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UNDERSTANDING HAITIAN WOMEN'S HEALTH CARE IN IMMOKALEE, FLORIDA, USA

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UNDERSTANDING HAITIAN WOMEN'S HEALTH CARE IN IMMOKALEE, FLORIDA, USA

Dissertation

A dissertation submitted in partial fulfillment of the requirements for the
degree of Doctor of Philosophy in the College of Arts and Sciences at the University of
Kentucky

By
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2018

ABSTRACT OF DISSERTATION

UNDERSTANDING HAITIAN WOMEN'S HEALTH CARE IN IMMOKALEE, FLORIDA, USA

This social science research project takes a critical approach to understanding the health of a population by using the health care system as an entry point through which we can see how large-scale social processes produce a particular health care landscape in the rural, im/migrant farmworker community of Immokalee, Florida, USA. Using a multi-scalar analysis of health care, I investigate how anti-immigrant legislation and neoliberal economics influence the experience of health care for health care providers and Haitian im/migrant women navigating these processes. First, I argue that anti-immigrant and pro-market discourses have been successful in limiting the accessibility to health care services by all immigrant and low-income groups. Second, this serves to shape the landscape through the use of punitive funding changes that impact service availability, denying immigrants and low-income people the right to care. Third, health care providers work to provide care to immigrants despite fluctuating policy and funding, serving as the main point of tension between our politicized, market-driven health care system and their marginalized immigrant patients. Finally, I use the case of Haitian immigrant women in Immokalee to explore the ways that these processes impact service utilization and accessibility. I conclude the project with a discussion of the relevance of this information to enacting effective changes in the way we approach immigrant health in Immokalee and beyond using a combination of policy and planning to re-shape the environment to be one that is supportive of immigrant health and health equity.

KEYWORDS: Health care, Florida, immigrant, Haitian, women, policy

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June 2, 2018

UNDERSTANDING HAITIAN WOMEN'S HEALTH CARE IN IMMOKALEE, FLORIDA, USA

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June 2, 2018

“"All diseases have two causes, one pathological and one political."
-- Rudolf Virchow

“You can cut all the flowers but you cannot keep Spring from coming.”
-- Pablo Neruda

For the Haitian women I met in Immokalee, and
for my tiny loves

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despite their busy schedules. Their commitment to the work that they do was always inspiring. Most importantly, I am forever grateful to the amazing Haitian women who took the time to talk to me about their lives, experiences, and struggles in Immokalee and in Haiti. I was continually inspired by the strength of the women I spoke with and their commitment to their children. I promise to continue working to help enact the changes that are needed in Immokalee through my work.

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Introduction / *Geographies of Health (Care)*

Marie is a 65-year old Haitian woman who has lived in Immokalee since she came to the United States 30 years ago. She works part-time at a tomato packing house, earning about $8000 a year. She lives alone in a public housing development, though one of her daughters (also born in Haiti) lives nearby with her three American-born children. She does not own a car, nor does she know how to drive. She speaks only Haitian-Creole. Though she qualifies for Medicare, she rarely has money to afford her medications, which have multiplied since her diagnosis with diabetes and high blood pressure at her last doctor's appointment three months ago. She likes her Haitian doctor at the local health center and says that she tries to follow his directions to take care of herself. She is careful to eat healthy foods and walk every day. However, she admits that she feels 'tired' lately, because she works to help provide financial support for her children and grandchildren and she has several unpaid bills that have gone into collections. She has also been having severe leg pain that she has not had examined yet because she is waiting until she has more money and a ride to the local clinic.

Wideline is a 19-year old Haitian woman living with her sister and aunt in a small apartment in Immokalee. She has been living in the United States for ten years. She recently graduated high school and is currently looking for a job. She speaks both English and Haitian Creole fluently. She considers herself to be in excellent health. She has never been to the local clinic for medical care, because she does not earn any money to afford care, nor is she eligible for health insurance of any kind. She had severe stomach pain last year and had a friend take her to the emergency room in Naples. They recommended a biopsy of her ovaries, but she has not had the procedure. She suspects that she may be pregnant currently and says she will see the doctor at the local health facility if she has any problems.

The health care environment of Immokalee, a rural farmworker community with southwest Florida, presents a number of challenges for the mostly im/migrant population that lives there. These opening stories – an amalgamation of the stories I heard during fieldwork in Immokalee between 2014 and 2016 – detail just a few of the issues that Haitian women living in Immokalee, Florida face as they try to navigate a complex, fragmented, and politicized environment in order to maintain their health. For many Haitian women, the health care landscape is unable to support their health needs for a variety of reasons. This dissertation research looks at key aspects of the health care environment --- the political economy of health care, the provision of care, and the utilization and accessibility of care -- in an effort to understand the socio-spatial processes that shape this landscape into the one seen and experienced by Haitian women in Immokalee.

Geographies of health care have emerged as an integral part of the subdiscipline of medical geography since its formalization in the 1950s with the work of Jacques May. May, the 'father' of medical geography, was a surgeon who worked in Siam (now Thailand), Central Africa, and the Caribbean in the 1940s and 1950s. His interest in the development of a 'medical geography' stemmed from his observations in the field that his patients responded differently to surgeries there than he would have expected based on his medical training. He related the differences to the environmental context in which health and disease are produced, beginning an ongoing focus on disease ecology within the field of medical geography. In his seminal 1950 article on the methods and objectives of medical geography, May stated:

> Today we recognize that disease is a multiple phenomenon which occurs only if various factors coincide in time and in space. The focus of interest widens to encompass the relationship between the various factors of this complex and their respective geographical environments. This can be called 'medical geography' (p.9).

In other words, for scholars and physicians interested in how and why diseases spread, we must consider the various factors that produce disease within specific environments. This idea set the stage for later scholars that wanted to expand the idea of 'environment' to consider how the geographies of health care impact disease patterns.

Beginning in the 1960s, the scope of medical geography was challenged to expand beyond disease ecology. There were increasing calls for the discipline to explore the spatial-temporal aspects of health care delivery and utilization. The 1969 publication of Shannon, et al's discussion of distance as a factor in the accessibility and utilization of health care, followed by Shannon and Dever's (1974) book *Health Delivery: Spatial*

Perspectives, marked the start of a long history of research into the geographies of health services. This early health services research in medical geography often explored these issues using spatial science that has produced data for health care planning. Geographers studying health care have since looked at the distribution of health care 'resources' across space, including institutions, providers, knowledges, and technologies. Many of these studies stem from an interest in spatial inequities in care provision, a question that is inherently one about the health care needs of an area: what is the spatial relationship between health care needs (demand) and the distribution of health care resources (supply)? Investigation into this question has provided information on several spatial trends important for health care planning, including the dearth of health care facilities in many rural areas, the problem of overcrowding in hospitals in urban area, and the uneven distribution of primary care physicians across the United States. However, an important question that emerges out of all this work is, why are resources distributed in inequitable ways? In an attempt to answer this question, geographers have extended their work on availability to include research into the reasons that health resources might locate in one area and not another. This work often employs a much broader range of tools than their predecessors using spatial science. An excellent example of this is John Mohan's (1998; 1988) work on the political economy of the British health care system that explores how economic restructuring has impacted the location of health services over time. In sum, work on health care availability has produced spatial information that can be used in health care planning to improve the location and distribution of various health services within an area.

Even if equity in service availability was achieved in an area, would all people automatically use these services and have the same health outcomes? While geographic studies of health care availability have produced useful information on the distribution of health services, these locational models alone cannot explain spatial inequalities in health and illness. As a result, geographers began to explore issues of health care access and utilization. This work has primarily sought explanations for the spatial patterns of disease through investigations of differential access to biomedical health care services. The concept of 'access,' a widely used term that is often ill-defined inside and outside of geography, is used to describe a broad range of overlapping issues, including availability of services, the socio-cultural acceptability of services offered, barriers to entry into the health care system, and unequal utilization of services. In public health, Penchansky and Thomas (1981) offer a broad definition of access as the "degree of 'fit' between the clients and the system, measured along five key dimensions: availability, accessibility, accommodation, affordability, and acceptability (p.128-129). I understand each of these five factors as inherently spatial, both reflecting and producing inequitable spatial patterns of health and disease. Powell (1995) distinguishes between three interrelated aspects of access: area-level availability, spatial accessibility, and social accessibility. The concept of access is both related to and distinct from the notion of utilization, the latter being a function of the interplay between social, economic, and geographic factors (Field and Briggs 2001). For geographers, access can perhaps be best understood as a relationship between a broad range of actors (including individuals and health care providers) with differential access to power operating within an often-contentious social network and situated in place, and these relationships produce uneven distributions of health care and disease outcomes across space. So, while health cannot be boiled down to just a function of health care access, the ability to access care is a good indicator of many other issues, including level of political empowerment, especially for marginalized populations (low-income, black, foreign-born, women, LGBTQ, etc).

This is where this project starts – it takes a critical approach to understanding the health of a population by using the health care system as an entry point through which we can see how large-scale social processes produce a particular health care landscape in a rural, im/migrant farmworker community. Using a multi-scalar analysis of health care, I chose five key areas of the health care environment to investigate how they interact to produce the particular health care environment that we see in Immokalee – policy, economics, provision, utilization, and accessibility. I explore how anti-immigrant legislation and neoliberal economics influence the experience of health care for health care providers and Haitian im/migrant women navigating these processes. While it is a case study of Immokalee – a migrant farmworker community with its own 'place-ness' that impacts health care for those giving and receiving care there – it is also a study of the common socio-spatial processes that unite the experiences of people in places like

Immokalee across the US that are rural, low-income, and/or with a large im/migrant population.

Immokalee – "My Home"

Immokalee is a rural agricultural community of around 25,000 in southwest Florida. It is located in inland Collier County, which includes the wealthy city of Naples on the Gulf Coast approximately 100 miles east of Miami on Interstate 75. The majority of Immokalee's population are immigrants or the children of immigrants from Mexico, Guatemala, and Haiti – 45.6% of Immokalee's residents are foreign-born and 81% speak a language other than English at home (US Census Bureau 2016). Immokalee is a major agricultural center, where companies hire low wage migrant laborers each growing season to pick tomatoes, citrus, and peppers, or to work in the packinghouses that get these products ready to sell. The town is the first point of work for many migrant laborers, and many follow the sun northward in April through either the Appalachians or the Eastern seaboard, known as the Eastern Migrant Stream. They return to Florida in November to begin the cycle again. Immokalee is familiar to many outside of the region due to its location as the site of a successful migrant labor movement in the 1990s surrounding the low wages paid to tomato pickers and purchased at low cost by fast food restaurants like Taco Bell and McDonalds.

Haitians in Collier County (who number around 10,000) often work in two main industries: the service sector in Naples' booming tourism industry and in migrant agricultural jobs in Immokalee. Both of these sectors are seasonal and are often low-paid with no medical benefits. Approximately 29% of Haitians and Haitian-Americans residing in Collier County have an average annual family income of less than US$10,000. In Naples, around 90% are considered legal immigrants; in Immokalee, that number is much lower—only about 75% are citizens or legal residents (HCCC 2008). In addition, almost half of those in Immokalee have been in the U.S. for less than five years.

Immokalee and the surrounding area have a limited number of services available due to its relatively small size and an overall lack of funding. In terms of health services, the primary health care provider is the Health Care Network of Southwest Florida, a federally-qualified health center and community health center that operates over a dozen health facilities across Collier County, including 3 sites in Immokalee. These three sites provide children's care, women's care, family care, and dental services (Health Care Network 2018). There are very few private practice offices in Immokalee and no specialist facilities. The closest hospitals are a small, for-profit hospital in Lehigh Acres (30 minutes north of Immokalee) and a large, non-profit hospital in Naples (45-60 minutes southwest of Immokalee). Several charitable organizations are present in the community, but they offer few health services. There is also a large branch of the Collier County Health Department that offers an array of public health services, including immunizations, STD testing, prenatal services, and public health education.

While there has been some research in Immokalee on the health of the town's migrant farmworker population, Haitians have not been the focus of most of this research. To address this gap in knowledge about the needs of the Haitian population, the Haitian Coalition of Collier County (a local non-profit organization) hired Dr. Gilbert Saint-Jean, a physician and epidemiologist that has done extensive work in Little Haiti, to construct and administer a survey of health care needs for Haitian immigrants in Collier County (including the cities of Naples and Immokalee) in 2008. This survey found that Haitians in this area often live in desperate situations in Immokalee, particularly in regards to the quality of their housing, and that there are many unaddressed health problems in both Naples and Immokalee. In addition, they discovered that the rate of health care coverage for the Haitian community is well below the national average: only 18.5% of Immokalee respondents and 45% of Naples respondents report having any form of health care coverage (HCCC 2008). As a result, many Haitians either go without formal health care or they use the services offered by low-cost/free clinics in the county. Importantly, the survey indicated that there is much interest by the Haitian communities in the county in improving their access to health services.

This research focuses in particular on Haitian women. Haitian women in Immokalee tend to be either older women who arrived during the first big exodus from Haiti in the 1980s, or they are younger women of childbearing age that work in the packinghouses or stay home with their children while their partner works in agricultural labor. I chose to work with Haitian women in particular because they remain a relatively invisible minority in the region, despite their large numbers. There are few health resources targeted specifically to Haitians in the area. At the same time, they are a multiply disadvantaged population from the perspective of health researchers in that they are at once poor, black, female, foreign-born, non-English speaking, and rural. Conversations with health care providers indicated that they have particular difficulty connecting with this "hard to reach" population that faces chronic health issues at unusually high rates. In a series of health fairs that I helped to coordinate with the Haitian Coalition of Collier County, we recruited several organizations to offer free health screenings. After one such event in Immokalee, a volunteer nurse was shocked when she told me that 9 out of 10 blood pressure screening participants tested hypertensive, and two older women had readings so high that they were immediately transported to a hospital for treatment. Another nurse providing glucose screenings found that many more women were diabetic than you would find in the general population. Other common conditions included eye problems, such as blindness due to unmanaged diabetes, and depression. The existence and persistence of health disparities among Haitian women in Immokalee led me to two multi-scalar questions that drive this research. The first one is spatial: How does policy shape the health care landscape in Immokalee to produce the fragmented and limited services that are available to Immokalee's residents? Second, how do these socio-spatial processes shape the provision, accessibility, and utilization of care in Immokalee?

