for a reason, so your situation might be bad here, but you know what you are going to is worse, so you would not leave the frying pan to go back into the fire, so until they catch you physically, they might catch but they also couldn't and all you have to do is wait and hope for government to change, not hope they will change so, you just have to wait it out, that's what most of my co-workers have said have said, you just have to wait it out. He is going to leave.

Shelly explains that due to the challenges involved with migrating to the U.S., along with the sacrifices needed to survive in the country once participants arrived, not to mention the economic limitations of their home country, she among others did not see how returning home at this point

would improve quality of life. Instead, participants found ways to enact a survival strategy that is built on local community connections and creativity. In the next section I will briefly discuss some of the ways participants have been able to navigate their structural limitations and personal fears in order to find ways to maintain their health and wellness in the U.S.

#### Navigating A Culture of Fear

The fear of deportation still looms large in the minds of participants, as it is this central anxiety that supplies all the other avenues of fear they experience. According to Kim, "the fear or superstition or whatever you call it are more than what Americans realize makes up an illegal immigrant, I want to say, it's central to of how we live." The issue of fear creates major health vulnerabilities among participants. Says Sandra, "the fear of being deported, I see that as the number one reason why many undocumented immigrants stay unhealthy, and why they avoid seeking any kind of preventative care." Without this fear, Shelly believes that many people who are living in the states would be more apt to seek treatment despite the high cost of service because "take that fear away and you get a more accurate read regarding the health of immigrants." Shelly sees the anxiety related to medical spaces as a deep-seeded personal barrier that limits the trust that people in her situation can afford to give. This fear once again connects to the previously discussed ideas related to the American dream and the idea that participants' sacrifices will end with them being in the same position they started, or worse. Peter explains that the anxieties related to deportation simply as "who wants to go back to the same thing that they tried to run away from in the first place." He sheds light on the attitudes most participants carry with regards to why the possibility of deportation is so debilitating and why he must take drastic measures to make sure he avoids any situation that could potentially lead to this outcome. Shelly captures this point fully when she explains that,

The fear of being sent home, the fear of being deported, makes any decision an immigrant makes, I want to say, makes them umm, even if you do know that something is wrong, even if you do know that I need to get this done medical wise, or I need to see a doctor, just the thought that they could use your information to send you back, will not make you go, so until that fear is removed, nothing can be done that will significantly help undocumented immigrants stay healthy.

Shelly comments on the crippling effect of constantly having to navigate a dominant space that reproduces these elements of fearfulness. Her experience speaks to the idea that immigrants must keep this fear in mind and embodied it in order to protect themselves in the United States. She must allow her fears to guide her instinctually to avoid situations that could be damaging or lead to deportation. According to Shelly's earlier comment, take this fear away and the well-being of individuals who share her immigration status would see improved health outcomes regardless of high costs. Pat confirms by saying, "yes, the cost of health care is high but I promise, if immigrants know what the price is and they know that they won't be questioned about their papers, most immigrants I know will find a way to work and get that money, give us a chance and we will do it." This is a point that was also supported by Serena who says, "if worst case scenario, there is no way to give us free health care, if there is a price sheet how much things cost, if we know that going in, and that we won't be harassed, most immigrants will work 7 jobs if they need to make sure they save to have this money." Pat and Serena suggest that because migrants like them are familiar with how to make sacrifices and be resilient they would be able to access better health services if they were able to avoid the anxieties related to deportation. They argue that the stress of not knowing much services are before entering a medical space also heightens the anxiety they experience because they are unable to prepare beforehand.

It is only when people without papers face major health crisis that they feel compelled to seek out medical treatment. In such cases, their lack of trust in the medical system leads to seemingly deceitful ways of interacting with the system. Pat said,

sometime like, you might use some else's identification to go to the doctors, like if so looks like you, like sometimes you have to get crafty, (.), just to go see a doctor, so sometimes when you are illegal, you have to be like let me do something illegal, because, there is, I don't have any other, choice, and I don't want to die.

For this group to be able to survive in a space that is structured with dominant anti-immigrant discourse they must find creative and strategic ways to manage their health and well-being, similar to what Pat describes. Beverly reflects on how things have changed in the 25 years she has been in the U.S., where she could have more easily access the system without detection. She says,

For sure the time period was much more welcoming then, because I remember I had a terrible stomach pain for days, and I went to one of the biggest hospitals in New York, Belview, and I just went in and tell them my name, made up a social security number, they never checked that, gave them an address, I lived at 1915 union street so I gave them 1519 union street because I knew someone living there. I just gave them that information and then they called me in to see the doctor, you get your medication and go home, and they send a bill in the mail. Then I just tell the person at 1519 that I wrote the wrong address cause I was sick. Now you can't do that, now you have to have picture ID that matches the social security.

Beverly's story is one that shows the lengths people in her position must go through to obtain the treatment they need when things get dire. The creativity she invokes to obtain service in the past

is no longer possible with the current revamped medical structure, set to enact violence against poor bodies, so she has to find new ways to get treatment should it come to that. According to Beverly, she was willing to take the risk to supply an address because "if you do not pay, they will track you down, so you better find a way to pay." This creates added stress for this group because their aim is to avoid detection, but in extreme cases they must circumvent the system in order to access the care they need, which ironically makes them more vulnerable.

Serena and Sandra also note that at times not having papers forces individuals into a corner when faced with medical emergencies, whereby they must consider breaking a law to gain access to service. Serena states that "sometimes someone has the same problems you have, so you just pay them for some of their medication even though it wasn't prescribed to you, it's still better than nothing at all." Resorting to these tactics are some of the only avenues left for people out of status, whereby they risk further health complications because they are forced to find solutions outside of the constraints of the system. Sandra goes further by saying, "when I got pregnant, I had to find a way to get insurance to get checkup, so once my boyfriend found someone who could get me a (fake) social security it changed everything." While participants stressed that they did their best to avoid breaking the law, in situations like Sandra's breaking the law was a way to obtain the relief they required.

Troy and Francis share the same attitude regarding the need to navigate the system in diverse and creative ways. They mention that they have had to make difficult choices on whether to break the rules to support their health or suffer the consequences of not receiving treatment. Troy states that, "sometimes it's hard not to listen to the other voices that are calling you to do something illegal to survive like selling drugs or stealing, you get so desperate that you have to consider anything as a man with a family." A point Francis understands when he shares that,

"sometimes things get so bad you wonder why I don't just go and sell some drugs because things can't get much worse." For Troy and Francis, the thought of engaging in criminal action is symbolic of the desperation they experience as part of their masculine identity, whereby their ideological need to act as a provider creates varied levels of desperation. According to Troy, "you just can't do things like that because you will prove them right... that you are a criminal." He echoes the words Grey told Bello as she described her plans to run. Maxine mentioned that "the medical service is more advanced in the U.S., so attempting to return home for treatment would be a waste of time," so she must find a way to seek out health services in the U.S. For Troy and Francis, finding a way around their limitations was the only real option, selfdeportation was never an option in their mind. As I discuss in the next chapter, group solidarity and ideas of community are valuable resources that help people without papers gain the treatment they might need.

## **Reflections and Reflexivity**

Globalization creates the need for mobility, it creates a fluid environment that forces people to move through diverse cultural spaces. This is very important to keep in mind, with connected systems, faster transportation and economic systems that depend on each other for success, these overlaps will most definitely create the need for growth in immigration. In fact, even how centralized economies are becoming, whereby five countries are responsible for the majority of world's economies (Kreppmeier & Ankel, 2019), I would say that for certain groups to survive migrating is the best and quite possibly the only option available. Now, what we need currently is not more fear based strategies but an attempt to get ahead of this on a national level by creating policies that redirect the flow of immigration into less overheated spaces (Ericksen, 2016). As in, how can immigration agencies help get immigrants already in the country in search

of work to maybe look for jobs in North Carolina, as opposed to New York. This speaks to the notion of Super-Diversity, where former closed off cultural environments are now seeing rapid increases in different types of people, which suddenly shifts the traditions that have previously associated with that environment, thus spawning a cultural fear related to change (Eriksen, 1999). The historical strategy has been to tell all the people who do not look like you to leave, but that will not work for much longer due to the globalized structures we are creating that speak across national boundaries. We are also seeing the types of policies that limit immigration based on national origins, which is also a way to manage and direct the flow of immigration using fear, which hardly ever works (Eriksen, 1999).