Immigrant health care in Immokalee cannot be understood without an analysis of the political and economic processes shaping the health care landscape. At a fundamental level, health care in Immokalee is driven by the contentious politics of immigrant health policy at the state and federal level. Chapter 1 reviews the history of health policy relating to immigrants since the enactment of EMTALA in 1986. This history is a highly contentious one that has drawn divisions between those who are "deserving" of health resources, and those who are not. Chapter 1 argues that most discussions surrounding immigrant access to health care has so far been narrowly focused on the access of *undocumented* persons to health care; however, political discourse over the deservingness of immigrants to care at the state and federal level impacts not just the undocumented, but legal low-income immigrants as well. In the United States, where access to health insurance mediates access to care, it is important to investigate how anti-immigrant, pro-market discourses have been successful in limiting the accessibility to health care services by all immigrant and low-income groups. The success of these policies in limiting health care for low-income and undocumented persons has produced an unsustainable approach to immigrant health care.

Politics shape the availability of care for immigrants through key legislative decisions on how to allocate funding for health. In Chapter 2, I explore how funding changes serve as a means to enact anti-immigrant and neoliberal policies in health care, denying immigrants and low-income people the right to care in Immokalee and the state of Florida more broadly. This results in an inequitable burden of the total health care costs on hospitals, as well as the concentration of poor health outcomes among certain marginalized populations. In other words, services are becoming less available for the people that need them most, with hospitals and (to some extent) government shouldering much of the burden of the costs for care in our market-oriented health care system. By looking at the ways in which current politics work to reduce funding to the health facilities that serve im/migrant populations, we can see how anti-immigrant and neoliberal discourses become written into the health care landscape. These policies do not make economic sense for anyone other than health insurance companies, though they are often justified to the electorate in terms of needed spending cuts and cost-effectiveness. Rather, they serve as punitive political measures toward low-income, uninsured, and non-citizen populations.

To understand how large-scale, socio-spatial processes directly impact health care providers and the patients that seek their services, it is important to take into consideration the experiences of these populations in the health care system. Health care providers are at the front lines of health care delivery, providing care to immigrants despite fluctuating policy and funding. The rising tide of unhappy health care providers may be a testament to just how frustrating this experience may be. Chapter 3 starts from a conversation I had with a public health nurse in the early stages of my research, in which she expressed frustration not just with health care more generally, but with certain groups in particular, such as Haitians living in the southwest Florida area. Following this conversation, I explored the experiences of nine other health care providers (including physicians, nurses, health educators, and administrators) working with Haitian immigrant women in Immokalee. In this chapter, I argue that health care providers serve as the main point of tension between our politicized, market-driven health care system and the marginalized immigrant patients that require care, especially care for chronic conditions and prenatal health. At the same time, health care providers do not often have the tools they need to effectively understand their immigrant patients' complex needs through the current focus on "cultural competency" rather than on training providers to see (and act against) the socio-spatial processes that produce the frustrating health care experiences they encounter daily.

At the heart of this project, however, are the Haitian women that seek services in the complex health care landscape in Immokalee. Chapter 4 explores the utilization and accessibility of care for 30 Haitian immigrant women using interview material collected between 2014 and 2016. Haitians are the largest immigrant group from the Caribbean in the United States. Though Immokalee is a community comprised mostly by immigrant groups, a majority of these groups are Spanish-speaking. However, nearly 10,000 Haitians live in the county, with minimal access to health and social services specific to them. In this chapter, I present spatial information showing where the women interviewed go to receive care and the often-circuitous ways they have to travel there from Immokalee. As a rural community, Immokalee is relatively isolated, inland from the wealthy city of Naples on the Gulf Coast. That geographic isolation – noticeable on any map – is maintained through planning and policy decisions that have kept Immokalee's residents socially isolated as well. This type of isolation can be seen in the experiences of the women I interviewed, similar to the opening stories of "Marie" and "Wideline." The result is a variety of barriers to health care access that prevent Haitian immigrant women from staying healthy or getting the care they need – barriers that are shared across socially and politically marginalized populations in the United States. The women who shared their experiences with me also shared their suggestions for how health care can be improved. I present these recommendations for change in the last section of Chapter 4, with an eye toward how changes outside of health care could have a bigger impact on immigrant health than focusing on just medical services.

While the scope of this project is the health care environment in Immokalee, the relevance of this project can be found in its exploration of the socio-spatial factors that shape the health care landscape – factors which impact all places in the United States, though they do so differentially along lines of social stratification. Immigrants across the US must contend with federal anti-immigrant policies that hinder their ability to maintain their health, though there is some variation across states. Health care facilities and public health departments serving rural, low-income, and/or uninsured persons face similar funding challenges in Florida as they do in California or New York. Health care providers everywhere attempt to use biomedicine effectively against health conditions that are at once biological and social. Navigating all of this, immigrants across the US seek to maintain their health and thus their livelihoods the best they can. For these reasons, I conclude the monograph with a discussion of the relevance of this information to enacting effective changes in the way we approach immigrant health in Immokalee and beyond using a combination of policy and planning to re-shape the environment to be one that is supportive of immigrant health and health equity.

1 / Policy /*Deservingness of Immigrants to Care*

'Deservingness' is socially produced, politically determined, and institutionally implemented …" (Quesada 2012, p.895)

Immigrant access to health care is a contentious topic in American political discourse. Though conflict over health resources has recently escalated with Obama's signing of the Patient Protection and Affordable Care Act in 2010, immigrants' rights to the services they need to maintain their health has been a political sticking point for decades. This is particularly true in the state of Florida, where immigrants or first-generation Americans make up around a third of the population. The issue is not just about the (in)ability to access health care when needed, but also their "deservingness" of government assistance or protections more generally that impact their ability to live healthy lives in the United States. Immigrants – regardless of their legality or citizenship status - often face complex challenges in every aspect of their lives, including housing, culture, and education. In this chapter, I use policy analysis to argue that the discussion of immigrant access to health care has been narrowly analyzed through a discussion of the access of *undocumented* persons to health care; however, as we see in the state of Florida, political discourse over the deservingness of immigrants to any type of care or protection impacts not just the undocumented, but lawfully present low-income immigrants as well. This morality discourse has material consequences for immigrants by limiting their ability to access the services they need to maintain their health, producing an unsustainable immigrant health care system.

Immigrant Health in Context

Migration is a central aspect of the human experience. In 2015, the UN Population Division estimates that there were 244 million international migrants, up from 173 million in 2000 (UNPD 2015). In that same year, the United States was home to 41.3 million immigrants, making up 13 percent of the US population (Zong and Batalova 2015). Economic and political inequities, environmental disasters, and humanitarian crises have pushed millions of people to seek life away from their homes, while globalization has allowed for quicker, more open access to other places – at least in theory. In reality, many countries have responded to the global movement of immigrants through the creation of policies designed to keep certain groups (especially low-wage and/or low-skill workers) out of their borders or to restrict immigrants from receiving various economic or political benefits after they enter the new country. In both the United States and Europe, politicians expressing anti-immigrant positions have ridden the current wave of nativist populism to increase their presence in local and national governments, promising tougher regulations on security or cuts to government assistance for the foreign-born.

Immigrants not only move across borders, but also from one milieu (and health system) to another. Immigrant health is then a product of both the context from which they come and the context into which they enter. Low- and middle-income countries often have different burdens of disease, and within those countries, people may be exposed to different diseases at varying rates depending on their socioeconomic status, occupation, education, and access to resources like clean water or healthy food. However, upon arrival in the United States, immigrants are often healthier than the average American (the 'healthy immigrant' effect), including lower overall mortality rates and rates of certain diseases (Kennedy et al 2015; McDonald and Kennedy 2004). One explanation for these patterns of health is self-selection - immigrants are more likely to be younger and able-bodied and thus able to travel to find employment. Within 10-20 years, however, their health indicators worsen to look more like the native-born American population, especially in terms of chronic diseases (Leclere et al 1994; Antecol and Bedard 2006; McDonald and Kennedy 2004; Cunningham et al 2008). Arguably, this decline in health is attributable to the many barriers immigrants face as they try to live healthy lives. Immigrants regardless of status are more likely to work in precarious jobs that do not provide health insurance, and immigrants have lower rates of health insurance coverage and use of services than native-born Americans (Derose et al 2007; Portes and Fernandez-Kelly 2012). They also may have limited English proficiency with which to access the health care system; they may avoid seeking health services or preventative care due to fear of deportation; they may live in segregated communities with limited health-promoting facilities; they may have limited financial and social resources to take advantage of things like preventative care; and they may face stigma and marginalization by the receiving country due to their immigration status and perceived cultural differences. Even in countries with universal health care, immigrants are less likely to use services and they receive poorer quality services than the native-born (Elliott and Gillie 1998). Many immigrants—whether documented or not—end up relying on health care safety nets, emergency services, and/or cultural healers to receive care, if they seek care at all.

There are noted differences in health between immigrants with different statuses - for example, between a professional immigrant who arrives with a job offer that includes full medical benefits, a refugee fleeing dire political circumstances at home who is given temporary health benefits under a federal program in their new country, and an undocumented immigrant who is ineligible to receive health benefits and are thus limited to local free clinics. Yet, there are still important connections to be made between the experiences of immigrants across socioeconomic and immigration status, particularly in terms of how political discourse marks all immigrants as 'Other,' with potentially material consequences.

An investigation of immigrant health care must be grounded in an understanding of the policy that helps to draw distinctions between the native-born and the foreign-born and between immigrants that are "deserving" of resources and those who are not. We must consider how politics and their underlying ideologies work to help or hinder all foreign-born persons as they seek to maintain their health in the country to which they travel. Without this broader understanding of politics as an upstream factor influencing immigrant health in the United States, medical and public health efforts aimed at improving immigrant health (care) risk narrowly focusing on issues such as cultural and linguistic differences that may impede access, missing the more fundamental social causes of disease (see Castañeda et al 2015). In the United States, where access to health insurance mediates access to care, we can see how anti-immigrant, pro-market discourses have been successful in shaping the accessibility to health care services by all immigrant and low-income groups. Even since the enactment of the Patient Protection and Affordable Care Act of 2010, over 32 million nonelderly people remain without health insurance - more than half of whom are below 199% FPL and 21% of whom are noncitizens (KFF 2015). While 'legal' immigrants are more likely to be insured than undocumented immigrants, they are still less likely to be covered than native-born citizens.

Debates over immigrant ‘deservingness’ to care has shaped immigrant health reforms since the 1980s, institutionalizing discrimination against immigrants – especially low-income immigrants - through regulations on access to insurance. The resulting policies have entrenched an uneven spatiality of health care coverage and accessibility for immigrants, with some states (such as Florida) enforcing stricter barriers to access than others. The policy discussion that follows illuminates the intersections between immigration policy and health policy, providing an important point from which to understand how boundaries between the native-born and foreign-born (‘us’ and ‘them’) are enforced through restricted access to the resources needed to maintain health.

Theorizing Deservingness and Access

Deservingness refers to the quality of being worthy or qualified for something due to merit or some other characteristic or action. It is an attribute bestowed or inscribed upon someone or something – to be deserving is to be judged. Deservingness entails a division between those who deserve something, and those who do not, and the boundaries by which we define deservingness vary from one person or group to another. The problem, however, lies in the material and symbolic consequences of being deemed *un*deserving by people, groups, or institutions that have political power. Immigrants – as ‘outsiders’ – often run into these consequences in their quest to obtain employment, health insurance, and/or public assistance. As Quesada (2012) succinctly explains it, "‘deservingness’ is socially produced, politically determined, and institutionally implemented …", while one’s vulnerability to being judged as ‘undeserving’ is often bodily inscribed (p895). Deservingness political discourse is often steeped in nativist, classist, gendered, and/or racialized terms that draws from a long history of discrimination against people of color, immigrants, and women. In addition, this language is often wrapped up with conservative notions of individualism, hard-work, and the attribution of ‘need’ to character flaws rather than social processes. In our market-based health care system, there is no health care access for all, so claims to assistance are questioned for everyone, but especially for people born outside of the United States or who are low-income, under the assumption that we must evaluate whether someone truly ‘deserves’ access to these increasingly limited resources. Impoverished ‘illegal’ immigrants without health insurance are judged as less deserving of assistance than middle-class resident immigrants who pay for private insurance through their employer; however, both may face discrimination due to their status as foreign-born.

In a special 2012 issue of *Social Science & Medicine* on immigration, legal status, and deservingness to health care, Willen argues that the moral assumptions underlying questions of immigrant health care access remain relatively understudied and undertheorized, despite strong division over immigration reform and health care reform in the United States. Deservingness is a discourse employed to limit access. For example, undocumented immigrants are totally forbidden from receiving government assistance – Medicaid, health care marketplace subsidies or tax credits, SNAP and TANF benefits, and so on. Sargent and Larchanché (2011) call these issues "medical citizenship" or the "policies of entitlement that demarcate the rights of citizens and noncitizens" (p.348). However, the focus of Willen's editorial – and the special issue as a whole -- is limited to illegality and health. Many of the problems the contributors discuss are faced by all immigrants, not just ones without documentation. For example, within political discourse, there is often the assumption that immigrants come to the United States due to some sort of pull factor (such as a desire to take advantage of our health care and education systems), rather than a push factor (such as difficulties finding employment in their home country due to exploitative global economic policies). These assumptions may contribute to discrimination against anyone that looks, acts, or speaks like an immigrant, regardless of immigration status. In addition, while undocumented immigrants may be barred outright from receiving various public services or assistance, all immigrants may face political barriers to receiving care or assistance, such as by enforcing a waiting period for legal immigrants in need of Medicaid benefits.

The demarcations between those who deserve care and those who do not rely on the construction of borders ('b/ordering practices'), both material and symbolic (van Houtum 2002). Borders separate, define, and exclude membership in a group, as well as who can benefit from membership. These borders are inherently political, as all space is political, because they are in the process of being actively constructed (and contested) by the people within them. Institutions such as the American health care system play an integral role in constructing these boundaries through the process of providing care to only certain groups deemed eligible for health care funding by lawmakers. In her discussion of

Cambodian refugees trying to access the American health care system, Ong argues that the health field 'normalizes citizenship' by identifying those who are citizens and thus eligible for assistance and those who are not, helping to construct biopolitical subjects (Ong 1995). Enforcing boundaries within these institutions not only encourages assimilation and the production of a certain type of citizen, but may also help to create conflict between those who "should" have access to declining social safety net spending (Lamont and Molnar 2002). Because of the restructuring of the health care and immigration systems, citizenship is "increasingly defined as the civic duty of the individual to reduce his or her burden on society" (Ong 2003, p.12, citied in Horton 2004). A 'good' citizen does not need assistance from the broader society. However, challenging the trope of the needy and dependent immigrant, few immigrants list health care or government assistance as a top reason for moving to the United States, and they tend to use less health care overall than the average American (Ortega 2009). Further, many immigrants pay taxes into the system that they are barred from getting back. Importantly, non-citizen immigrants are excluded from the political process, lacking even the right to demand rights to health care (Willen 2012).

In the rest of this chapter, I will review how the concept of deservingness is employed in policy and discourse at both the federal and state levels, focusing specifically on the case of Florida. Florida is a fascinating case study through which to understand the ways in which immigrant rights (or a lack thereof) are institutionalized using nativist, gendered, and classist appeals to the native-born public. Political discourse in the state of Florida, like many states in the southern US, frequently focuses on the state's large and increasing immigrant population. Since 2000, the immigrant share of Florida's population has increased from 16.7% to nearly 20%, with over 3.6 million immigrants now residing in the state. The changing demographics of the state have been accompanied by escalating anti-immigrant rhetoric, both in government and in public discourse, surrounding the financial cost of providing health services to immigrants in the increasingly neoliberal American health care system where immigrants may not be eligible or able to afford health insurance when they need medical treatment. Currently, several key politicians with connections to Florida are in the political spotlight, which gives us insight into the ways the state serves to divide persons living in the United States into those deserving of care and those who are not.

Methods

To explore these ideas, I conducted a search of Florida State Congress documents for references to ‘health,’ ‘health care,’ and ‘immigration.’ I also searched local and state newspaper databases for political statements on immigration, welfare, and/or health care made by current and recent Florida lawmakers. This was aided by the fact that several Florida politicians were either campaigning for elected offices in state and federal elections during the 2016 political season, or they were vocally supporting the positions held by those who were running. For these politicians, I was able to search major news organizations and candidate websites for up-to-date information on candidate positions. I then combined this information with historical information (such as voting records) on various political figures at the state and federal levels since the passage of EMTALA in 1986. I ordered this information chronologically for analysis, which is presented below.

Changing Health Policy

EMTALA

Much criticism has been levied against the Emergency Medical Treatment and Labor Act of 1986 (known as EMTALA), which was one of the first pieces of legislation to directly address the issue of immigrant health care access. The law was a response to the practice of ‘patient dumping’ where hospitals that didn’t want to cover the treatment of the uninsured would have emergency patients dropped off at struggling inner city public hospitals. At its core, EMTALA ensures that all people have the ability to access lifesaving treatment, regardless of their citizenship and ability to pay. Opponents have claimed that the law allows immigrants to overuse hospitals as a place to get “free” health care; however, there is no right to health care for anyone in the United States. Even with EMTALA, the hospital only has a duty to provide care in an emergency situation or if labor is imminent, and only if they are one of the vast majority of hospitals that accepts public Medicare funding. However, after the initial examination to determine the issue and stabilization of an emergent health problem, uninsured people may be referred or transferred elsewhere. It is up to the hospital to determine if they will provide treatment to these cases. As Horton (2004) points out, hospitals are then in the position where they participate in the construction of deservingness, because it is there that a decision can be made to provide care or not.

The financial pressure of this policy is felt at the hospital level, because even though hospitals must provide care, they may not be reimbursed by federal money for this care. Undocumented persons can obtain federally-funded Emergency Medical Assistance if they are otherwise financially eligible to receive Medicaid. This is available in the event of an emergency, allowing hospitals providing often-expensive emergency care to receive some sort of federal reimbursement for the care they provide to undocumented persons. However, these funds are used primarily to cover emergency labor and delivery. In addition, while there has been some attempt for the federal government to reimburse states that have a high cost burden due to the uninsured (like Florida, which received $8.7 million in 2003), it is estimated that $2 billion a year goes unreimbursed each year nationwide (Footracer 2009). There was discussion of providing additional federal funds to hospitals shouldering a disproportionate share of the costs of the uninsured in order to cover the cost of providing emergency room treatment to uninsured patients in 2003, along with the stipulation that hospitals would have to obtain legal status information from patients. Health care providers were concerned that this practice could potentially turn away patients with legitimate emergencies in fear of being deported, or keep patients away until the last minute, which could lead to poorer health outcomes. This proposal was later tabled.

Another consequence of EMTALA has been the issue of hospital repatriation. The law, which was designed to prevent patient dumping, has actually led to situations in which uninsured immigrant patients were sent back to their home country by the hospital. There are companies that assist in medical repatriation, assisting hospitals with the transfer of care across the border, marketing themselves as the more affordable option, especially for long-term care. This puts hospital administrators in charge of deporting immigrant patients deemed too expensive for continued care. The alternative is for the hospital to shoulder the cost of providing care for the uninsured person, which can –and has – cost millions for a single critically ill patient.

Interestingly, no state has been able to sue the federal government for requiring them to shoulder the cost of treating the uninsured. However, in 1995, the then-governor of Florida, Lawton Chiles, brought the issue before the US Court of Appeals Eleventh

Circuit. Chiles (who at the time had just been re-elected after a close race against Jeb Bush) sued the federal government, arguing that because the United States did not properly enforce immigration policy, the state was incurring “disproportionate and unfair expenses” in providing public services such as health care and education to undocumented persons (Ortega 2009). The court dismissed the case, citing the fact that how the borders of the country are policed is up to the federal government, rendering the case a legislative issue, rather than a court issue. Later, in 2012, Florida changed the definition of just how much of an emergency service should be covered. Prior to that year, the state law covered care necessary to *relieve* or *eliminate* the emergency condition; now, the policy is to just pay for *stabilization* of an emergency. The issue of unreimbursed health care following EMTALA continues and has shaped the availability of hospital care in the United States in important ways, discussed in Chapter 2.

Welfare Reform

Restrictions on immigrant health care began in full force with welfare reform under President Bill Clinton. The Personal Responsibility and Work Opportunity Reconciliation Act (PWORA) of 1996 ushered in a number of changes meant to limit access to public assistance at the state and federal levels. Prior to this legislation, only immigrants that were clearly deportable were unable to obtain Medicaid benefits. With PWORA, all non-permanent and/or undocumented immigrants became ineligible to receive public assistance and thus deemed “undeserving” of American health care resources. Consistent with neoliberal calls for reduced federal spending, this moved the financial responsibility of immigrant health care to the state level – if states wanted immigrant health care assistance, they would have to pay for it themselves. Considering that most state budgets have to be balanced at the end of the fiscal year, pushing the cost of immigrant health care to cash-strapped states would require a large budget or some heavy-handed cost-reduction measures, such as the move toward managed care programs. Federal level waiting periods also exist before even *legal* immigrants could obtain government assistance, regardless of whether they would otherwise qualify. Politicians justified (and continue to justify) a five-year waiting period for immigrants by arguing that it prevents the arrival of immigrants who are “public charges” without the financial means to support their life in the United

States. For example, sponsors of immigrants must sign an agreement (USCIS Form I-864) that the immigrant will not become a public charge.

The push for welfare reform was arguably both a cause and a consequence of how the public views the recipients of government assistance. The neoliberal turn in American politics in the 1970s helped to start and fuel the notion that people can succeed if they just work hard enough – with lack of ‘success’ being explained by individual laziness or even social decline. The manufactured issue of welfare fraud (and the emergence of the so-called ‘welfare queen’) became an issue that the average American cared about, breeding anger about people taking advantage of public resources (and thus the hard-earned tax dollars paid by middle-class Americans feeling increasingly strapped for cash with stagnant incomes). Views of immigrants became tied up in the value of their contributions to society, whether they are hardworking, and especially their socio-economic status. Low-income immigrants (regardless of legal status) were viewed suspiciously as potentially coming to the United States to take advantage of the country’s ‘generosity’ in terms of public assistance. This judgment was applied especially harshly to women of reproductive age, for which welfare reform “helped solidify in public opinion the frame of the state-dependent woman who uses her reproductive capacity to take advantage of U.S. resources” (Viladrich 2012; Derose et al 2007; Rose 1993; see also Chavez 2004). Restricting assistance became a punitive measure against all low-income people for being poor, and in particular against low-income immigrants – a supposedly “fitting punishment for those who could avoid this difficulty by choosing to leave” (Clark 2008, p.242).

In terms of health care, welfare reform ushered in a number of restrictions at the state and federal level that created barriers for immigrants needing medical care, including cuts in federal and state spending on public programs. It remains up to the state to decide how to handle the issue of low-income and immigrant health care. Florida maintains a five-year waiting period before immigrants can receive any sort of public health assistance. Though there have been numerous attempts to reconsider the waiting period, the proposed changes have always died somewhere in the state legislature. When the state Children’s Health Insurance Program (Florida KidCare) was reauthorized in 2009, legislators had the opportunity to extend Medicaid benefits to lawfully present immigrant children with no waiting period. They opted not to do so and did not reauthorize this until 2016. During this time, expansion of health assistance to lawfully present immigrant children would have opened up federal funds for the state of Florida, and it would have used unspent state funds already earmarked for children's coverage (Advincula 2013). While some states provide health care coverage to undocumented pregnant women through the CHIP Unborn Child Option (which emphasizes the health of the fetus, rather than the mother), the state of Florida does not offer any state-funded programs of this sort. However, pregnant women can receive prenatal care through various programs at community health centers and public health departments, while coverage for labor and delivery can be obtained by applying for Emergency Medicaid after the emergency takes place. These barriers, based in welfare reform, continue today. Importantly, these barriers persist not just for undocumented immigrants, but for legally present low-income immigrants in the state of Florida.

Affordable Care Act

The Patient Protection and Affordable Care Act (shortened as ACA or "Obamacare") was signed into law by President Barack Obama in 2010, making it the first significant health reform legislation since the creation of Medicaid and Medicare in 1965. The ACA attempts to address several issues in health care delivery in the United States, including inequitable access to care and rising health care costs, through reforms in both health insurance and the health system more broadly (APHA 2012). Arguably, the most visible and controversial aspect of the ACA centers on improving access to care for uninsured Americans. This was accomplished primarily in two ways. First, the law sought to close gaps in Medicaid eligibility by expanding coverage to additional groups, including low-income adults between 44% and 100% of the Federal Poverty Level. The federal government offered to cover 100% of the cost of the expansion for states in the first three years, then 90% of the costs after that. Second, access to insurance coverage was going to expand to middle-income Americans through the creation of health insurance exchanges. This allowed people to purchase their own insurance if it wasn't offered by their employers or if their incomes did not qualify for federal insurance programs. Coverage purchased on the exchange could be subsidized if the consumer qualified using income and household eligibility criteria. The formulation and implementation of the law have been far from perfect, however. The law was and is controversial, with several key points blocked and/or challenged by Republican opposition to Obama's health reform plan. When it was signed into law, it had zero Republican support. Multiple states, including Florida, refused to participate in the Medicaid expansion plans, leaving millions of low-income Americans without health insurance who would otherwise qualify for the program.

In Florida, the failure to expand Medicaid has had bizarre consequences for health coverage. Medicaid expansion would have allowed millions of additional low-income adults and families to qualify for assistance, extending coverage to up to 100% of the Federal Poverty Level. Households earning more than that (100% to 400% FPL) would receive subsidies to help pay for the costs of insurance, ownership of which is mandated by federal law. Because some states refused to expand Medicaid, and the law didn't take that possibility into account in its wording, people in the 44% to 100% FPL range are not written into the bill. This means that hundreds of thousands of Floridians who make 44% to 100% FPL fall into what is known as the 'coverage gap,' earning too much to qualify for Medicaid under the original criteria and too little to qualify for tax credit or subsidies. This gives assistance to many middle-income groups, but not many low-income adults, especially working adults. As a result, Floridians in the coverage gap must pay for health insurance entirely out of their own pockets (which is financially out of reach for many of these families) or they go without coverage altogether. Currently, the state of Florida still has over three million uninsured, ranking it in the top three of all states in the number uninsured. In addition, twelve percent of the uninsured in Florida do not qualify for assistance of any sort due to immigration status (KFF 2014a). Florida Republican Governor Rick Scott – who made his career by opposing the ACA – has famously flip-flopped multiple times on Medicaid expansion in the state, at one point saying he had to support it "in good conscience" after witnessing a family member's illness. At the time of writing this, Scott is currently against the ACA again.