The friction that emerges between ethnic groups who occupy the same space due to the accelerated movement of people across the globe has reshaped our ways of interacting with the idea of the "local." There is simply no more local to speak of. The increase in migration and immigration has changed the way groups do togetherness, and in some areas has created the need for rituals of solidarity in these overheated spaces to protect vulnerable groups. Mobility does not obliterate culture differences and it does not obliterate inequality either, but it does offer us the opportunity to see inequalities like never before (Eriksen, 2016). Central to this idea of overheating is how groups attempt to hold on to traditions on the local level, while ideas of progress and connectedness which are central to incorporating new ideas and ways of engaging with the world. There is a need for immigrants, even the immigrants without papers, in industrialized nations, especially in a globalized society, and as such officials are looking to regulate the environmental landscape by trying to gain more control regarding who is allowed to enter. The contemporary social issue here is that governments have turned back to fear as their base strategy for trying to get this done. When you consider President's Trump's agenda of

building a wall along the southern border of the United States, he is symbolically highlighting this move towards managing which bodies are allowed to cross into the U.S. and influence its ideological landscape. This is one way to manage the cultural/ideological environment, by clearly symbolizing an attitude of exclusion, while still presenting a globalized structure that economically influences the rest of the world. So, I would say that we are moving towards greater rates of immigration for groups that are displaced by said global economic structures. And those groups are left to deal with the anxieties that accompany entering a space where the dominant group feels similar anxieties to them because they have been conditioned to fear those who are seen as deviant outsiders.

I think current conversations about people without papers has been one built on friction. Probably perpetuated through polarized political discourse, but that's just an opinion. Every society has its way of being closed, it is the act of exclusion that allows for a society to be a society. Structures are designed to have closures, communicative structures are no different than regular structures in this way (Eriksen, 2016). I think this also refers to the notion of Super Diversity that I mentioned earlier, which is a society where people can no longer take community for granted (Eriksen, 2016). Super Diversity creates the conditions for re-centering community as an important making, whereby our identities feel safe and comfortable within the borders of said community. Like a fish being unconcerned with water while in it, once the fish is removed from water it at once becomes aware of the value of H2O (Eriksen, 2016). Identity is a scarce resource when we feel the threat of a rapidly changing space, when the communities that are responsible for shaping our identities are changing beneath our feet. I think that is what we are seeing when it comes to the treatment of people out of status, a fear associated with unknown agents imparting change to local traditions, customs, environments, and economies. As Americans, we

tend to focus squarely on the threat, and not the potential benefits that arise from the mixing of cultural outsiders. This leaves those who are here without access to have to manage both sets of fears, theirs, and the fears of American citizens.

## Conclusion

This chapter focused on the theme of fear as a health disparity that participants must personally overcome in order to be willing to engage with dominant medical spaces such as hospitals. Taken together, the findings regarding how fear impacts health decision making for people without papers presented in this chapter suggest the need to look beyond aggressive immigration policies that aim to induce fear among this population with the hope that immigrants will voluntarily return home due to said fears. In addition to reforming immigration policies that restrict access and promote a narrow understanding of why people choose to immigrate and live in the U.S. without papers, it is important to look at the role communication plays in fostering and reproducing personal fears via public discourse. Participants discussed their fears related to with deportation as influencing their need to avoid medical spaces all together. They also mentioned more immediate fears related to losing their job for taking time off, fear of being stigmatized in medical spaces, and fear that they would not be able to afford the medical treatment they received. However, participants also suggest that the fear they experience forces them to be creative in the way they navigate the health system when in need of care as will be discussed in the following chapter. The next chapter attends to the final research question of this project which ask how people without papers support their health despite their structural in access.

#### **Chapter 6: Community: A Silent Network of Resistance**

Agency refers to a cultural group's ability to react and respond to shifting stimuli in their social environments (Dutta & Basu, 2008; Dutta, 2016). To be an agent is to take part in everyday acts in a manner that highlights ones' awareness of the structural elements impacting choice, and to navigate the limitations of a structure in nuanced ways (Dutta, 2007). Despite the structural limitations and inequality of access to health that participants face they were still able to find ways around these closures by relying on their shared experiences and knowledge. Given the added personal restrictions related to the fears people who are out of status experience in their day to day life, having a supportive community network that shares or has similar experiences is essential for their survival, according to all the participants I interviewed. Shelly understands her community, "as they biggest reason why illegal immigrants are able to stay here, it is our backbone of support." She speaks to the multiple ways people in her close circle have leaned on each other to make ends meet and deal with some of the challenges that come with being out of status, particularly those associated with accessing health care.

When presented from a culture-centered perspective, agency operates as a marker for understanding structural inequalities and ways to potentially reduce such inequalities by listening to the experiences of those who are already involved with such tacit negotiations (Dutta, 2007; Dutta, 2008; Dutta-Bergman, 2004). Meaning that, the voice of authority with regards to understanding how complex social structures negatively affect marginalized groups should come from within those cultural spaces. In this instance, participants highlighted how they enact agency when dealing with issues that stem from them being out of status by turning to their

support structure. The theme of community broadly encapsulates the multiple ways participants discussed how their support systems helped them maintain their health and wellness in the United States. This section related to the theme of community has been organized into three sub-themes which talks about community as subaltern solidarity; community as a source of wellness and health information, and community as silent networks of resistance. While it is important to note that participants did not all share in the same community, as cultural connections are also important for keeping these collectives together, participants none the less stressed that they would not be able to survive and meet their health needs in the U.S. without such support networks.

### Subaltern Solidarity as Survival

For survival, being healthy and having access to healthcare are essential. Research participants mentioned the multitude of ways they negotiate health in terms of the solidarity they experienced with other individuals who are out of status. "I was blessed for the support I got from so many people who understand the situation. Just knowing that so many (people) were looking out for me and cared for me really gave me strength," Kim explained when discussing her pregnancy. She says that the solidarity she experienced while being pregnant without papers was one of the main reasons why she was able to remain in this country. In this instance, solidarity refers to the support people without status receive from others who have shared similar experiences (Dutta & Pal, 2010). Participants indicated that most of their health needs are met due to the information and emotional support they receive from others who have shared similar struggles.

For immigrants like Nancy and Beverly, they were willing to migrate to the United States because they knew they had a support system to help them navigate their new

environments. Nancy offers an example to highlight the importance of her support system; she says,

Boy, it's good, really good, it's good to have a community of people. It's good because people understand your situation and because they understand they help you, they will reach out and look out for you and give you the support you need, because they know. For example, when I first came there was a lady who looked out for me and my family so much, I couldn't have done it without her. She found us jobs, did everything to help get us on our feet because she knew we came here with nothing; she even wrote to people to ask for support for me when I was out of a job, so it is good, very good, we needed to have that sort of support.

Nancy's example speaks to some of the direct and material ways people in her position go about supporting each other. She pins her ability to survive in the U.S. on the support she received when she first arrived from someone who she says she "barely knew her before I came up." The theme of solidarity was common among all participants that were interviewed, whereby they attributed their ability to survive in this country to the material, psychological, and emotional support they received from their cultural community. Troy explains that he feels a certain level of responsibility to give back to those who share a similar struggle to him, he states,

It is a great joy to be able to be a source of motivation and encouragement to the community, especially people who are from the Caribbean diaspora, there are people who I engage with every single day who have issues with their status, who live under the radar, so when you interact with those people and they are open with you about their situation, you now have to use your personal experience to motivate and encourage them and help them find ways to survive because someone did that for me.

Like many participants, Tory takes pride in his ability to help other immigrants who have yet to find their footing in the United States because he had a similar support structure when he arrived. He speaks to the cultural factor that allows for some of these connections of solidarity to emerge when he mentions the Caribbean diaspora. He also originates from the Caribbean. Participants talked about it being easier to identify with people from a similar cultural background because they share the symbols and rituals; their shared ways of communication allow them to feel a sense of unification that tends to create ease which is uncommon in their new setting. Participants like Peter and Luke talked about how important accents are in allowing them to feel a sense of safety and let their guard down. Peter explains that, "when you hear that Portuguese accent, you already know that people will look out for you because they know where you came from and why you are here." The communication rituals that are familiar to individual's cultural make-up becomes one of avenues that participants used to forge connections and build local support networks when they first arrived at the U.S. These cultural connections are important for providing mental support to help individuals rationalize the stress that comes with not having papers. Francis suggests,

This is where, the experience doesn't only help you, but it helps those of your fellow country men, who might feel depressed or sad based on his situation, you then can now become a motivator where others can say, this maybe your situation now but if I made it you can as well, and now your story can become a source of influence, to let them see that no matter what the circumstance you can make it.

He speaks to the solidarity that is achieved through shared suffering and discourse, where his narratives of past struggles can offer a source of comfort for those who are currently suffering from similar struggles. Francis touches on the importance of having this kind of cultural support

system to help deal with the mental health challenges that comes with a high stress lifestyle. As participants do not have access to mental health professionals, they rely on each other as a source for dealing with the mental challenges of being surrounded by dominant structures with limited access. Francis shares Troy's feelings about his duty to give back in any way he can; this is a trope common among participants whereby their past experiences allow for symbolic identification to occur with those who share a similar cultural make-up.