From the very beginning, the role that immigrants ('lawfully-present' and otherwise) would have in the health reform was heavily debated, with the Republican party strongly opposed to the possibility of undocumented immigrants receiving health care coverage under the ACA. In the now infamous video, Rep. Joe Wilson (R.-SC) interrupted Obama's speech to Congress about the ACA with shouts of "You lie!" when Obama said the bill would not cover illegal immigrants. However, Democrats took an exclusionary position on undocumented persons very early on, because politically, to suggest otherwise was known to be a controversial (and potentially career-damaging) approach. As former Sen. Max Baucus (D.-MT) explains, “That’s too politically explosive …. Very politically charged” (Galarneau 2011, p.423). Florida politicians again created political careers on these issues. For example, junior Sen. Marco Rubio (R.-FL) (also a former Republican presidential candidate and former Speaker of the Florida House of Representatives) co-sponsored a 2013 bill with Orrin Hatch (R.-Utah) that would have placed a five-year waiting period on undocumented immigrants who receive a green card seeking health insurance *subsidies*. Though the ACA does not place this restriction, this discourse again comes back to the distinction between legally-present and ‘illegal’ immigrants. Even allowing undocumented persons to participate in the health insurance exchanges *with their own money* is considered by some conservatives as encouraging illegal immigration.

The full significance of the law for immigrant health remains to be seen since the law is still relatively new. However, the ACA does directly impact several important aspects of immigrant health care, both positively and negatively. Lawfully-present immigrants can purchase coverage in the insurance exchange and receive tax credits without a waiting period. The law also sought to provide an additional $22 billion over a five-year period to Federally Qualified Health Centers, which serve as a source of primary care to millions of low-income and uninsured Americans (including immigrants) each year. However, many uninsured lawfully-present immigrants are in low-income working families that would qualify for the Medicaid expansion or tax credits, so failure to expand this program in certain states leaves many immigrants without coverage they would otherwise qualify for (KFF 2013). In addition, lawfully-present immigrants will continue to face the five-year waiting period for Medicaid assistance in all states. For undocumented persons, the only way that undocumented immigrants might potentially benefit from the ACA is through the additional funding provided to FQHCs that serve this population. This population may not receive Medicaid or marketplace subsidies. They are barred from even purchasing unsubsidized health insurance on the exchanges with their own money. In other words, while access may be expanded for some middle-income, lawfully-present immigrants, low-income and undocumented persons may face even greater barriers to getting the care they need (Derose et al 2007). This further contributes to the overburdened community health centers and hospitals that serve this population, particularly in states that opted out of Medicaid expansion (KFF 2013). This relationship will be explored further in Chapter 2.

Attempts to dismantle the changes ushered in by the ACA continue today, led almost entirely by the Republican party. With the election of President Donald Trump in 2016, various aspects of the law have been challenged, including the mandate that everyone have insurance, the provision of subsidies to help offset the cost of health insurance, and the funding of public health insurance programs. While a total "repeal and replacement" of the law has so far been unsuccessful, some important changes have taken place. In December 2017, Trump signed the Tax Cuts and Jobs Act, part of which repeals the ACA tax on people who do not obtain insurance – thus removing the incentive to obtain health insurance. Then, in January 2018, the Trump administration gave states the ability to impose work requirements on Medicaid recipients. This impacts primarily childless able-bodied adults. Additional measures to re-marketize the health insurance exchange have also been enacted, causing increases in health care premiums and the loss of insurance providers in the exchanges.

The 14th Amendment

According to the 14th Amendment of the US Constitution, all persons born or naturalized in the United States are citizens of the US and the state in which they reside, and they are also subject to the same protection under the law as native-born citizens. Though birthright citizenship is a right under federal law, some conservative politicians have suggested revisiting this amendment due to what they see as being a large number of children being born in the US to immigrant mothers, especially undocumented women. These US-born children, who are American citizens according to the Constitution, have been termed 'anchor babies' in public discourse, with the argument being that immigrant women purposefully have their children in the US in order to stay in the country and take advantage of American resources. The idea of 'anchorage' is essentially a spatialized revamping of the 'welfare queen' concept originating in the 1970s, traditionally used against low-income black women and solidified by the 1996 welfare reform act (Viladrich 2012; Derose et al 2007; Rose 1993; see also Chavez 2004).

As recently as August 2015, former Florida Governor and former presidential hopeful Jeb Bush made the news when he remarked “If … pregnant women are coming in to have babies simply because they can do it, then there ought to be greater enforcement. … That’s [the] legitimate side of this. Better enforcement so that you don’t have these, you know, ‘anchor babies,’ as they’re described, coming into the country.” Though he argued that it wasn’t practical to get rid of birthright citizenship altogether, others have gone as far as to make that suggestion. Current US president Donald Trump, a Republican who won the 2016 election in part because of his strong stance on immigration and the border, has said that he does not believe that children born in the United States to immigrant mothers are American citizens. He has also said that he would challenge the 14th Amendment in court.

Discourse around the legality of birthright citizenship often contains gendered, racialized, classist, and nativist undertones. In the U.S., where reproduction is intimately linked to rights to citizenship, reproduction has become a contested and political process. The pregnant immigrant body reflects discourses about race, nation, health, and the future. In the biomedical view, pregnancy is a pathological condition that requires the intervention of modern bioscience through prenatal care, genetic screening, and surgical technologies during childbirth (Ong 1995; Sharpe 1999). For example, pregnant women are told to eat or avoid certain foods, to participate in particular activities, and to allow their bodies to be fully screened (inside and out) in order to be a good mother. Pregnant bodies are seen to require “counting, control, and confinement” by biomedicine and, arguably, the same could be said for immigrant bodies (Dyck 2003, p.365). This is related to health and disease, and a long history of framing immigrants as dirty, risky, and hypersexual. For example. Chavez (2008) has written extensively on the so-called “Latino Threat”—the fear of the over-reproducing ‘Mexican’ immigrant. As Park (2011, p.6) argued in her research on Asian immigrant women: “Pregnant women … embody a walking target for the expression of a number of national anxieties regarding the quality and quantity of our citizenry,” and this applies to low-income immigrant women from any country entering the US. These fears are often encoded into the structure of our society through policy aimed at keeping the immigrant Other at bay.

Aside from the fact that birthright citizenship would be difficult to challenge in court, the problem of ‘anchor babies’ is not widely acknowledged to exist outside of political soundbites. Most of the children born to immigrant women in the US are born to lawfully-present women. There is also very little evidence that public resources are a pull factor in a person’s decision to immigrate to the United States. Rather, immigrants (documented and otherwise) arrive in the U.S. seeking employment, reunification with family members, or escape from political oppression. In addition, there appears to be quite a bit of misunderstanding among the American public as to whether undocumented persons can access services. Undocumented women are wholly unable to obtain TANF (welfare) benefits, SNAP benefits (food stamps), or government health insurance like Medicaid or Medicare. They are eligible to receive Emergency Medicaid funds if they must utilize the emergency room for something like labor and delivery. They are also eligible, for at least a period of up to 45 days, for Presumptively Eligible Pregnant Women (PEPW) Medicaid that can cover at least some part of their prenatal care. However, the women do not receive payouts from these funds; rather, these funds go to the health care provider to help defray the costs of care. So, it is unclear which ‘American resources’ are being supposedly exploited by undocumented women who have a child in the United States. While the child of a low-income immigrant mother would be eligible for assistance since s/he is an American citizen, it is his/her right as a citizen under the law. What is so fascinating about this conversation is it again rehashes the issue of who is deserving of care, but through the case of children of immigrants – viewed in public discourse as being at once native-born and yet still an immigrant. The law is clear, however – children born in the United States are US citizens.

Discussion

It may sometimes seem like anti-immigrant politics have reached a high point in recent years, particularly after the 2016 election with candidates running (and winning) on platforms of immigration control and border protection. However, current discussions are just another iteration of past anti-immigrant and neoliberal discourse. Legal rights to services for immigrants have been reduced or challenged numerous times, as the policy discussion above indicates. A distinction is made between immigrants and the native-born, and between lawfully-present and undocumented immigrants. In states like Florida that have a large immigrant population, politicians have often couched their language in terms of easing the economic burden of the additional people to treat or care for, regardless of immigration status. In many ways, restricting access to services is the most common option for politicians seeking to look tough on immigration – it may appear to be easier and less costly than actions like building a border wall or deporting unauthorized persons.

Florida is an especially interesting place to understand the current political climate. It is a national swing state, with a very large immigrant population that could potentially shift the vote toward more pro-immigrant policies. The state voted for Bill Clinton in 1996, who won handily against Bob Dole. The 2000 presidential election was notoriously close, with the state eventually going to George W. Bush after a lengthy recount process that gave him only a 537 vote lead over Al Gore. Bush won Florida in 2004. Then, Obama won in both 2008 and 2012, the latter election by less than 1% of the vote. Donald Trump went on to beat Hillary Clinton, 49% to 48%, in 2016. The politics are equally as close in statewide elections. The 2014 gubernatorial race was within 1% between former Governor Charlie Crist (a former Republican and Independent) and the incumbent Rick Scott (Republican). Scott became well-known for supporting Arizona's brutal approach to immigration, calling for the same sort of ID card and approaches to policing. This didn't happen, perhaps because of the political implications of doing so. Similar with health care reform – the current governor was against it, then for it, then against it again. Scott is term-limited and so he is ineligible for re-election in this year's 2018 gubernatorial race.

Many of these arguments surround the legal status of immigrants. Immigration law in the United States has seen a series of changes since the first immigration law was enacted—the Naturalization Act of 1790. The notion of an 'illegal immigrant' started with the Chinese Exclusion Act in 1882, and that was reinforced with the creation of the Border Patrol in 1924. Since then, immigration law has been variously exclusive to different groups. Currently, all documented immigrants and refugees must undergo a health examination in their home country prior to arriving in the United States, which could partially explain "the healthy immigrant" effect. Once in the U.S., it is recommended that all immigrants undergo a more thorough (unfunded for non-refugees) health screening at a local public health department in order to identify health problems (such as HIV and tuberculosis) and begin treatment. Immigrants arrive with one of two types of visas: those for immigrants seeking permanent residence and full citizenship in the U.S. (which have country-specific caps) and those for temporary workers, families, and students (which do not have country-specific caps). After initial health screenings, immigrants are entitled to different public services, if at all.

However, a large number of Americans seem to agree that undocumented persons should not be able to get access to things like health care because it might entice them to come here and then stay here. All in all, many politicians (pandering or not) and a large percentage of the Floridian (and American) public want to keep immigrants from coming here and hope to do it by restricting access to the sorts of services that keep immigrants healthy and economically secure. The conversations seem to focus on poor women coming here to start families and on people coming from low-income countries. The neoliberalization of the health care system since the 1970s has put an emphasis on the cost-effectiveness of care rather than on access—and health services have been re-imagined according to a market ideology, rather than through universal provision. In the U.S., this means that one's inability to afford health insurance is the most significant and immediate barrier to health care for individuals. Some of the characteristics of the American health care system that have significant implications for health care quality and access include the privatization of public hospitals and the consolidation of power by medical corporations (Whiteis 1998); the decline of primary care and the rise of higher priced specialists (Sandy et al 2009); higher financial burden on hospitals to provide care to the uninsured; and calls for cuts in public spending on programs like Medicaid that cover low-income families. However, there are contradictions within the current market-based approach. It is ironic that we have a market-oriented health care system that also prevents a whole group of people from purchasing insurance or participating in our current health insurance exchange. From a market perspective, it might make sense to allow predominantly young and healthy undocumented or new legal immigrants to purchase insurance coverage because it creates a larger risk pool and it could lower premiums. However, many uninsured immigrants work in sectors that do not offer insurance benefits, such as in agricultural work and construction. If someone, such as an immigrant, does not have coverage through their employer (as is the case for many uninsured people, regardless of immigration status), then they have to pay out of pocket, avoid care altogether, or use alternative (and potentially less effective or regulated) modes of medicine. More than likely, they will remain uninsured. As we have seen, uninsured people still require health care, utilizing emergency room services (following EMTALA) to obtain both emergency care or even non-emergency services. While hospitals can receive some reimbursement from Emergency Medicaid funds for the provision of care to the uninsured, these funds are being cut under the ACA (see Chapter 2). This is clearly very costly – more costly than providing preventative care or even universal care.

But why, if there is an economic argument here, does the fight against immigrant health care continue, even though the costs of not providing care exceed the costs of providing care? It can't be just solely a neoliberal argument – it is the intersection of neoliberal economics with anti-immigrant and nativist discourses that drive this bizarre system we currently have. The consequences of these issues are many, and current discourse (filled with misinformation) steers the conversation away from the important work of thinking about the social and public health costs of not providing care (Willen 2012). As Ortega (2009) notes wryly, prison is the only place that an undocumented person can receive non-emergency care. Even the ACA fails to provide equitable access to coverage. Not only does the law place barriers for immigrants to receive insurance coverage, but also the failure of states to expand Medicaid disproportionately impacts rural, Southern, black, and immigrant populations (KFF 2017). Political and public discourse explains this lack of equity as fitting for specific populations – punitive against unauthorized persons and low-income persons who are seen as criminals, too lazy to work, and so on. However, as Ortega (2009, p 203) has argued, "Excluding immigrants from public health care programs has not achieved the goal of deterring illegal immigration. Instead, excluding immigrants from federally-funded health care has not only adversely affected immigrant health, but also imposed significant burdens on states and hospitals." Because immigrants are singled out as draining American resources, native-born Americans evaluate and judge people marked by skin color or language differences, which further helps to normalize and institutionalize discrimination, essentialism, and racist/nativist attitudes toward others, regardless of status.

Conclusions

Is the deservingness to health care by immigrants a moral, ethical, or political question? Arguably, the accessibility and affordability of health care blurs the boundaries between all three. Can we accept that millions of human beings living in the United States have very limited opportunities for care when they get sick? Can we accept that, because of institutionalized discrimination against non-native persons, some people get sick and even die because they do not have the opportunity to receive treatment? Do all people have a right to health care? Do health care providers have an obligation, beyond a legal one, to provide care to someone that cannot afford it? It has become commonplace to avoid the moral questions in health care. We try to avoid moral issues – as messy as they are – by hiding in science and objectivity in health care, and yet we cannot escape them. The rise of ethics committees in hospitals and insurance companies attests to this.

However, political decision making cannot just be ethical decision-making, or else no decision-making would ever get accomplished. At the very least, there is a strong economic justification for providing some sort of health care to immigrants, regardless of legal status. Punitive measures that seek to put health care out of reach for undocumented persons do not deter illegal immigration; rather, they encourage poor health among immigrant populations, overuse of resource-strapped emergency rooms, and billions of dollars in Emergency Medicaid funding. Two major health care changes would relieve some of the economic burden on hospitals: removing the five-year waiting period for new (authorized) immigrants to receive Medicaid assistance and allowing all immigrants to participate in the health care exchanges, regardless of citizenship status. This would expand coverage to approximately millions of immigrants, potentially saving hospitals billions annually in unreimbursed expenses relating to care. In addition, citizenship status is key to accessing the health care system for immigrants, so making more opportunities for immigrants to obtain citizenship will expand access and thus decrease the economic burden of immigrant health care (Derose et al 2007; Leclere et al 1994). Immigration reform efforts should consider the possibility of changing the status of undocumented persons through an amnesty program, which would make these immigrants eligible for the changes associated with the ACA (Marrow and Joseph 2015). Additional funding would be needed for the community health centers that provide the bulk of the care given to low-income, uninsured, and undocumented persons. The most cost-saving approach in the long run would be a universal or single-payer health care system that provided basic care to all person residing in the United States. Some states have tried to implement subnational programs to care for the uninsured, such as Massachusetts and San Francisco, but these programs have had their own challenges (eg Marrow 2010).

Beyond policy, a more lasting solution would be to change the discourse around immigration from one of obligation, burden, and resentment toward one of justice and equity. Discourse about immigrants that centers primarily around their legality dehumanizes immigrants and erases the long history of immigration in the United States (Nagarajan 2013). The idea of an ‘illegal immigrant’ arriving to use American resources fuels resentment in the native-born mind that is perpetuated in the media and by politicians. If health care is a human right – and according to the United Nations and most other wealthy counties in the Global North, it absolutely is – we must work to insert messy conversations about morality, rights, and justice back into the political debates on immigrant health.

2 / Availability / *The Political Economy of Health Care in Florida*

"It all comes down to money. More money, better resources, better care" (personal communication, July 15, 2016)

Anti-immigrant and neoliberal policies come to impact the bodies of immigrant women in Immokalee in multiple ways, one of which is the availability of health care services. A population that has high rates of chronic diseases and that cannot receive the appropriate care – due to a lack of services or an inability to access those services for some reason – are at higher risk for worse health outcomes. Health care availability for the low-income and uninsured is actively influenced by state and federal policies and funding priorities. Using a combination of policy research, health services data, and interviews with health care providers and administrators, this chapter considers how the availability of care to immigrants has changed over time in Immokalee – which, although a specific context, shares similarities with other marginalized places across the United States. I argue that funding cuts serve as a means to enact anti-immigrant and neoliberal policies, denying immigrants (regardless of status), low-income, and uninsured people the right to care. This results in an inequitable burden of the total health care costs on hospitals, as well as the concentration of poor health outcomes among these same populations. In other words, services are becoming less available for the people that need them most, with hospitals and (to some extent) government shouldering much of the burden of the costs for care in our market-oriented health care system. These funding debates occur within the context of an already challenging rural health service environment – difficulty attracting enough health care providers, high health care needs, long distances to health services, and more. By looking at the ways in which current politics work to reduce funding to safety net health providers, we can see how anti-immigrant and neoliberal discourses become written into the health care landscape, serving as punitive political measures toward low-income, uninsured, and non-citizen populations.

The Changing Health Care System

Health systems are always in a state of change, shaped by the institutions, culture, people, and policies that constitute them. Much debate in the United States has centered around how to provide health care within a market-oriented health system and especially the high costs of trying to do so. The current cost of health care – provided and financed by a patchwork of various entities and organizations – is unsustainable. Estimates indicate that we are expected to spend upwards of 20% of our GDP on health by the year 2020. As a result, much of the national debate on health care focuses on the need to reduce costs of care while maintaining the market-based approach to health provision typical of neoliberal capitalism. Neoliberalism is a revival of Adam Smith's idea of letting the 'invisible hand' of the market allocate resources with as minimal government intervention as possible in order to foster economic growth. It is 'new' in that it is a reorganization of the political and economic arrangements in society under the goal of laissez-faire but now within a different global political economy, emphasizing deregulation and a roll back and privatization of social programs previously associated with the 'welfare state.' These changes were enacted globally since the 1970s through the work of Milton Friedman and his protégés at the University of Chicago, who advised Ronald Reagan, Margaret Thatcher, and many others on market 'freedom.' Though reducing government involvement and regulation of the economy is often touted as a selling point in neoliberal ideology, significant government interference is needed to produce the conditions needed for the free-market to flourish, such as breaking up unions (Williams and Marthappu 2013).

Today, discourses abound that emphasize a free market as the best way to allocate health care resources, in attempts by both Republicans and Democrats. In a time of unprecedented public debt, there have been many calls for both less spending and more revenue. Reducing costs often means cutting spending on government health care programs or decreasing the cost burden on the insurer through increased health insurance premiums, deductibles, and co-payments for the insured person – rather than addressing waste within the system such overtreatment, health insurance fraud, and unnecessary administrative complexity that adds up to at least 20% of all health spending (Berwick and Hackbarth 2012). Health care is often discussed as a commodity rather than a public good to be paid for with tax dollars. There is also much interest in decentralizing health care from the federal level to the state or, more ideally, to private industry, which replaces the social citizen with the consumer citizen (MacGregor 2001). Health care has thus become a consumer choice rather than a public good, with those who can afford it gaining access and the poor being left without adequate care.

Neoliberalism has impacts on places beyond just in health care. If we look at the broader determinants of health, we can see how neoliberal ideology has shaped communities through privatization, decreased access to public goods, poorer employment benefits, as well as divestment in urban areas and the ignorance of rural places as capital moves and accumulates unevenly. This has major impacts on people's ability to get a job, get a quality education, access the resources they need to maintain their health, manage the stressors and working conditions they face, and so on. Krieger et al. (1993, p100, cited in Whiteis 1998) explain the four primary ways through which social relations shape the patterns of health and disease we see across populations: "(1) by shaping exposure and susceptibility to risk factors, events and processes; (2) by shaping exposure and susceptibility to protective factors, events and processes; (3) by shaping access to, and type of, health care received; and (4) by shaping health research and health policy." Each of these areas have been impacted by neoliberal policies. For example, Whiteis (1998) and McLafferty (1982) have shown that capital has been divested from urban places, especially in predominately black neighborhoods – these areas were the most significant predictor of hospital closure in the 1980s. The result is poorer health outcomes and increased risk for poor health concentrated among particular populations and in particular places. In the literature review that follows, I will briefly discuss several key areas of health care that neoliberal capitalism has influenced in the last few decades, including health insurance and funding for hospitals, community health centers, and public health.

Health Insurance

The structure of our health insurance system shapes the health care system, as it is the primary source of funding for health facilities and the means to access otherwise expensive care for patients. Movement in the private health insurance industry has been toward consolidation of small health plans into larger ones and/or into for-profit status (Kongstvedt 2004). As of 2017, the five largest health insurance companies by market share are UnitedHealth, Wellpoint, Kaiser Foundation, Humana, and Aetna, and together they control around 40% of the health insurance market. At the same time, these insurers are adapting to new rules enacted under the Affordable Care Act. For example, they must now cover a basic set of benefits known as “essential services.” In addition, they are no longer allowed to deny coverage due to pre-existing conditions, nor can they refuse to cover the services needed by a high-cost patient, such as chemotherapy. While these constraints may push insurers to pay for things they had not had to pay in the past, there are a number of ways that insurers can still make profits in an increasingly profit-friendly health system.

Prior to the ACA, health insurance could be obtained through either your employer or through a government program, if eligible. If you could not access health care through your job – either because they didn’t offer insurance coverage benefits or because you could not afford it – you had very limited options outside of qualifying for a government insurance program based on income, old age, or disability. With the enactment of the Affordable Care Act and the creation of the health care marketplace, Americans now have another place to purchase health coverage. Rather than ensure universal coverage to all Americans, the marketplace introduced yet another market for health insurance companies to find consumers for their products. Their potential client base expanded through the addition of millions of Americans newly eligible for coverage. There has been some debate, however, on just how “profitable” these new insurance exchanges can be for health insurers. Much of their profitability depends on the demographics of the consumer base, and several companies have pulled out of the exchanges altogether. In addition, the Affordable Care Act sought to increase access to Medicaid coverage by reducing restrictions on eligibility and increasing the income maximum needed to qualify for the program. However, due to the devolution of federal power to the states, many states opted out of this expansion, leaving millions of people in the so-called ‘coverage gap’ – they make too much to qualify for Medicaid under the original eligibility requirements, but they make too little to qualify for tax subsidies to purchase insurance on the exchange. Oddly enough, this keeps millions of Americans from becoming consumers on the health care exchange.

Federal health coverage has itself seen changes in recent years. Medicaid – the federal assistance program for low-income families and individuals – is administered by the Centers for Medicare and Medicaid Services and it is funded by federal-state matching. However, since the 1990s, Medicaid has become increasingly marketized through a movement away from Fee-For-Service (FFS) toward a managed care model in most states. Managed care (such as HMOs and PPOs) is “designed to cut costs by shifting the financial risk from the insurer to the provider and the patient, [and it] has become the preferred payment model” (Whiteis 1998). This is achieved through approaches like increasing cost-sharing between patients and the insurer, incentivizing lower-cost care including preventative care, reviewing the medical necessity of various services, and moving toward ‘management’ of high cost patients and services. The idea is sold as a way for states to cut costs and improve quality of care for the poor, potentially even allowing states to expand access to more people with the saved funds found through market forces (Maskovsky 2000; Vladek 1995; Holahan et al. 1995; Henley and Clifford 1993). As Salmon (1975, p.613, cited in Rylko-Bauer and Farmer 2002) has noted, the "very structure [of HMOs] is designed for profit making" and sets in place the conditions needed for the corporatization of health care.

By passing the costs of care onto providers, a number of changes have occurred in the availability, provision, and accessibility of services that show a different reality than the one touted by neoliberal policies. For example, hospitals have had to increase prices, link payment to physician productivity, privatize, or face closure. In addition, providers have shifted away from poor areas with a large number of Medicaid patients or refused to accept Medicaid patients altogether because they receive less reimbursement due to the intermediary costs of a managed care organization (Horton et al 2001). Safety-net providers, who depend most heavily on Medicaid funds, have had to merge horizontally and/or vertically, while some have had to switch to a for-profit status (Lipson and Naierman 1996). Reduced costs has not meant an expansion of Medicaid coverage either, for example in Pennsylvania (Maskovsky 2000). While there has been some backlash against the perceived inefficiency of managed care, including high administration costs of nearly 30% of operating costs and accusations of profiteering, states increasingly use a managed care model to offer Medicaid. In 2014, 77% of all Medicaid enrollees are in a managed care plan, up from 40% in 1997 (KFF 2014b; Rosenbaum 1997). Medicare has also seen a movement in this direction through the Medicare Advantage program (Kongstvedt 2004).

Rural places have been particularly affected by the transition to managed care, because “there were fewer opportunities for cost savings or profit enhancement owing to the nature of rural markets” (Ricketts 2000, p.639). This is not a movement about increasing access; it is a push for increased marketization of health services to create more sites for profitability within the health system.

Hospitals

Processes occurring in the health insurance industry are also driving the structure and organization of hospitals. Since the enactment of the Emergency Treatment and Active Labor Act (EMTALA) in 1986, hospitals have increasingly had to shoulder the burden of covering the costs of the insured. All hospitals that receive Medicare funding must at least examine and stabilize anyone that enters the emergency room, regardless of their ability to pay. To help offset the costs of providing at least a minimum amount of care to the uninsured, hospitals receive Medicaid disproportionate-share hospital (DSH) funds. However, emergency room visits are not the only source of financial stress for hospitals – ER visits make up only between 2% and 10% of health care spending (DHHS 2008). Though ER visits by the insured are often blamed for the poor financial situations of many hospitals, a number of factors are at play that have put increasing financial stress of hospitals, particularly in places with a large low-income and/or uninsured payer-mix.

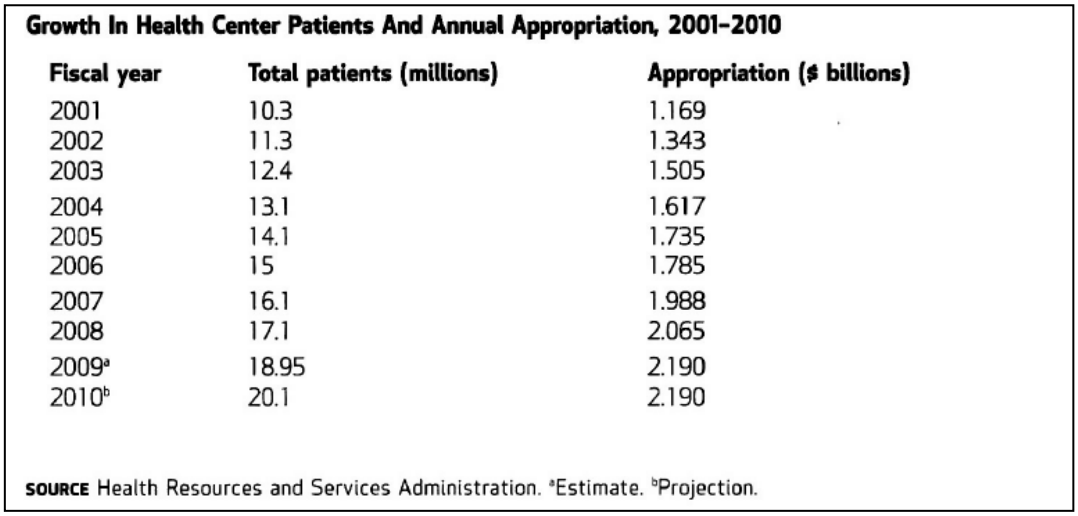
Medicaid payments are an important source of funding for hospitals. The expansion of Medicaid in some states has resulted in a changing payer-mix that includes a decrease in charitable care provided by hospitals. This has not been the case in states that did not expand Medicaid. As cost-cutting strategies come to dominate Medicaid financing, hospitals face increased financial pressures. As part of the Affordable Care Act, hospitals agreed to reduced DSH payments beginning in 2018. This was justified under the idea that hospitals will need less of this money because more care is being compensated through Medicaid and the insurance exchanges. This is expected to occur alongside other changes in supplemental payments to hospitals. To compensate for reduced payments, especially in the era of managed care and decreased Medicaid budgets, hospitals have had to charge for services that were previously free or low-cost to indigent patients, increase physician workloads or incentivize physician productivity, merge with other organizations, privatize, or even close (Whiteis 1998). To convert non-profit hospitals to for-profit enterprises, corporations purchase hospitals, then close some, consolidate others into local and regional networks, develop referral networks, and make cuts in services and staff (ibid.). The number of private, for-profit hospitals have increased from 11% in 1998 to around 19% in 2018 (AHA 2018). A recent study also found that nearly 35% of rural hospitals are vulnerable to closure, and this is especially true in states that did not expand Medicaid (Ellison 2015).