Karen mentions that it is only with the knowledge offered by fellow group members who understand her situation that allows her to survive in the U.S. She suggest that people without papers "must have a community to survive, you need a community more than anything when you are undocumented, without that group of people to support you then you will not be able to succeed in America, you cannot make it here, no not here." Her comments highlight how important these connections are for people who are new to this country, as participants explain that they must learn to navigate the system without being detected, and their community is critical in this regard. Beverly highlights this point when she states,

You have to have someone, you can't just jump and come to the states like that, no, you have to have someone to help give you a push start, you have to have someone, who is aware, it's not like you already live in the states, and you are just moving to a different state, no, that is different, but coming straight from back home to no one up here, no that cannot work, no, you have to definitely have at least one person, someone to at least let you stay with them for a few weeks, or a month, just to get you started you know, but just to come here, with no community, no you won't survive.

She mentions the value of having a community to rely on to get started, whereby members of that community draw on their lived experiences to offer critical information. This type of

network is needed to share knowledge about the shifting cultural environment and the limitations of being a subaltern body in a dominant space. "When I first came here I had to learn how to take buses, these bus systems are different, where to get off one and transfer to another, so my friends tell me that I have to call the bus company and tell them where I was going and then they would give me the bus information I needed, little things like that someone teaches you," Angela explained. Beverly and Angela discussed how important it is not to take things for granted when in their position, "even the simple things are complicated in America," explained Angela. Beverly and Angela capture the need to have mentors when one migrates to the United States because it is not often that immigrants already have family members to stay with once they arrive.

In addition to figuring out how to get around, participants like Beverly and Kim also discussed the value of having someone who is willing to put them up for a while. Participants discussed that one of the most important forms of support they get from their networks is having a place to stay, either when they first arrive to the U.S. or as Kim puts it "when things got hot." What Kim refers to is when people in her position feel that ICE might be closing in on them, so they have to leave their homes, as such they consider things as getting hot. Luke explained, "there was a period when my parents and I were living in my aunt's living room for a few months, and I later realized that it was because immigration was trying to track us down, and we had to bounce from family to friend's house for like a year." Luke shares that as a high schooler his family was able to remain in the U.S. because of the shelter his family received from those people in his cultural network. In these moments, having a place to stay becomes crucial because other family members might also be on ICE's radar, as Luke explained they had to bounce from place to place to avoid such detections. Additionally, not having a safe space to stay creates major health disparities that would leave individuals extremely vulnerable to disease and illness.

Pat sees these "silent networks" as havens for people out of status that helps them figure out how to survive in this new cultural environment. Pat stated, "Yes, they help you out because they know like, you don't have a choice, you especially, when it comes to the live-in home health aide jobs. Like, you get one quick, and you stay there for a week and you can make some money, some cash of course, so family, community, they help a lot." For participants such as Pat, being able to work and provide for herself and family is only possible through networking with individuals who share similar experiences. In turn, this supports her wellness by reducing the added stress that comes from not having a job or the result of not having a job, which is not having money to survive. Pat mentioned before how PWP who find themselves in these conditions at times are forced to turn to sex work as a way to make an income.

Angela explained that "it is very important because when you come to a strange place, you're lost, America is a very crowded place and it will confuse you, especially coming from a small country to this vast one." She recognizes the mentoring she received when she first arrived as crucial because it has allowed her to help many others including her family. Angela goes on to detail that it can be extremely demoralizing and debilitating when immigrants come to the United States without any support. She says, "I have friends who came here before me and didn't have anywhere to sleep and they slept in parking lots and they bathed in Wal-Mart bathrooms but that didn't happen to me, because those same people later gave me shelter, so that's why I say I am one of the privileged ones." Angela suggests that having a group of people to rely on when you are out of status creates a type of privilege that elevates her even in her subaltern position. She speaks to Spivak's (1989) idea of the subaltern within the subaltern whereby marginalized

groups feature its own hierarchy based on the resources available to certain individuals in that group. In this instance, such privilege is only possible by having a supportive community to lean on. Angela describes a friend who faced major health risk because they lacked a place of residence, which she says is common for immigrants who come to the U.S. and are not able to find a supportive immigrant community

Marlene shares a similar tale to Angela about the dire conditions immigrants face when they are living in the United States without any communal support system. She states,

I have a friend who when she first came up here, when she would leave the house that we use to live in to baby sit and clean, she didn't have anywhere to go on the weekends, but she never tell the white lady that, no she couldn't, she would ride the train for the two days, day in and day out, when it stopped she would go to McDonalds wash her face until it's time to go back to work. Now she owns a bunch of properties in New York and have helped so many like us find jobs.

Marlene's story details some of the hardship that comes for people out of status when they have to survive in the United States alone. Marlene and Angela explain how their friends were forced to find creative solutions to manage their hygiene due to their lack of support system. She also mentions working at a job that she lived at, this was an important point of conversation for many (female) participants, where their networks would help them locate jobs where they could live in the employer's home while they worked, as a way to offset high living cost. Similar to Marlene's friend who would ride the train in order to have some place to go, participants often relied on neighbors, church colleagues, friends, and family members to offer a place to stay, when doing live-in work, without having to rent somewhere on their own for their days off. This is one of the strategies participants discussed as being extremely helpful for allowing them to save enough

money to start building a life of their own and at worse cover any potential medical expenses. Pat shared that, "when you are undocumented you can get live-in jobs from people who are documented but they knew I wasn't, so they would like put me on their jobs and just pay me cash, no question asked, people look out for you." Pat details that part of the help she receives from her support network is being able to gain work under the table. This kind of aid is only possibly based on the trust participants are able to afford to people who shared similar struggles, either because of shared cultural background or shared understanding of their limitations. She comments on the importance of having immigrants who are documented in her support networks, as such access allowed her to gain work that she would otherwise not be able to. Participants connect these opportunities to work and make money as essential to their wellness and health in the United States because without a source of income they would not be able remain in this country. They would experience even higher degrees of stress which would eventually lead to further health vulnerabilities.

## Community as a Hub for Health Information and Wellness

According to Shelly, when it comes to seeking out medical services the first, and at times the only option that PWP have is to turn to their local networks for answers. She said, "well my friends were important, you know, they tell you what not to do, give you directions, ok, they will say this is the bank you can go to open an account where they don't ask for much information you know." Shelly says members of her community work the system to get healthcare, particularly when it comes to potential medical emergencies. She comments on the importance of getting directions, knowing where to go, but more importantly knowing where to avoid. Having key information of this sort is valuable to people in her position to survive as agents in an unwelcomed environment. Shelly explained, I THINK that is a big reason why illegal immigrants are able to stay here, because the community is the backbone of umm, you know, what helps you stay motivated, umm, gives information, because most undocumented people will not go ask a doctor or a police man, or some authority figure for information, even if they do need it, they would rather ask their cousin, their friend, you know someone who they think know the information, they would rather get it from a friend or family member than the actual authority that might know the most about it, so I am going to go to my group first for information, and any health care issue, I will go to them first and see what they know and then I move or make a decision based on what I hear.

Like Shelly, many participants mistrust the systems around them, so they rely mainly on their local connections for information, support, and direction. Shelly highlights a central issue in traditional health communication scholarship that deals with patients' willingness to be open with medical professionals and how reduced information exchange between patient and physician tends to lead to a breakdown in communication and poor health outcomes (Lupton, 2003). The health system is not different, as Nancy recalls being warned by friends to not give out her information to hospitals because that information could later be used to locate her. She explained:

We need information more than anything because of the lack of status, because of that I won't give out my information. A friend warned me when I first came up that any kind of information you give hospitals can come back at you. So because I don't have these things I don't go to these health places, I avoid those situations. People tell me that they want address and all kinds of identifying information, if they get your address then how are you suppose to hide anymore?

Distrust in the medical system is cause of health disparity for most of my research participants. Nancy proclaims a need for more accurate health information about the rules and regulations of the health system for people in her position. Because she is unsure of the ins and outs of the health system, she relies on the information from people close to her, which is not always the most up to date or accurate. "Sometimes the information is a little distorted or outdated when you get it but it's the idea that I can trust my community," explained Shelly. That trust in the community functions as a blanket of protection that offers members the opportunity to gain a sense of what a medical space might be like before they take the risk of going there.

Participants suggest that their distrust stems from the way this group is represented in political and media conversations, as discussed in chapter 3. The stigmatization and political rhetoric surrounding this population has led to negative associations for people out of status when thinking about seeking medical service in formal settings. To navigate these structural limitations, participants I interviewed rely on community networks in order to find ways around these issues of trust and stigma. These networks supply the communicative resources needed to challenge, and at times avoid the dominant structures that surround them. Serena explains that,

Your community helps you with finding out information. For instance, my father has this issue with his eyes, and someone told us about another state close by that could do the surgery for free, so because of your community and the people that you know you find these things out. So, you have to go to another state and they tell you to take the train instead of driving, it's safer things like that. So you find ways around it (in access) and it's based off your community, they know something they pass it around and it helps you make it work.