Hospital mergers and alliances have become the primary organizational strategy of hospitals, with a fewer number of health corporations owning hospitals in each state (Whiteis 1998). This is true for both non-profit and for-profit hospitals. For example, the top 5 non-profit hospital systems -- Ascension Health (MO), Trinity Health (MI), Kaiser Permanente (CA), Dignity Health (CA), and Catholic Health Initiatives (CO) -- own 220+ hospitals (Becker's Hospital Review 2015). This phenomenon is even more pronounced in for-profit hospitals, with the top five systems (Community Health Systems, Hospital Corporation of America, Tenet Health care, LifePoint Health, and Prime Health care Services) owning over 500 hospitals (Becker's Hospital Review 2015). Managed care has pushed health care providers to adapt through, for example, vertical and horizontal integration, which provides them with more private-pay patients and greater power when negotiating with managed care organizations (Lipson and Naierman 1996). However, "such strategies appear to be successful for community-based primary care clinics, but other providers-including hospitals that cannot quickly develop primary care capacity … are more vulnerable to health system changes" (ibid., p.33). Cost-cutting strategies are thus enacted as a means to stave off closure, particularly in places with a large number of uninsured and low-income people, such as rural and urban locations.

Safety Net Providers and Community Health Centers

With neoliberal economic policies, health care safety net providers – the institutions and professionals that provide care to the socially disadvantaged – have had to compete for funds in an increasingly profit-driven, privatizing system while also fighting against budget cuts for the services they provide (Horton et al 2001). For example, before the proliferation of managed care organizations in Medicaid, providers would be reimbursed using fee-for-service by the federal government. Medicaid revenues helped offset the costs of providing care on a sliding scale or to subsidize care for those who could not afford care at all. Once managed care organizations began acting as middle men between federal funding and safety net providers, FFS payments were reduced or organizations were paid a fixed monthly capitation rate, meaning less revenue for safety-net providers already operating on tight budgets. Charges have been levelled that MCOs have resulted in less accessibility by patients, higher workloads for professionals and clerical workers, increasing bureaucracy, and no change in overall health outcomes (Waitzkin et al 2002). Though federal funding to safety net providers has increased under both Presidents George W. Bush and Barack Obama, the increase has not kept up with the need to offer services to a growing number of patients. The idea behind the ACA was that there would be much fewer people who were uninsured and straining the budgets of these health facilities. CHCs and other safety-net providers are funded by a mix of mandatory and discretionary funding, so there are ongoing concerns that cuts in discretionary funding (which has to be approved by Congress) could significantly impact CHCs ability to provide care. Many of these facilities operate on an extremely narrow budget margin, so even small cuts in funding could result in the elimination of less cost-effective programs or even facility closures.

Table 1: Growth in Health Care Patients and Annual Appropriation, 2001-2010. From Iglehart 2010.



Growth In Health Center Patients And Annual Appropriation, 2001–2010

Fiscal year	Total patients (millions)	Appropriation ($ billions)
2001	10.3	1.169
2002	11.3	1.343
2003	12.4	1.505
2004	13.1	1.617
2005	14.1	1.735
2006	15	1.785
2007	16.1	1.988
2008	17.1	2.065
2009[a]	18.95	2.190
2010[b]	20.1	2.190

SOURCE Health Resources and Services Administration. [a]Estimate. [b]Projection.

When budgets get tighter, they have to find additional funding elsewhere and/or cut the services they provide, limiting their ability to provide comprehensive charitable services. This has led to a “convergence between nonprofits and for-profits in their treatment of the low-income population” through “increased internal bureaucratization, (2) expanded partnering, and (3) partial adoption of for-profit techniques and goals” (Horton et al 2001, p735). In other words, safety net providers have had to adapt to the challenging marketized context in which they provide health services in order to continue providing care to the underserved. Safety net providers have been relatively successful in this endeavor due to their ability to (and need to) network and partner with other providers to stay solvent (Lipson and Naierman 1996; Rosenbaum et al 2010). CHCs and other safety net providers are also aided by the fact that they offer primary care services, which are increasingly important to a system pushing for cost-effectiveness.

Safety net providers increasingly face other challenges too. For one, they are meant to be a safety net, designed to catch the few patients that fall through the cracks of the traditional health care system. Safety net providers, however, are increasingly relied upon to provide primary health care services to low-income, uninsured, and uninsured populations. They are also limited in their ability to provide non-primary care services, and providers often find it difficult to partner with specialty or nonemergency hospital care for their uninsured patients (Gusmano et al 2002). Demographically, an aging population means that more Americans are going onto Medicare and have chronic health conditions that require primary care management and specialty care. This can be a challenge for safety-net providers due to the cost of frequent visits and complex, chronic health problems. And, reports have shown that almost half of the areas designated as “medically underserved” in the United States are lacking a community health center in the first place.

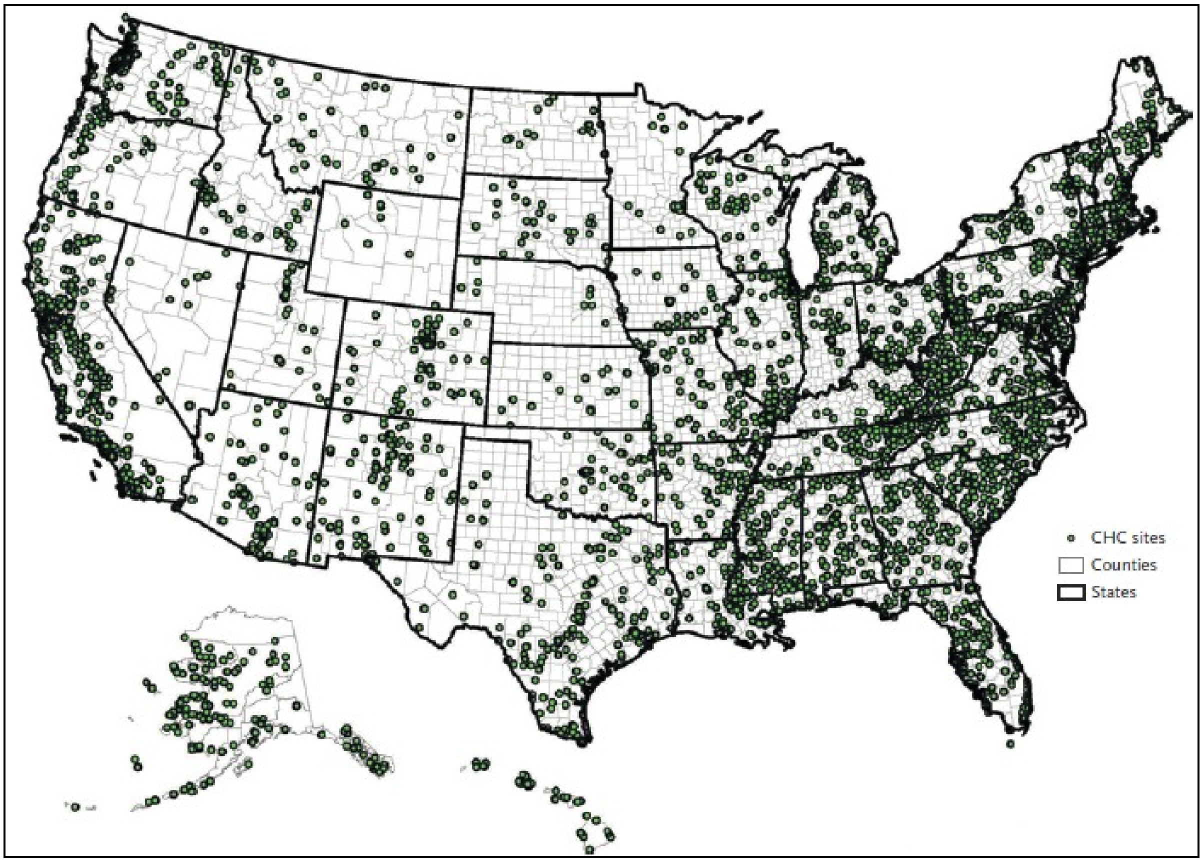


Figure 1: Distribution of Community Health Centers in the United States, 2008. From Adashi et al 2010, citing the Robert Graham Center 2010.

Ultimately, while community health centers and other safety-net providers may find that they have additional funding in some respects due to their provision of primary care, challenges in insurance reimbursement, access to insurance by their patients, changing demographics, and an increasingly competitive health service environment mean that they must adapt to survive, because without them, millions of Americans would go without health care.

Public Health System

It is worth mentioning that ultimately the most cost-effective approach to health – prevention – gets a lot of lip service from the health industry, and yet funding for public health research and programs remains less than 5% of all health spending. Public health departments used to offer primary health care to low-income and underserved populations;

since the 1980s, however, many health departments have moved away from primary care to focus on the ten "essential services" of public health, including disease surveillance, health education, and ensuring a competent health care workforce. The Affordable Care Act includes a number of provisions for public health and preventative care, including funding for tobacco cessation programs for pregnant women and incentives for health providers to offer preventative services with no cost-sharing. The ACA also provides a list of new research grants that agencies like the CDC can use to investigate infectious and chronic diseases. There is still room for debate though when it comes to federal public health funding as we have seen with fights over discretionary funding for Zika research. Despite the lip service paid to prevention at the federal level, however, state funding for public health has been volatile, especially since the Great Recession. As state budgets require balancing each fiscal year (unlike the federal budget), states strapped for money in difficult economic times often cut spending on social programs, education, and public health (Mays and Hogg 2015). The recession resulted in state budget cuts in public health that have not returned to pre-recession levels. This has meant a reduction in the services offered in local health departments, including HIV education and family planning programs. Many of these programs are outreach oriented and culturally appropriate for the state's immigrant communities. Across the US, numerous studies have shown a significant negative correlation between poor health outcomes and state/local health department expenditures, such as infectious disease morbidity (Erwin et al 2012), rates of low-birth rate in areas with high poverty (Bekemeier et al 2014), preventative deaths due to infant mortality, cardiovascular disease, diabetes, and cancer (Mays and Smith 2011), and incidence of HIV (Bousquet and Auslen 2016). Cuts in funding for public health and other social services falls right in line with neoliberal calls for less "welfare state" spending and a push toward private provision of health services.

In the rest of this chapter, I will discuss how these sorts of neoliberal policies enacted at the federal level have directly impacted the availability of care for low-income, uninsured, and/or im/migrant populations in Immokalee, Florida.

Methods

To find the data necessary to understand the relationship between health care funding and the availability of health services, I used a combination of policy research and analysis, data research, and interviews with health care providers and administrators. I started by doing policy research into changes enacted at the federal and state levels using search terms including ‘health care,’ ‘health insurance,’ ‘hospital,’ ‘health provider,’ and ‘public health.’ I used Florida’s Online Sunshine system to search state-level legislation, and Congress.gov to search federal legislation. I then timelined relevant policy information and did additional reading in both academic and non-academic news media sources to look for trends in health care availability and funding. To gain an understanding of the changes taking place in the local health system since the 1980s, I used facility websites and other publications to find additional information about specific facilities in the Immokalee area, including their organization and financing. Finding historical data for specific community health centers was challenging; however, I was able to find more general information on state and federal funding for these types of facilities. Hospital data was also difficult to find, because this information is proprietary; however, I was able to look at state patterns of funding for hospitals and the total amount provided as Disproportionate Share Payments. I was also able to read the annual reports of some local facilities that made that information available. State and local health department budgets, funded primarily through state funding, were publicly available.

After conducting this background research, I obtained the participation of ten health care providers (2 physicians, 1 physician assistant, 2 nurses, 2 health educators, and 3 administrators) to participate in a single, approximately hour-long semi-structured interview about health care availability in the Immokalee area and their experiences providing care in a safety-net facility (Table 2). Participants were identified through direct contact and referrals from other participants. Questions may have included topics such as funding, budgets, and variety of services offered by their place of employment (Appendix A). While I was not able to get line-by-line budgets for the local facilities, I was able to identify several patterns through interview material that show the connections between health care economics and health care availability.

Table 2: Health Care Provider Research Participants by Position, Location, and Job Type

Position	**Location**	**Job Type**
Nurse	Public health department	Refugee health
Health educator	Public health department	Maternal health
Health educator	Public health department	Sexual health
Nurse	Primary care	Chronic disease
Physician	Charitable organization	Ophthalmology
Physician	Primary care	Adult health
Administrator	Primary care	As expected
Administrator	Primary care	Nursing
Administrator	Primary care	As expected
Physician assistant	Hospital	Emergency care

Calls for cost-reduction measures in government have been particularly vociferous in the state of Florida, where a shifting demographic toward more foreign-born individuals have been accompanied by escalating anti-immigrant rhetoric surrounding the financial cost of providing services to an increasing number of low-income and/or immigrant populations. The current governor in Florida, Rick Scott, is one of the original and most vocal opponents of the Affordable Care Act. Former Florida governor and former candidate for the republican nomination Jeb Bush has been a strong opponent of welfare programs. Marco Rubio, current junior senator of Florida and also a former Republican candidate in the primaries, is well known for his role in trying to increase barriers to public assistance for immigrants, even those who came to the US legally, by advocating for things like long wait periods for benefits. Politically, there is much support for these barriers to health access, forcing many low-income and uninsured people to rely on health care safety net facilities to receive any sort of care. For this reason, I found it important to interview health care providers in a rural, low-income location with a primarily im/migrant population to understand how neoliberal changes taking place in the federal and state levels might be impacting the work they do at safety-net facilities.

Voices from Immokalee: Health Care Providers

The primary source of health care in Immokalee is a network of non-profit health care facilities that are classified as both a community health center and a federally qualified health center (Figure 2). This network offers general/family practice, pediatrics, women's care, dental care, and mental health services, as well as several on-site services including a pharmacy and a laboratory. In addition, there are a small number of other private providers not affiliated with the community health center that offer family medicine. There are no specialists in Immokalee as of this writing; however, the small planned community Ave Maria 8 miles south of Immokalee offers limited OB-GYN services (but no contraception).[1] There are no hospitals located in Immokalee; the closest is a small, private, for-profit hospital located 30-40 minutes northwest of Immokalee. This facility houses a 24-hour emergency department, a critical care unit, and a range of clinical departments, such as primary care, cardiology, neuroscience, oncology, orthopedics, and more. The most frequently utilized hospital – a large, private, not-for-profit hospital – is located in Naples, 45-60 minutes southwest. It is part of a system with two hospitals (700+ beds) and a variety of medical institutes that offer a comprehensive array of services, including a birth center, surgery, and emergency services.

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[1] Ave Maria is a relatively new planned community surrounding Ave Maria University, both of which were owned and co-run by Tom Monaghan, founder of Domino's Pizza. The school and community were designed to be a conservative Catholic enclave in inland Florida. The local OB-GYN office is open part-time and does not offer contraception, following the current teachings of the Catholic Church.

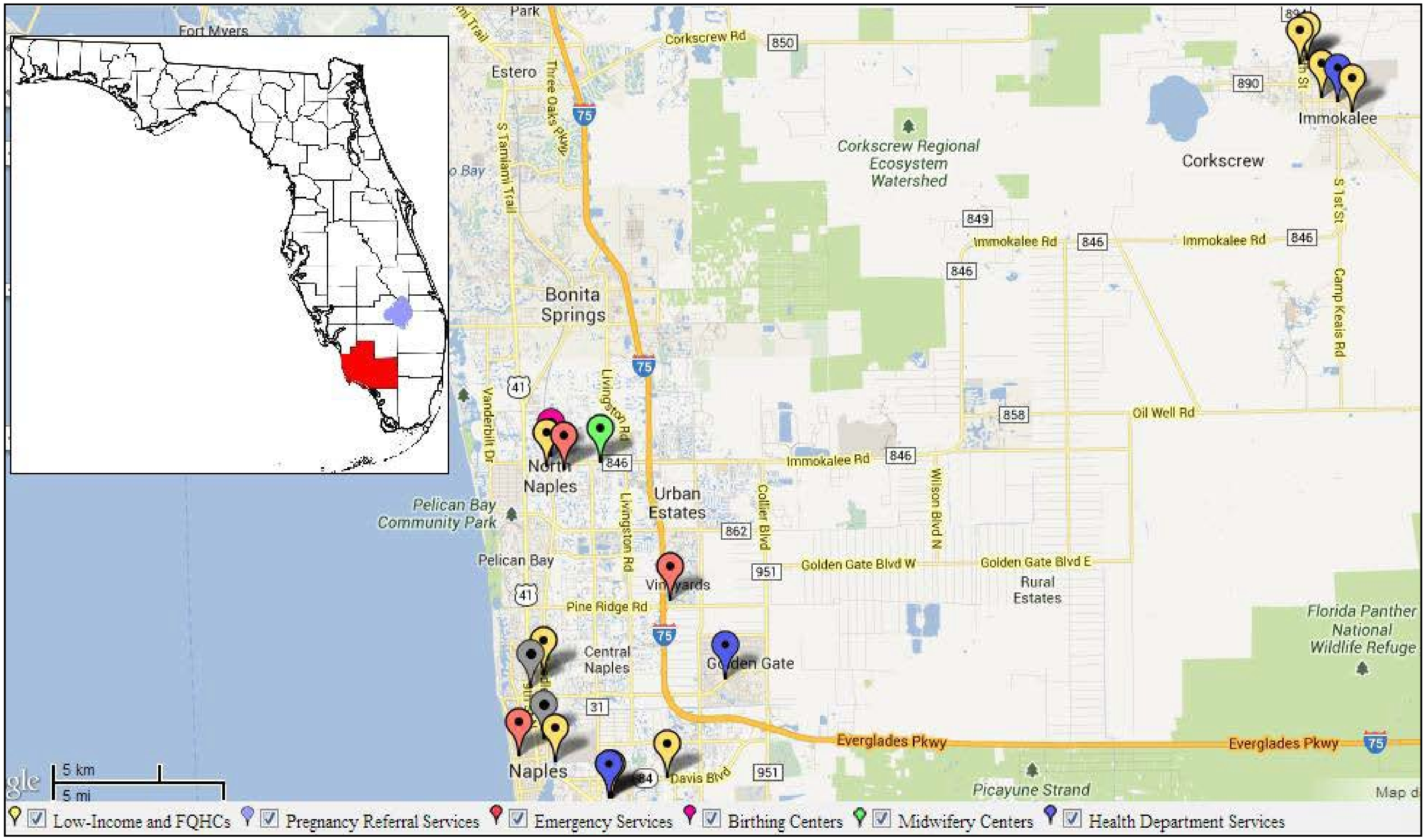

Figure 2: Health Care Facilities Offering Non-Specialist Care for Low-Income and Uninsured Residents, Collier County, Florida. Yellow pins indicate facilities providing services for low-income residents. Red indicates emergency services. Blue shows the locations of Health Department services. Pink is a hospital birth center, and green is a midwifery birth center. Grey indicates the locations of pregnancy referral services.

Because the community health center and the local public hospital depend on state and federal funding to provide services to a large number of uninsured and/or low-income patients, I conducted interviews with 10 health care providers and administrators to understand how changes in funding for these types of patients impacts the services they offer. Not all health care providers could articulate the political and economic processes at work in their place of employment, but all of them noted some of the changes that they had had to contend with as providers that provide a window into how state, national, and global processes impact the small town of Immokalee. These changes mirror those happening across the health system: restructuring of health facilities, volatility of funding for the work they do with low-income and immigrant patients, and challenges with staffing and availability of services in rural areas. I will explore five particular articulations of these challenges in more length, using extensive interview material to show how providers and administrators understand and negotiate a challenging health service environment.

Mergers and Acquisitions

In order to stay financially solvent – and thus able to provide much-needed health care services in Immokalee and the surrounding area – health facilities have opted to utilize corporate strategies such as restructuring and merging to reduce costs and maximize efficiency (Zuckerman et al 2001). This is similar to trends seen across the health system following the increased marketization of health care, particularly since the expansion of managed care in the USA and in Florida in particular. Approximately 77% of all Florida Medicaid recipients are enrolled in a managed care program, initiated by reforms enacted by former governor and former Republican presidential candidate Jeb Bush (KFF 2014a). As Lipson and Naierman (1996) have noted, this has been an effective method for community health clinics to stay afloat, and this has been true for the community health center in Immokalee. Founded as a non-profit in 1977, the organization started as two small trailers in Immokalee providing basic medical and dental services to the town's poor and underserved migrant community. As Immokalee's population grew, so did the organization in response. While rural hospitals were closing across the country in the 1990s, this non-profit was building new facilities and expanding their options for care. It now has 21 health care sites across Collier County as well as a mobile children's health care unit, several of which were incorporated into the network of facilities through acquisition of previously existing organizations and facilities. They have several projects in planning to expand operations, including additional services for pregnant women (through a take-over of a Naples OB-GYN office), an urgent care facility in Naples, and elderly care in Naples. Partnerships also exist between the organization, public health departments, private health facilities, and higher education. An administrator at one organization that was subsumed within this network of health care facilities explained that they had lost funding due to changes in Medicaid reimbursement and so had to merge with the organization to continue offering services to pregnant women. Changes in reimbursement and funding meant that money that had been coming into the organization regularly dried up quickly, and they were forced to either merge or close. The merger allowed the organization to almost triple the amount of Medicaid reimbursement they received for the services they offered, in addition to receiving additional grant money for various programs they could now offer. These types of agreements allow smaller organizations to stay afloat and continue offering their services, and the trend toward partnerships and networks in Collier County mimics trends we see across the United States.

The local hospitals also provide a prime example of how national trends can be seen at the local level. Two private, for-profit hospitals are located outside of Immokalee – one in Lehigh Acres, 30-40 minutes northwest of Immokalee; another is in Naples, 33 miles southwest of Immokalee. Each of these hospitals has undergone several changes in the structure and organization of their facilities. The Lehigh Acres facility is an 88-bed hospital with emergency services and rehabilitative care. It was built in 1965 and has undergone several expansions. A health care provider at the Lehigh Acres hospital explains the changes his employer has been through in recent years:

> It is technically [a for-profit hospital], it just got recently purchased by a group called Prime Health Care out of California. They typically buy distressed hospitals and Lehigh has been considered a distressed hospital due to its payer base, due to the fact that it has lost a significant amount of money through a variety of owners over the past several years – probably the past 8 or 10 years – and Prime Health care has a history of taking poor performing for-profit hospitals and turning them into non-profit hospitals, so they have a foundation that does that. … It was most recently a part of a CHS or Community Health System hospital and prior to that it was part of HMA – Health Management Associates. HMA was based out of Naples,

> Florida. They owned a number of hospitals in Florida. … CHS bought the entire group and has since sold off Lehigh Regional because it was underperforming for what their standards were, but they did keep the Physician's Regional chain together. So that's still owned by CHS, where Lehigh Regional has now been sold off (personal communication, July 15, 2016).

The corporation currently managing the hospital, Prime Health care, is ranked fifth in the United States in terms of number of hospitals owned.

Similarly, the Naples for-profit hospital has undergone several changes in ownership. Originally built in 1999, the hospital was purchased in 2006 by Health Management Associates, which was a large hospital corporation based out of Naples. HMA, which at one point owned both local for-profit hospitals, owned over 70 hospitals across the country. However, the company was under investigation for unethical practices, including Medicare fraud. A 2012 *60 Minutes* documentary interviewed one hundred former employers who alleged that the company encouraged a high rate of hospital admissions (especially patients 65 and older), regardless of medical need (Hornblower, et al 2012). A New York Times article from 2014 lists several lawsuits brought against the company for Medicare and Medicaid fraud (Creswell and Abelson 2014).[2] Perhaps as a result of this bad press, HMA agreed to sell to Community Health Systems in 2013 for $3.6 billion. CHS, a publicly-traded hospital corporation started in 1985, grew through acquisition of several companies including HMA and now owns over 150 hospitals with over 26,000 beds – the largest hospital company in the country by number of hospitals owned.

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[2] On a related note, the current governor of Florida, Rick Scott – one of the earliest and most vocal opponents of the Affordable Care Act – got his start in health care management. He was one of the co-founders of Columbia Hospital Corporation, which later became Columbia/HCA, one of the largest for-profit health care companies in the US. He resigned following an investigation into the company's Medicare billing practices. The company (but not Scott) was later found guilty of several felonies and settled with the federal government with the then-largest fraud settlement in US history. Scott left the company to become a venture capitalist, and then later the two-time Republican governor of Florida.

Fluctuating Insurance Funding

The management histories of these particular for-profit hospitals encapsulate the types of changes we see happening in hospitals and clinics nationwide, particularly ones struggling to stay afloat with a large low-income and/or uninsured population:

> I think one of the reasons that the hospital struggled for many, many years is the payer mix. There's a large percent of the population that have no insurance and the hospital ended up writing that off and that's a huge issue. Hospitals around the country, certainly around southwest Florida have the same issue. … So, the hospital has tried a number of things over the years to try to increase [payments]. It typically doesn't work because if, you know, they will not typically decline folks for treatment. If someone has an emergency, they have to treat them, regardless of their ability to pay …. And it does put a tremendous strain on the emergency department. … But 60% of the hospital are those types of patients that, in theory, probably, you know, at least half of those could quite easily be seen in a primary care facility, so, but they choose to come to the emergency department (personal communication, July 15, 2016).

Because of the large portion of Immokalee's residents that are uninsured or underinsured, the local hospitals and the network of health care facilities depend on either Medicaid payments or grants to help cover the cost of service for these patients in addition to tax benefits for writing off charitable care. When asked where most of their funding comes from, one administrator at an organization acquired by the primary health care network in Immokalee stated:

> HRSA. It's grant money, and then, in addition for the Medicaid patients, we get what is known as a wrap fee, so let's say the Medicaid reimbursement, and this is part of us merging … was a benefit, is, let's say I would say for a visit I would get $47, well, with the [acquiring organization], seeing that same patient, we get $146 with the wrap rate, so there, the insurance is then private insurance, there's all kinds of different grant monies that come in – we've got behavioral health grant money, we had a scribe grant. I still get some Healthy Start monies for the Healthy Start screenings and assessments, but their funding for prenatal care, that went away a couple of years ago, so … and then like I said, a lot of it is HRSA grants and the revenue that we're able to generate from the patients. We're actually having a retreat next Friday and, for the goals and strategies and one of them is going to be cash collection, to try to increase our cash collections, because there is a lot of patients that don't want to pay, but we're going to look at strategies to start to push that (personal communication, April 8, 2017).