Serena details the importance of her network in helping her find ways around the lack of access to affordable medical care that comes with being out of status. Having this type of information that is vital for this group to maintain their health in a stressful and taxing environment. Serena was able to draw on her network resources to navigate her fears related to travel and cost to obtain the treatment her father needed. For Pat, knowing which doctors were immigrant friendly, and which doctors were not, was valuable information, that, she said, allowed her to maintain good health without being detected. She shares a story of her experience,

Like one incident where I remember being really sick, I had severe stomach pain, I was winching and crying, rolling around in the bed for like a day or two, I had no choice, I could not risk going to the doctors or hospital because I had no papers, but I was in terrible pain and afraid to go because I was like what if I go and they call immigration on me or something like that, so I just suffered through it until my mom's friend told us about this Caribbean doctor that they took me to and we pay a little bit of money without having to give any information.

Pat was able to resolve her medical issue because of the relationships that her and her family had with others who had similar experiences. Knowing which medical spaces to go to and which ones to avoid was something participants discussed as crucial information that helps them meet their health needs. As Pat suggests, participants highlighted that their cultural connections played an essential role in locating doctors who would provide them with the service they needed without much questioning. Peter explains that usually doctors who are from the same country or cultural background whose main clientele is people from that country are the ones who community members recommend. He appreciates these kinds of spaces because " you just blend in when you go there, you hear your language everywhere, so you go and they ask how you

paying and you just say cash, and that's that." He suggests that these spaces exist all around the United States, but you have to be of a certain cultural make-up to understand where to look and what to asks for. The issue of trust is not a concern in these culturally-regulated spaces according to Pat and Peter. Peter states,

yeah, bro, there are doctors and dentists from (my country) everywhere, and they are set up regular and will take Americans and everybody but you have to know what to ask for in (our language) and you can't really know unless someone tells you, you know. Like you might go and ask for a Dr. Thomas, but there is no Dr. Thomas there, it's just a way to say I want the doctor who I can pay under the table. But if you ask that in (English) they probably tell you that person doesn't work there.

Peter highlights the implicit role communication plays in keeping these networks secure from potential outsiders. He suggests that vernacular plays a key role in regard to how these medical spaces enact resistance to support people who otherwise lack access to treatment. This discursive strategy marks the creativity that groups must enact in order to circumvent the closures they face in a dominant society (Pal, 2013). Peter's comments connect back to the concept of identification presented in Chapter 3, whereby immigrants often suffered anxiety related to having an accent that is different than the American one, which tends to produce a certain amount of stigma in dominant medical spaces. Here, Burke's (1950) identification works the opposite way with accents, communication style, and language by erecting a symbolic barrier that keeps these resistive networks insulated. This not only highlights the creative agency needed to survive with limited access, but it also shows this group's understanding of the potential of communication that allows them to implement language strategically to maneuver around the structural restrictions they face. Peter's comments also highlight how important cultural cues are for

identification/participation in these networks that connect immigrants of similar cultural makeups. Angela offers a similar example when she states,

Sometimes, there are doctors who are from (your country) that you originate from that people tell you about, where you can pay a low cost for service. For instance, there was this doctor that was from (my country), where I came from and you can go to him with your \$50 and you can get treatment without insurance or nothing like that, you could not go to any other doctor because it would cost much more than \$50, so he does it to help people in our situation.

Angela sees doctors who are from her country as being more sensitive to her situation. Peter's narrative also suggests the same with regards to the access and protection that a shared cultural language affords, namely trust. Ricardo also subscribes to the importance of shared communication in the manifestation of these network connections; he suggests, "if you must have treatment, you usually can find people everywhere that speaks your language, and they will have connections, I couldn't imagine some of the places I've met folks (from my country), in a lot of states. You just have to find people that have the language." Once again, their stories highlight the role of shared communication as a crucial factor in being able to locate these types of networks that can lead to medical spaces that are immigrant-friendly. According to both Angela and Peter, these spaces are only an option if individuals get that information shared with them from someone in their network who either have visited such places or heard about someone who has. Like Shelly explained earlier, participants are much more apt to trust information that comes from their local networks than official sources.

The types of health institutions that participants are able to access without a social security number, insurance or without the fears related to deportation, which are also affordable

are limited. As such, these spaces then have to carry the burden of having to supply treatment for a rather large population that either has nowhere else to turn for treatment or does not feel comfortable going elsewhere for treatment. Angela explains that,

the only problem is when you go to these doctors, you have to wait hours and hours, you sit and wait for god knows how long, because he is a very good doctor, and he does his work thoroughly, but he is always crowded with undocumented folks trying to get their health intact, trying to get whatever problem they have for that day resolved and he would never turn anybody away.

Angela explains that due to the challenges with taking time off from work for this group, having to wait long hours in order to obtain health service is sometimes not possible, which leads to continued avoidance. According to Angela, because this is "one of the only avenues you have to get treatment when you are in that position," it is important that doctors like hers are willing to take such risks. Her comments about the long wait times are indicative of the need people out of status have for medical attention and how limited their options are in the current medical environment. Her comments also speak to the lack of trust that many immigrants feel with regards to doctors who are U.S. citizens. Without such immigrant-friendly doctors, even despite the potential long waits, according to Angela, "I would have suffered." For her, like many other participants, having a medical space to go to that she can afford and feel safe and comfortable communicating with the medical professional is important because she would not be willing to enter more dominant health spaces otherwise.

Steve claims that "it's just experience you know and listening to what other people said about a place and paying attention to how these things work," when talking about how he knows where to get treatment. He goes on to say, "when you have a condition like mine, you have to

constantly be working around the system, use family member, friends, church, something." He comments on having to deal with the long-term treatment needed for a blood clot he experienced a few months back. He suggests that he is still alive today because of the support and information he received from the people in his support network. He says, "well, you need information and you usually have to find that on your own or friends and family, who have been in the system before, you have to find someone who knows the system, someone who has been in the situation, other immigrants like myself. They show you the way to move around certain things." He reiterates the point that people in his network are essentially the information hub that he relies on to maintain his health and prevent future medical problems related to his blood clots. Shelly explains how vital this information source is for combating the barriers to health access people without papers face, especially the personal challenges that are associated with the anxieties surrounding deportation. She says,

I mean trusting yourself to get the information is another piece, because the information is always there, it's just that people tend to not see the information because they tend to not trust it, or trusting the information and who is giving that information is a big part, I want to say choosing the information wisely is the hard part because the information is always there, but some people don't trust where that information is coming from.

Shelly's comments bring back into focus the issue of trust, discussed in Chapter 3, that stems from the stigmas produced through poor representation and framing, which makes it challenging for people in her position to trust "official" channels of information. Shelly highlights how her network's ability to supply relevant information allows for them to move about despite the limitations she faces. The type of information that Steve references with regards to navigating the health system is the type of resistive communication that allows this subaltern population to

maintain some type of health and wellness in the United States (Dutta, 2017). These cultural networks are built and sustained through strategic communication that rely on cultural discourses as a means to establish trust and create a border against potential disruption.

What participants described are discursive communities that stretch beyond physical boundaries and run beneath the fabric of a dominant hierarchical structure by drawing on cultural vernacular as a means of identification. The one problem with these networks based on how they are designed is that it becomes challenging for immigrants of different cultural backgrounds to access such avenues of information and support, which means if an immigrant's cultural group is not widely represented in an area it might be tough for that person to find the information they need to circumvent their limitations and get the treatment they need. This could explain why people out of status tend to be pooled in large culturally diverse urban areas such as New York and Miami. These spaces would provide the opportunity to identify with similar cultural bodies in order to construct a much needed support system

The following section of this chapter will discuss how these community networks that participants rely on for information, support, and direction to help meet their health and wellness needs functions as a discursive network of resistance that helps members avoid having to consider self-deportation as an option. This includes discussing cultural remedies as means to deal with non-severe health issues, offering mental and emotional support, utilizing culturally relevant spaces such as churches as hubs for disseminating resources and information to immigrants who are hard to reach, and those who have gained status advocating for and representing those who are still without status.

## **Subaltern Solidarity**

Many participants during the interview process spoke about how their network constantly helped them find creative ways to navigate the limitations of the structures around them, including the health system. They spoke about how these networks were key resources that helped them remain hopeful about their current situation. Luke says, "it (community) is really helpful to make you not feel so alone in this, to have people who share your situation, who live those experiences because everywhere else it's hush hush, you don't talk about it, so it makes you feel less alone." For Luke, like many other participants, knowing that others are here also fighting to survive, creates the type of solidarity that makes the fight a bit easier. Angela also suggests that her community helps keep her spirits up. "It's positive because my community here hold me up, people are very social and supportive of each other, people always check to make sure that you are ok," Angela explained. For Angela and Luke, they rely on these connections to engage in the type of communication that they otherwise would not be able to, it becomes an important source of self-expression which is important when dealing with a high amount of stress (Esposito, 2010).

By gradually grafting and nurturing their community networks, participants suggest that at times they are able to establish more formal support structures that are able to reach and support those who are without any support system. Many participants like Steve, Troy, and Nancy have come to rely on churches in their communities as a formal structure that facilitates these types of "silent "connections and provide additional support such as counseling and material items to those in need. Troy explains that, "some minsters will use the church as an avenue to help some of the church members who lack status, they help them survive, help them get legal advice because now a days there are a lot of members who are suffering." He sees these as the types of spaces where people are able to get the help they might need without having to

disclose why they are in need. He explains further, "my church created my brother's keeper, it's a local fund used to provide money and supplies for those who are less fortunate, it provides a place to stay for awhile, make sure people have food, that kind of stuff, and most of the times the people who this fund helps are people who are out of status." Troy argues that using the church as a structure for reaching those immigrants in need is something that use to be more widespread before recent times. "It's more difficult now to (do) than it was before to provide that kind of support because even church leaders are afraid of potential backlash, but this should not stop them from protecting these folks." Troy believes that without the church as a formal support structure then many immigrants in his position will be left to fend for themselves which can lead to harm. He extrapolates by saying,

I have this church brother who hardly spoke when we first met, but then I invited him over a couple of times and he confided in me that he doesn't have papers and the reason why he comes to church is because he doesn't want to listen to the other voices calling out to him. To the point where he felt like he was going to use illegal means to survive. To survive he has used the church as a haven to help find some work or find food when he is in need.

He uses this story to explain the importance of the church as a formal support structure within his network that is capable of reaching those who otherwise would be left to navigate structural closures alone. Troy believes that places like local churches with cultural ties could be a great hub for disseminating much needed health information and resources such as flu vaccinations to people who are desperate for treatment and do not know where to turn. Steve agrees as he said the church was instrumental in helping him recover from his surgery. He explains that, "the community plays a role in a lot of ways, especially the church, it is good to find a local church

when you are here like this because they will help you out, if nothing else offer you a community of people." Steve argues for the church as a hub for expanding his community and establishing a support system that will offer the resources needed to survive. He continues, "it starts with donations and once you go to that church the pastor will help you and talk to you about certain things and everyone will come together and give you the support you need. The church will look out for people without it mattering who you are." While Steve and Troy advocate for the church as a space to establish meaningful connections for PWP's survival, it is important to note that they frequent churches that align with their cultural backgrounds, who share the same discursive practices, much like the cultural doctor. Hence there are limits on the reach such places have with regards to connecting with this vulnerable population.

Nancy also articulates the importance of her church. She explains that she sees "the church as a haven of rest, being there for the wary, wary meaning people in our position who are frustrated and tired of always having to survive." Collectively, participants like Troy, Steve, and Nancy believe that churches all over the United States should operate in solidarity with immigrants out of status. Because the church has a protected status with the U.S. government, they believe that these spaces can offer the protection and sensitivity that most other dominant institutions, such as hospitals, are unable to provide. They contend that because of the church's historic stance in many of their cultural communities, the issue of trust would not be the same as if going to seek out health information from more official sources. In this manner, participants utilize the churches' unique status creatively to work as a resource for helping other immigrants out of status survive in the United States.

## **People helping People**

Participants were adamant that despite their limitations, inaccessibility, stress, and fears they were not willing to self-deport and return home for a multitude of reasons. They claim that they are able to survive and meet their health needs in this country because of the supportive relationships they have with other cultural bodies. Troy highlights this point when he said,

That is a concept, that uhh, it's just not being talked about, you know, how people umm, in the quest for survival, when it comes to their families, their loved ones it's no longer a question of what they are willing to do to survive, and initially you come to the United States willing to roll up your sleeve and you know uh, and work you know, with your hands for what you want and feel proud of yourself. I mean you have situations where like it is either mom, or mom and the children back at home and you really need the money to help them, or they are here with you and you do not have a way to survive, so you turn to whatever you need to do to survive and that is something that the Trump administration doesn't understand. People help people survive.

In situations such as Steve's and Troy's, one strategy is to fall back on the collective. According to Troy and Beverly, immigrants can survive in this country because of the close-knit communities that they participate in. Shared wisdom capital is vital when faced with health-related crisis. Migrating is a challenging process that involves making sacrifices to be able to gain economic sustainability. One sacrifice these immigrants made when they moved from a less developed country to a global economic powerhouse that is the United States was that they forego the relatively accessible healthcare they receive in their native countries, along with some of the traditional cultural remedies that they once relied on. Jun (2016), points to the uphill battle people without papers face when negotiating health in a dominant, unfamiliar health system,

such as the one in the United States. In these cases, it is a community of folks who share in these experiences of marginalization that operate as the counterbalance to the weight of being below a dominant order.

Community as imagined solidarity deals in matters of identification and unity (Burke, 1950; Hawley, 2018). It establishes the notion that people can share a common identity and be bound together through responsibility, shared experiences, and in this case, their means of enacting resistance. It plays upon the inkling that all people in this position are all of the same kind (solidarity). Nancy believes this is important; she states, "it's impossible to do on your own, for sure. Because all the time that I found a job it was because of the connections I had, it was someone I knew, someone saying they might know somebody that knows somebody, and they end up helping me out." Once again Nancy foregrounds the importance of securing employment for her survival and well being in the United States. She connects her wellness to her ability to remain in this country, which is only possible by being able to secure work. Her network is the only source she trusts for obtaining the information and resources needed to work and maintain her health and wellness in the U.S. despite her limited status.

For many participants, the attitude that they are bound together is an important concept that feeds the connections that they desperately need to survive in the United States. Troy and Maxine said that people without papers in the U.S. need more collective voice, more representation in order for these networks to have greater effect. "Those of us who are here, who have lived under these statuses, who understand the problems, we are going to have to let our voices be heard for those who cannot be heard, by protest or going out to vote for the right people," Troy explained. He speaks to the way subaltern populations tend to be rendered voiceless due to a lack of representation and limited input in how they are represented in the

dominant arena (Spivak, 1989; Dutta, 2008). "The presence of the subaltern voice in the discursive space becomes a resistive act" (Dutta, 2010). Until such shift in representation and policies have occurred, people in Troy's situation are left to seek outside representation in order to try and improve the policies and structures that limit their avenues of survival.

Karen claims that for things to improve for immigrants currently living in the United States without status, it will require a strong show of solidarity by those immigrants who have been able to gain permanent stay. In effect the representation has to change and that starts by gaining an understanding as to what people without papers experience as they try to navigate dominant structures that close off certain avenues of access. This project attempts to scratch the surface of the problem of representation by drawing on a cultured-centered approach to ethnographic research to highlight the challenges that people without papers describe as facing when attempting to access health care services in the United States. The CCA illuminates the role of structures in perpetuating health disparities, noting that differentials in health outcomes ultimately reside in inequalities in organization of societies, institutions, organizations, and the way certain groups get represented (Dutta, 2008). CCA is conceptually geared towards foregrounding the voices of those in marginalized spaces whose narratives tend to be absent from the way they are represented in the dominant order (Basu, 2013). Many participants, like Jack and Luke, also believes that representation from the ground up is needed. Luke argues that,

I think undocumented voices need to be head, and our concerns need to be thought of, and I don't think everybody has an inside scoop on how life is here, so try to understand how a certain individual who is afraid to go to the dentist or clinic live, compared to their neighbor who sees that as their right and have the ability to go whenever they want. I just think it's important for undocumented immigrants to be heard.

For Luke, he does not see his story being represented fairly in the discourses surrounding this population. He advocates for subaltern resistance that draws on the lived experiences and narratives of those individuals who are marginalized to rupture the dominant political themes and stigmas surrounding people in his situation (Basu, 2013). Serena feels similarly when she states that, "I feel like poor representation hurts us, I feel like if it is your job and you are going to report about people, you should take the responsibility to view both sides, interview both sides before you give your take, or don't give your take at all." She advocates for immigrants to show solidarity to her position by being a voice in conversations regarding how they are treated, especially when it comes to health care access. She suggests that by listening to their stories of survival, academics, media persons, and politicians alike would have a more accurate read on why immigrants are willing to stay in the U.S. despite the personal and structural limitations that they have to navigate. She goes on to articulate that,

if you are going to represent somebody else's way of life, somebody's means of survival, it shouldn't be about what you think is happening, don't think, because there are so many different routes, so many different ways that people survive, and some of these citizens if you check back, their parents, grandparents came here using the same methods we did, but they become so far removed that they just assume it's certain brown and black skinned people who are the culprits.

Serena argues that more citizens should try and understand the immigrant experience because many American citizens and their families share similar origin stories. She believes that better, more accurate representation would create opportunities to build the type of trust that leads to solidarity between immigrants and citizens. The type of solidarity network that could advocate for the types of policies that would benefit both groups without the need to incite fear-based

strategies. Research participants appear to suggest is that if more citizens heard their stories and understood their struggles then politicians such as President Trump could not so easily frame them as deviants. Building networks that are able to span beyond just their cultural groups would open up avenues that have previously been closed off. Marlene claims that while her community networks are strong and create opportunities for her, it is also quite limiting because these groups are the only ones she feels comfortable expressing herself in. She says,

what happened was isolation, you stay within your cultural group because they can understand your struggle, because 9 out of 10 times they went through it or had family that went through it, so it is easier to stay within your group, there is not going to be any fear of anyone retaliating or alerting the authorities for any reason, if anything they are the ones that offer you help, they help you out, but you tend to be sheltered, closed off from everyone else... You have citizens who think why did you do it that way, and then you have other immigrants from different country who have it way worse. Their entire family still lives back home and they send all of their money back, so you become closed off because it's safer, its easier for you because Americans think that you are taking what's theirs, when in reality we are here doing all the jobs that they refuse to do.

Marlene's comments highlight how these cultural networks allow for participants to have vital interactions while being insulated from the potential dangers of the surrounding environment. While these communities offer protection and valuable communicative resources for participants, they are limited due to a lack of diversity that comes from limited in-group cultural perspectives. In this way, vital information can be slow to permeate through the group as trusted sources are often limited. Beverly believes that more immigrants who have non-resident alien or citizen status needs to take on a larger role in supporting and facilitating these "silent" cultural

networks and offer a more amplified voice. She explains that, "it just hurts, when you see someone who came from somewhere or some family member came from somewhere and paved the way for you, and now you are here saying that you don't want to help anyone or don't want anyone else to come, that is being selfish." Beverly suggests that the American cultural logic of individualism is not the way people in her situation survive in the United States. Nancy highlights how solidarity between immigrants and citizens on the local city level can provide much needed support for those with limited access. She explains,

yes, big time, I can tell you, if Miami Dade politicians behaved like Broward, Broward said ok, ICE can do what they want to do in our county, they allowed for whatever to happen. I am glad for whoever is in charge here in Miami, the representation supported us, because they said they would not allow that to happen in Dade county, so that helped me a lot and did not stop me from taking the bus and living because I know they were not going to just come and take people off the bus in this city.

Nancy shares an experience that highlights the power of solidarity and how impactful such support is when it comes from citizens as well. She suggests that because her local city representative was of an immigrant, they were more willing to stand with people out of status in order to provide protection from the president's executive order. While her network is important and valued, she believes that more politicians and citizens should operate with this sense of solidarity, especially those who share immigrant roots. For Nancy and other participants, they are able to survive in this context because of the creativity and solidarity that stems from a collective that is constantly probing for ways to navigate the restrictions of a dominant system. In Troy's words, "it's people helping people."

## **Reflections and Reflexivity**

One of the major challenges with doing research with a group that is quite diverse is trying to think about how to conceptualize them as a collective without overly defining them as one. While participants obviously shared similar experiences due to their status limitation, they none the less relied on the previous cultural connections as a resource for navigating health in the United States. The difference in cultural make-up was significant because it supplied the symbolic cues that helped participants gain a sense of comfort and set up trust with each other through their shared discourse. While the narratives aligned with regards to the focus of the study, on the limitations of their statuses, participants also discussed how their cultural connections were important reminders of some of the cultural remedies that they used in the past to combat various health issues. This made it challenging to organize cultural remedies as a strategy used to maintain participants' health and wellbeing because of the multiple variations that were presented, but also because some participants suggested that they tend to avoid such remedies because they were unable to locate them or they were too expensive in the U.S. to actually be beneficial. I believe investigating these cultural remedies could be an area for future research with this population

#### **Inside-Out**

One of the first things you learn as a researcher is to not make assumptions about the field before you enter, even more so while you are there. It is pretty much the first thing they teach you in graduate school. Unfortunately, being someone who was raised within some of the same networks that were discussed, it was impossible for me to not take assumptions about community with me into the field. I relied heavily on my community of people growing up, in effect they helped raised me in many ways. In fact, what is and has been a challenging

phenomenon to try and explain or rationalize within this project is the idea of trust between researcher and participant. I believe I was afforded trust in many ways to enter people's homes with a recording device and a notebook because I was (am) part of multiple of these community networks. Of the 27 participants I interviewed, I knew 16 personally beforehand, and the rest spoke to me because one of those 16 individuals recommended me to them. Ironically, being a person who lived without status in the United States afforded me the type of access that most citizens might not have been afforded; access which most of my participants long for.

I was raised in a community that was largely dominated by Caribbean immigrants who lived relatively close to each other. While in high school I became part of different cultural networks that included those that were of people from South and Central America. While I did not speak their languages, I was able to make connections through sports and the shared absences I experienced with fellow classmates and teammates, such as not be able to get a driver's license or not partaking in certain field trips. For instance, one participant and I learned about each other's lack of status in high school because we both played on the soccer team and were both unable to partake in a soccer tournament that was being held in New Orleans. I expected the concept of cultural support networks as important theme beforehand, because they were a source of comfort to me; this meant that questions about community were used as a way to offer some kind of "structure" to the interview process. As I transcribed and analyze the data, I could not help but wonder if I was limited in my interactions with participants because I wanted to get to those questions about community before the interview time elapsed. It was when I returned to my journal while writing this chapter that I realized that my focus on community was important for multiple reasons. This started by understanding community as a "local" communicative

structure that afforded participants the type of autonomy to shape this structure in ways that they are otherwise unable to.

As I wrote in my field notes journal, "I think everyone I have interviewed thus far has had people around them. No one was alone, everyone either had a friend staying with them or extended family, but never alone. In fact, one home had so many people I was wondering if they were there to watch me and make sure that I was not doing anything that could harm them. I mean then again, that's how my house used to be (is), grandma always had people over, and we always had random people staying with us." I also remember visiting friend's homes and it was similar to mine, always alive and filled with interaction. It was not until I started to analyze participant conversations about the importance of their network that I made sense of the tacit solidarity that was happening back then. Ultimately, this brought me to a fork in the road, albeit four chapters deep into my research project that aims to serve as a dissertation; am I violating the trust and solidarity that these networks entrust in me by drawing on our history to access their lived experience as people who have suffered a great deal due to their lack of status?

I understand reflexivity as a communicative concept that constantly questions what effect research will have on the lives of those being researched (Ruby, 1995; Lawson 1990). Steier (1993) sees reflexivity as a "bending back" process whereby one is constantly revisiting the makings of ones' participation in a given cultural scene. I think being involved in a project that has so many unknown variables, which could create potential negative outcomes for the group I look to represent, not to mention the current political climate regarding immigration in United States, and the divide among citizens regarding how to be approach immigration reform; I believe I have to assume a responsibility with regards to this notion of bending back, to ask how my research is potentially affecting lives. I often struggle with the tension of being a former

insider, who has turned outsider, who is now looking back to the inside for answer from the outside. In addition to all of this, I find myself attempting to advocate for a group that has no legal status within the United States, whose very presence is framed as criminal by official outlets.

#### **Towards Solidarity?**

The culture-centered approach (CCA) investigates the fluid relationships between culture, structure, and agency by engaging with the storied health experiences of subaltern communities (Dutta, 2008). Within this process, CCA researchers work in solidarity with community members to identify relevant health issues and work toward locally-meaningful solutions that promote social change (Dutta, 2012; Dutta & Pal, 2010). This is the aim of CCA, one that aligns with my hope with regard to the nature of this project, one where the ideas presented are meant to bring into focus the knowledge available in marginalized spaces. My question to myself, since I started this project has been, is exposing that knowledge beneficial to those groups who rely on such insulation of such information to survive? Am I in effect implanting my own hopes and theoretical aspirations as a researcher on to the lives of individuals who could suffer material consequences? This tension becomes quite consuming when considering the relational ties I have to members of these particular communities.

As a scholar of Communication it became important to consider what solidarity means to me, beyond its linguistic definition. Dictionary.com defines solidarity as; "union or fellowship arising from common responsibilities and interests, as between members of a group or between classes, peoples;" "community of feelings, purposes;" "community of responsibilities and interests." According to such standard definitions, where would this dissertation project be housed, how does it enact solidarity with my participants as the term is traditionally defined? It

does not, that is my conclusion. How can I engage in this act of solidarity when I face none of the risks that my participants potentially face? What does it actually mean to show solidarity in this case, how does it look, what does it sound like, what fragrance is solidarity, what is the particularities of its taste but most importantly what does solidarity feel like? How can one possibly know that they are feeling the same thing as a group that has far less opportunities due to their lack of status? These questions led me to Durkheim's (1893) definition of the term, where he says "it is social cohesion based upon the dependence which individuals have on each other in more advanced societies." Durkheim's understanding of solidarity resonated with me as it highlighted social cohesion as the determining factor in an aim at solidarity. That was the first aspect I had to come to terms with as someone situated as a researcher, solidarity could only be an aim from my perspective, it could not be achieved. In an analogous manner, perfection is the aim, it cannot actually be achieved; but there is an inherent development that occurs based on one's attempt to be perfect or enact solidarity. I think my struggles center around the fact that I want to see myself as an insider who aligns with the frustrations participants discussed, but my position as someone who is able to call an academic research interview into being clearly shows that I am more in line with the dominant order surrounding this group as opposed to their subaltern positioning.

The writing of this dissertation project exemplifies the value of social cohesion in my opinion, as in, the support networks that offered me the tools needed to survive and be in this position to write about this issue also comes to life on the page. Solidarity for me with regards to this research project is situated in the dependence I still have on my groups to make sense of how to best utilize my current position in a way that they are unable to. When reading Tory's comments regarding "those of us who are here, who have gained status need to let out voices be

heard for those who cannot voice their concerns," it became clear that people in my participants' position were depending on people who are in my position to spread Troy's message. It is here that I theorize that these networks elevated me to be able to reach beyond cultural limitations to speak with/for/alongside those who helped facilitate my journey from hiding to writing.

Solidarity involves taking risks, as long as those risks could potentially lead to benefits for the entire group, in the same way participants would take risks in order to protect others in similar positions. In effect, solidarity with participants was achievable by recognizing how my position can be used to support group cohesion. The hope of this research project then is to expand group cohesion/solidarity to include those reading this document to create the type of society where people without papers can access the same human rights services, such as healthcare, that citizens do.

## Conclusion

The theme of community presented in this chapter aimed to tackle the third and final research question of this project which asks how people without papers navigate their structural in access to gain health care treatment when in dire need. Participants discussed how the solidarity they experience with other cultural bodies and other bodies who share their experiences of marginalization act as a support network that helped them meet their health and wellness needs. They highlighted the importance of having a support network when living in the U.S. without papers, as those networks supply key information and resources that come from sources participants trust. According to participants, their community networks are vital for helping them gain access to work, shelter, key information for navigating an unfamiliar system, and cultural doctors who would treat participants without the requirements of dominant health systems such as hospitals. Participants also suggest that these community networks are valuable

for supplying the emotional and mental support needed to survive in the U.S. while being out of status.

#### **Chapter 7: Conclusion and Reflexivity**

This dissertation project reflects the theoretical and empirical contributions to understanding, with the hope of potentially eliminating, disparities to health access among people out of status living in the United States. Media and political narratives about this group assume that by creating policies that limit the type of access available to this group, they will then eventually feel the pressure to voluntarily return home. Despite such perceptions, this qualitative research project that drew on the experiences of 27 out of status individuals living in the South Florida region, reveals the sobering reality that this population is completely resistant towards self-deportation despite the personal and structural limitations they face in the United States.

Research participants in this study explain how their health and survival needs often collide, leading them into double-binds and forcing their hands in making contextually-relevant choices. For instance, inability to procure health insurance means healthcare is often an expensive proposition. Yet, health needs of children must be addressed for fear that the immigrant parents will likely be persecuted for child neglect. But any attempt to provide healthcare to the child might require the parents to risk using false identities. In such situations, the research participants communicate about making choices that are deemed illegal (by civil society) to negotiate their illegal ascription (by civil society). We see mainstream structures snare people without papers in a double bind, thus doubly-violating them, once for their "illegal" status, and then again for an "illegal" act they are compelled to partake in for surviving in a structural network that stacks up odds against their survival due to their illegal status. The bind

becomes even more salient when there appears to be no way out of this bind, for returning to their country of origin is often not an option. In the absence of options, engaging in illegal acts comes at a cost: a need to always remain hidden, which is ironic considering their already erased subject location as undocumented immigrants.

Another double bind that research participants highlight is how their need to work to stay healthy is juxtaposed against the precarity of their professions, which offers little room to be healthy. Troy, for example, explains how most jobs that PWP get require long hours for low pay, and are taxing on the mind and body. Further, such jobs provide little wiggle room when it comes to doctor's visits or rest and recuperation.

Amidst these impossibilities, it is also evident that the research participants actively navigate the available structures to fashion their own narratives of survival, whether it be through using another person's identity documents or through seeking recourse to community support and wisdom as pathways to health and healing. In other words, we see how culture, structure, and agency interact to create composite meanings on health and survival. The cultural conditions that PWP live in situates them in particular subject positions with regard to the lack of access to mainstream resources of living a healthy and meaningful life. And in their day-to-day negotiations of these structures, they create local narratives on health and survival.

These localized vocalizations (Basu, 2011) about their subaltern subject position, and the consequent methodologies of survival and health, point to the fact that health communication in the context of PWP spaces is multi-nodal and culture-centered. A culture-centered approach forges entry points for listening to the voices of undocumented immigrants as they script their localized vocabularies on health and survival in the U.S.

## **Theoretical Implications**

I argue that research participants actively forge meanings of health and survival through an acknowledgment and performance of their subaltern cultural positions in engagements with structural restrictions that their cultural positioning brings. This argument, presented in the fourth chapter aligns with the culture-structure-agency axes of the CCA, which I adopted as a theoretical backdrop of this project. The culture-centered approach (CCA) to health communication posits that health-related meanings and messages are constructed within a cultural environment at the intersections of structure and agency. (Dutta & Basu, 2011). Specifically, in the context of subaltern spaces, the CCA states that local meanings of health are constructed by cultural participants as they narrate their lived experiences within available health-related structures/resources. Dutta (2004) explains that these local meanings are critical to interrupting health discourses that tend to be taken as all-inclusive without questioning who gets left out of the conversation, in other words, interrogating a dominant health narrative that normalizes dominant approaches to health, while limiting the value of other cultural ways of dealing with health and wellness (Dutta-Bergman, 2005; Dutta & Zoller, 2008; Lupton, 1995; McKnight, 1998; Zoller, 2003).

Conceptually framed within the CCA, this project focuses on the voice and agency of people without papers as they narrate their health-related experiences. As noted above, agency refers to a cultural group's ability to react and respond to shifting stimuli in their social environments. For participants, this meant relying on their community networks as an information and support resource that helps them navigate the restrictions they face daily. To be an agent is to participate in everyday acts in a manner that highlights ones' awareness of the structural elements impacting choices, and to navigate the limitations of a structure in nuanced

ways (Dutta, 2007). Participants were actively aware of the inaccessibility of the structures around them, in particular health structures which they often completely avoided.

When presented from a culture-centered perspective, agency operates as a marker for understanding structural inequalities and ways to potentially reduce such inequalities by listening to the experiences of those who are already involved with such tacit negotiations. Meaning that, the voice of authority with regards to understanding how complex social structures negatively affects certain cultures should come from within those cultural spaces. For instance, participants often discussed the importance of securing work to their well-being and how having a steady occupation made it easier to deal with potential health challenges. In short, the CCA is geared towards reversing the logic that people out of status are passive receivers, who can be managed by simply enacting aggressive policies (Dutta, 2007). It aims to amplify the voices of those subaltern groups who have been rendered voiceless due to prevailing health messages and structures which are geared towards a dominant audience.

CCA is also largely concerned with producing research that is informed by reflexive practice. The goal with situating this research project as concerned with reflexivity is to tackle the taken-for-granted attitudes which tend to go with academic research. It is important to recognize the responsibility we have as researchers to foster co-learning relationships with those individuals who we look to engage. Meaning to best represent this group and avoid potential negative consequences for community members, I had to continually re-interrogate my motives, goals, methods, and relationship with this research topic and the narratives put forth by participants. Further, having prior relationships with many of the participants that I interviewed offered a nuanced and complicated experience that dealt with issues of power, trust and representation from an outsider who was once in.

## **Representation and Subaltern Agency**

Recent governmental policies and agendas have helped to reify the uneven power structures that people without papers have had to face discursively and materially (Lupton, 2010). Discourse constructs and is constructed by the contexts in which it is uttered, meaning that health messages can produce certain bodies as favorable and others as problematic (Lupton, 1994). When considering that most health messages produced in the United States are geared towards citizens with adequate access to the healthcare system, it becomes important to ask how dominant forms of communication affects those who lack similar access (Hacker ;Anies ; Folb; Zallman, 2015). While President Trump's immigration (and other) policies does not directly speak to the health system, it generates and circulates anti-immigrant discourses that reinforce structural inequalities and individual fears by framing people out of status as unworthy of all public services.

The negative representation of people out of status within a dominant discourse affects the way individuals in this group makes day-to-day decisions. The restrictions that accompany being out of status creates various structural challenges for individuals who must navigate such limitations in creative ways. This is highlighted in the Chapter 4 of this research project that drew on participants experiences, related to the structure of the U.S. health system, where they articulated the challenges associated with interacting with a bureaucratic system while lacking essential resources. Situated in the narratives of research participants is a powerful sense of survival that is sustained by the need for individuals to support someone other than themselves. Troy's story highlights the way people without papers see solidarity as a necessity for their survival. As discussed in the Chapter 6, due to the need to support others in their community, finding a way around the restrictions of the system is vital for this group. This suggests that the

types of policies that are created to induce fear among immigrants does not lead to those individuals returning to their country of origin. As highlighted in the Chapter 5, policies such as Trump's executive order for the protection of the interior of the United States, limits the movement of immigrants and induces fear, but it does not accomplish its goal of forcing immigrants to self-deport. Survival, on the other hand, becomes critical to living a healthy and meaningful life in these limiting circumstances. Participants claim that their survival is possible only through the cultural connections they make with other immigrants who are in a similar position or have been in similar positions.

Lupton asks critical cultural scholars to expand the range of investigation done in health communication to include investigating how identities are informed by their discursive environment. Dutta and Basu (2010) share similar views to Lupton as they urge researchers to start investigating how discourse is central to the construction of different cultural approaches to health management. I displayed this in the Chapter 3 of this dissertation project by drawing on Burke's (1950) notion of identification to show how discursive markers such as "illegal" and "undocumented" stigmatized participants in a way that reduces their trust in the dominant health system. Dutta and Basu (2010) suggest that a limited scientific approach to human research has created a distance between the "researcher" and "participant," which in turn has produced the type of knowledge that presents one group as more knowing than another. A reflexive turn on human research forces us to bend back into noticing the co-production of knowledge in research engagements (Steier, 1993; Finlay & Gough, 2003, Dutta, 2010).

# **Reflexivity and Reflections**

# Trust

Revisiting my connections with participants on the page heighten my sensitivity towards this particular research endeavor. Even as I review this work, I find it troubling the ways in which I represented certain actors, and how the way they were represented was important to help highlight some of the complex issues faced by participants. While having past relationships to draw on helped, it also increased the sense that exposure could create additional vulnerabilities. Thus, in order to try to avoid such negative exposure, I had to try and show that trust was possible by doing a few things throughout the entire project.

First, I tried my best to reassure participants on multiple levels about the importance and value placed on confidentiality and transparency. From revisiting my own experiences this was something that I wanted to reiterate at multiple stages. This included using pseudonyms, having a verbal consent instead of a written consent, shutting the recorder off when requested, and giving a copy of the pilot study for this project, along with the transcript to each participant.

Second, going back was never an option in my mind growing up, so, survival in the United States was the only thing that mattered to me for a long time. To "bend back" was to realize that those experiences are shared by many participants and as such not asking participants to explain their reasons for staying in the U.S. was an important sign of respect that I aimed to communicate. Instead, I tired to show the value in the irreplaceable experiences which are rooted in ideas of community and social support. I was able to facilitate a type of co-learning research engagement, by discussing the limitations of my project and learning that many participants simply desired to share their experiences with those who lacked awareness regarding their struggles.

Third, without a community that supported and protected me, survival would not have been possible. It is one of the many reasons why immigrants are able to succeed in this country, people like my grandmother, who helped many bridge the gap between here and there. Those systems have to be kept sacred and protected. They are the networks that allow those with limited access to navigate and locate friendly spaces in an unfriendly society. Once more, there is a sense of vulnerability associated with talking about issues that might link back to various enclave communities. This is why I avoided making national cultural distinctions as much as possible, to limit the exposure of these groups' community systems. A part of the struggle in this process was to find ways to use discourse to conceal potentially damaging information. I did my best to reassure participants that their words would not be twisted in this project, which was a success and a failure.

Finally, reflecting on the role each actor played in my story showed me that my discursive moves were responding to certain relational expectations. I had to constantly consider how my relationship (including prior relationships) with participants affected what individuals were willing to share with me. I struggled with those moments because I was not sure how to represent myself as the researcher being implicated in some of the stories participants shared. In one instance, Francis says, "yeah, it's like when me and you use to go to lawn bush to cut this ladies house and she never knew that we didn't have any papers." He causally linked me to this experience which left me questioning the implication of such quotes that featured me as an actor. I think a more seasoned ethnographic researcher could have used those moments more effectively to illuminate the impact of relational dynamics on formal communicative exchanges. Ultimately, I left out most of the quotes that directly spoke to me as someone who shared

experiences with certain participants because I simply did not know how to represent this on the page.

#### Power

Talking about dominant systems and bureaucratic institutions with many of these individuals was an incredibly challenging task. While I had prior connections to some of the participants I interviewed, I felt implicated as they discussed ideas of class and power in relation to their situation. As I sat in people's homes with my recorder and notebook filled with questions (not to mention my Starbucks coffee cup), I felt the weight of responsibility that came with the authority of being able to call an interview into being. What I mean is that the communicative event that involves asking and answering questions creates a type of formality around the interview process that gave me an abundance of power as the individual asking the questions. I was being allowed entree into the life worlds of these individuals because I had unique access to a group that is often poorly represented. From a Communication Studies perspective, the interviewer has plenty of influence over the entire process, from the questions they ask, to the way they ask questions, and even the silence that is afforded between questions creates opportunities for the interviewer to dictate the direction of the interview. Over the course of the interviews and during the data interpretation process I struggled with understanding just how much influence I had over the answers that were provided.

Thus, as researchers, it is important to recognize the ways in which we help construct the environment in which we engage, and to reflect on how the questions we ask transforms the surroundings we are engaged with. As the knowledge that gets produced by the researcher, typically, is consequential to who is being researched. Furthermore, the rationality of the participant and researcher should offer reflexive possibilities for not only the participant, but the

researcher as well. Because communication constitutes our social world, it is also consequential to it (Sigman, 1995), which begs the question: what are we leaving behind as researchers after we exit the field.

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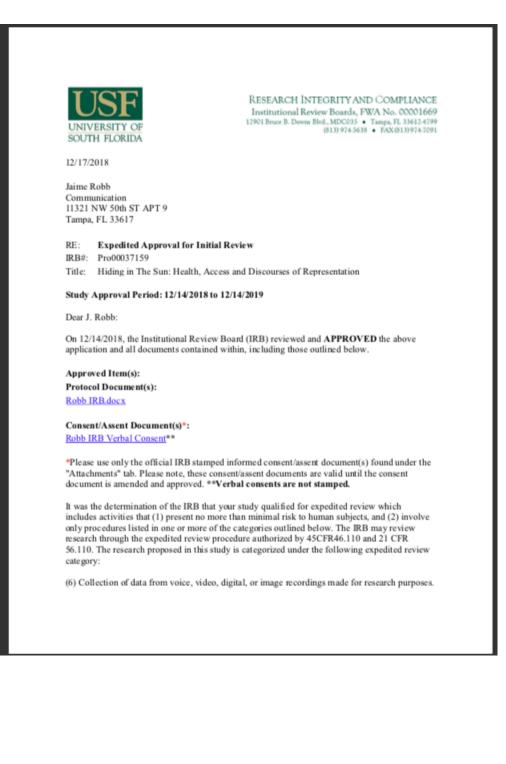
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# **Appendix A: IRB Approval Letter**



(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Your study qualifies for a waiver of the requirements for the documentation of informed consent for this verbal consent as outlined in the federal regulations at 45CFR46.117(c) which states that an IRB may waive the requirement for the investigator to obtain a signed consent form for some or all subjects if it finds either: (1) That the only record linking the subject and the research would be the consent document and the principal risk would be potential harm resulting from a breach of confidentiality. Each subject will be asked whether the subject wants documentation linking the subject with the research, and the subject's wishes will govern; or (2) That the research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval via an amendment. Additionally, all unanticipated problems must be reported to the USF IRB within five (5) business days.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely, 1

Kristen Salomon, Ph.D., Chairperson USF Institutional Review Board

## **Appendix B: Interview Guide**

### **Interview Questions**

1. What are your perceptions of now, versus when you lived with limited status health care in the United States?

2. What do you think of the labels "Undocumented/ Illegal" immigrants?

3. What are your perceptions on how American citizens understand immigrants who are labeled as "undocumented"?

4. How do you think your culture influences the way you think about health?

5. How do you think your culture influences your understanding of who should have access to health care?

6. What do you think were the major factors that influence how you addressed health issues while living with an undocumented status?

7. What type of health services did you access while living with an undocumented status?

8. Let's talk about family, friends, relatives, and partners.

9. How would you describe your relationship with health as a concept, while living in the States with limited access?

10. Were you responsible for your family's/partner's health?

11. While living in the states with limited access, did you feel prepared to address major health related concerns?

12. What are your concerns regarding access to health care for those currently living with an undocumented status? What were your concerns while living under an undocumented status.

13. How did your community (family, friends, etc.) help with addressing health concerns?

14. How did the communities you were involved with addressed health concerns given one's nonimmigrant status?

15. What issues affecting undocumented immigrant community do you think need to be addressed, immediately? Do any of those issues relate to health care and access to health services?

### **Interview Protocol 2:**

How long have you lived in the United States?

How long did you live in the United States as a nonimmigrant?

Let's talk about family, children and friends.

What health facilities did you visit while situated as an undocumented immigrant?

What did you do to take care of your and family's health?

What do you know about the Presidents executive order for the protection of the interior of the States?

What do you know about requirements for a doctor's visit?

While living as an undocumented immigrant did you ever avoid medical services due to fears associated with being an immigrant?

Have you used the emergency room as a means for avoiding doctors' visits?

How did you balance the pressures of your limited status and your health?

How prepared were you to address simple medical concerns given your limited status?

What are your concerns regarding the future of health care in the United States for those who lack legal status?