The same administrator explained in further detail the impact that changing funding had on his previous organization, which was acquired by another organization in 2014:

> April of 2014, Medicaid changed the reimbursement process, so I got some grant money from the county. I was, at the time, getting Healthy Start grant money. That went away. And that basically kept the [acquired organization] alive, because a lot of these patients are undocumented, and so they are paying a minimal fee. We get 'em the emergency PEPW [Presumptive Eligibility for Pregnant Women – a form of temporary Medicaid coverage], so we get money for the delivery, but I'm paying the doctors for those deliveries, you know? So, the funding was very tight. I mean, we always operated from payday to payday, kind of operation. And then in April of 2014, Medicaid changed the reimbursement process. I used to actually have two Medicaid workers that I *paid the state for* on-site with us, so once the undocumented would deliver that baby, I could get the Emergency Medicaid put through the same week. So that week, I would get them approved. That week I could bill for the delivery, so I always had a cash flow going, and when they changed that Medicaid reimbursement … the funds started to dry up and we were on the verge of going extinct and so we were able to structure a deal with [current employing organization] where they took over the operations and we were merged with them in July of 2014 (personal communication, April 8, 2016).

The organization, which provided women's health care services to the indigent in Naples and Immokalee, operated on such a tight budget that even slight changes in reimbursement or the availability of funding for their work could mean the demise of the organization.

This has been true for hospitals as well. Under the Affordable Care Act, for example, funding for the Disproportionate Share Hospital program is to be reduced by about $16 billion between 2014 and 2020. According to the Florida Hospital Association, Florida already receives less DSH payments relative to other states due to an arbitrary cap on these payments frozen since the early 1990s (FHA n.d.). The state currently receives less than $55 per uninsured individual, while other states receive up to 10 times that much (ibid.). Hospitals in states like Florida (a state that opted out of Medicaid expansion) would have to offset the financial shortfall by either providing less uncompensated care or shifting costs to the privately insured in the form of higher costs. A recent study cited Florida as one of three states most affected by these cuts (Dorn et al 2014).

All of the administrators expressed the importance of Medicaid and Medicare funding to the work they did and some frustration at getting enough funds to do that work. While eligibility requirements for Medicare –the federal health coverage program for people 65 and older – are relatively straight forward (age and/or disability), Medicaid requires the applicant to meet a variety of eligibility requirements based on income per family size, total resources, years in the country, and more – criteria that have become increasingly more stringent since Clinton's welfare reform bill in 1996 (see Chapter 1). Different types of Medicaid also have different requirements. For example, qualified low-income pregnant women can receive Medicaid for Pregnant Women; however, low-income immigrant women (both undocumented and those in the country for less than five years) are ineligible to receive this assistance. They can use Emergency Medicaid to cover the cost of the delivery at a hospital. Fluctuations in the ability of a pregnant women to receive Medicaid impacts the ability of health care providers to do their jobs in a way that is economically sustainable:

> If a patient comes in, it's a life-threatening situation or labor is imminent, I mean, I can't decline them. I mean, our hospital does not have labor and delivery services. … I mean, I've had patients come in who are pregnant and it's like, well, have you had OB care? Well, no. Where do you think you were going to deliver the baby? … well, I'm just going to show up here. Well … you need to plan ahead, so certainly EMTALA, you know, covers those things, so yeah, the patient comes in, we can't handle it, they have to get transferred, especially if you're talking about helicopter, then you're talking really expensive. … Yeah, I mean, if a patient that can't pay, I mean it's like, someone is eating that [cost] (personal communication, July 15, 2016).

A health educator explained that the ability to get women access to Medicaid enables the mothers to receive prenatal care earlier in their pregnancies, care during labor and delivery, and physicals after delivery for up to 60 days (personal communication, July 3, 2014). In addition, children born while under Medicaid coverage automatically receive coverage for their first year of life. This means that all of these services would be reimbursed to the health care providers by the Medicaid program – without this funding, this care would have to be provided as a charity that could be funded through fundraising or partial tax write-offs. A physician assistant at a local hospital discusses what that means for his job:

> …if the patients don't have or aren't eligible for Medicare and Medicaid and they don't pay, then we still have to provide the resources, the physical resources of the staff. Any resources, such as you know, splinting, suturing, x-ray, CTs – all of those have to come about, *so if you have a large non-paying population and they keep cutting Medicare, well, that means that*

> *they either don't update equipment or you're dealing with short staff*, which happens quite a bit – again that's a nationwide thing, not just necessarily a local thing… (personal communication, July 15, 2016, my emphasis).

Florida was one of the states that opted out of the Medicaid expansion written into the Affordable Care Act, and the Kaiser Family Foundation (2014) estimates that 764,000 Floridians would have received coverage under the expansion. As one nurse noted, "So if you're not pregnant, and you're not disabled, and you're younger than 65, usually you're without insurance. Now, these people could be eligible for the Affordable Care Act insurance, but most of them are too poor" (personal communication, January 29, 2015). He continued:

> Yeah, but that's why we have community health centers, because it was put here to address that need, and so we have a program called the sliding fee scale, which is if they can show that they are below poverty—which most are—they can be seen for 20 or 25 dollars for a doctor's visit and everything else is kind of prorated down. Which covers most routine primary care, pretty … fairly well. Although some people don't have the 20 dollars (personal communication, January 29, 2015).

To temper the unpredictability of funding and reimbursements, employees at two different facilities said that there was at least some interest in increasing cash collection to generate revenue from patients – both collection at time of service and collection of unpaid medical bills. The difficulties of obtaining payments from people that have very little money as it is cannot be understated.

Some of these patients are eligible to receive health insurance coverage, which would provide payments to their health providers, but with the failure to expand Medicaid, many go without care or they pay a very small sliding scale fee to their providers -- less than they would be reimbursed by Medicaid. While the ACA created the health insurance marketplace where families earning more than 400% of the FPL could purchase health insurance, administrators agreed that the changes were positive and negative:

> HA2: [The federal health insurance marketplace] was real rocky at first, because the plans that they offer, we aren't in network with them, so we had to turn away some of the plans … but now we're pretty much in network with most of them.

> HA1: And that was year two, and you know, they did end of year reviews after the enrollment period ended, and so we had reports we had to file and that was throughout the country, the plans they're offering, no one was taking it, so what good is it? So that was in year 3, they had went and were able to get decent fees from them and sign with those insurance companies and that's what it was all about was fees, you know? That's why [particular insurer] didn't participate.
>
> HA2: And actually, I think it's still cost for them, because a lot of them don't understand the plans still. They come in and they're like, I have a $5 co-pay, but you have like a $3800 deductible! [laughs] And they're like, no, they told me I'm only paying $4. Ok, you're going to pay the $4 today, but you're going to get a bill! [laughs] Because they have so, their deductibles are ridiculous, because they're trying to stay with the lower plans. They're not understanding that that's costing them the deductible to be higher, so that's one of the issues with them that yeah, I have a $4 co-pay, $10, but it's not, it's ….
>
> HA3: It's more expensive than other plans, yeah.
>
> HA2: It is, it is, definitely it is. Definitely (personal communication, April 8, 2016).

Similarly, an administrator explained that:

> I actually had a gentleman that came in, and his [federal marketplace] insurance only covered physicals. That's all it covered, physicals. He came in and he was like, why are my visits for my children getting denied? So I ended up calling and speaking with a representative and she's like, it only covers preventative visits … But for non-covered services, we can still offer the sliding fee scale, so if you come in and you're going to have an IV inserted and it's not covered by insurance, we can still offer you our slide, a discounted rate, for or services (personal communication, April 8, 2016).

One administrator admitted that many of their uninsured patients had decided to forego coverage available to them on the marketplace because the penalty for not having health insurance would be less than the total money paid out in deductibles, co-pays, and the like (personal communication, April 8, 2016). This leaves many of their patients paying on a sliding scale; however, sliding scale can be a challenge with a large low-income population. One hospital worker explains the changes in their policy for sliding scale:

> The hospital at one point had – or had tried – that is someone didn't have insurance, they had to pay a $100 co-pay for lack of a better term, up front. That lasted about six months. That was done under HMA. I had heard talk

> Prime was going to bring it back. It was supposed to start June 1, hasn't started yet, so, I don't know (personal communication, July 15, 2016).

It was not financially "worth it" for this hospital to pursue a co-pay from patients that did not or would not be able to pay.

In this situation, it would clearly be beneficial for providers of low-income and uninsured (or underinsured) patients for their patients to be able to access affordable health coverage, such as through Medicaid. One nurse explained that the expansion of Medicaid would greatly benefit the work they did, especially with the Haitian population in Immokalee, because:

> If they would expand Medicaid, that would cover almost everybody. Which they could possibly do, you never know. That would solve … more than half of the problems with Haitian women. 'Cause most of 'em do have residency. Its not like the Mexicans, where so many of them are undocumented. Almost all of the Haitians are documented, so they could benefit (personal communication, January 29, 2017).

However, one physician noted that Medicaid reimbursements were increasingly tied into patient surveys and other metrics of quality, an additional burden on health providers:

> I mean, the government certainly put more … standards isn't the word, but more evaluation tools, you know, based on patient surveys and things like that. I don't know how accurate and I don't know how fair that really is, um … you know, you may have hospitals that, kind of speaking in general terms now, hospitals that their patient population fills out the survey and they love the hospital, and then you may get hospitals like ours that the patients, either the survey never gets to them or doesn't fill out, so you get half as many surveys and maybe they're not as good so it looks like the hospital is bad, but in fact it may not be, it may just be the population that it serves. The government is now tying that into Medicare, Medicaid reimbursement, so that's kind of a big thing that all hospitals are looking at … Sometimes, it is a question of the numbers not truly reflecting what's going on (personal communication, July 15, 2016).

When asked whether he saw state or federal politics impacts the work that his employing organization did, one administrator remarked: "Yeah, let me answer this for you real easy: We actually have a lobbyist that works for us" (personal communication, April 8, 2016). Even though most of the providers and administrators I spoke with were relatively apolitical, it is clear that state and federal health politics impacts the jobs that they do.

Funding Changes for Preventive and Primary Care

In Immokalee, preventative and primary care is available, including public health services (offering immunizations, WIC, and health education), primary care for children and adults, psychotherapy in English and Spanish, dental care (which also has a mobile unit) and mammograms (also offered via a mobile unit). Most providers and all administrators expressed that they had noticed changes in funding and subsequent changes in the availability of certain services in recent years. For example, one health educator noted that, "As Healthy Start, I don't know *exactly* how the funding is, but it is, it's changed. It's changed … we have to do the services in a certain way so we can … keep our funding" (personal communication, July 3, 2014). While it is difficult to pinpoint any particular policy or legislation that is impacting how each program or organization offers preventative or primary care, most of the providers I spoke with echoed the above sentiment – funding has changed in recent years and that impacts how they offer services. Not all of these changes have been negative. For example, with the American Recovery and Reinvestment Act stimulus bill passed in 2009, funding was made available for (among a list of things) health information technology investments and incentives ($25.8 billion), community health center funding ($2 billion), as well as prevention and wellness ($1 billion). The community health center in Immokalee benefited from this:

> "Well, when you had that recession, and there was the stimulus, remember that? We got a lot of money to renovate our center. That was part of the stimulus. Because it was that construction money. And it wasn't so much to increase funding for what we are doing, but we got money to renovate our place and um, with the … Affordable Health Care Act [sic], I think that gives us more funding …" (personal communication, January 29, 2015).

The Affordable Care Act also directs additional funding toward preventative and primary care initiatives. For example, the ACA established the Prevention and Public Health Fund that currently provides nearly $1 billion a year for grants and funding related to a number of public health initiatives, including diabetes prevention, suicide prevention, and increased vaccination coverage. The creators of the ACA also foresaw a rise in primary care usage with additional health coverage options, especially among low- to middle-income families and in geographic locations with significant numbers of newly eligible uninsured persons. To meet this rising demand for primary care services, the ACA enacted several provisions including temporarily increased Medicaid and Medicare reimbursement rates, grants to support new Patient-Centered Medical Home pilot projects, scholarships and loan repayments for primary care providers, and additional funding for Federally Qualified Health Centers (Abrams et al 2011). The primary health care provider for low-income and uninsured individuals in Immokalee qualifies as a FQHC and receives some of this additional funding, which has allowed them to expand some of the services they offer.

Beyond federal funding for preventative and primary care, there is interest within the health care industry to reduce health care costs. For example, one nurse said this was an interest of the local Medicaid Managed Care plans:

> Also, there's the Florida Medicaid Managed Care programs, and I think they're getting more money also to do preventative care. The one that we have over here is called Integral. It's one of the big managed care plans out here and it's actually owned by this company and uh, they recently hired a dietician and a diabetes educator (personal communication, January 29, 2015).

Prevention of chronic disease would certainly reduce the overall costs incurred by insurers to provide health coverage to population that are deemed multiply at-risk of poor health outcomes. In addition, two administrators at a primary health care facility explained the relationship between prevention and primary care to emergency room usage:

> HA1: There's [reimbursement] going to more into preventing them to end up being in the hospital, so we're trying to get prepared for that…
>
> HA2: We have met with the ER department and have had strategy meetings of, you know, how can we reduce the number of our patients going to the emergency room, so we had started working with them to try to reduce ER visits. Additionally, they just opened [a emergency service facility] … and that's a contract group, but they did come out and meet with us as far as trying to reduce the emergency room visits… (personal communication, April 8, 2016).

However, these same administrators admitted that it was challenging to emphasize primary care, especially for adults. Their adult practice consistently loses money, which they have to make up for through the much more revenue-producing pediatric care department.

Changes in Needs for Specialist Care and Charitable Care

A major challenge associated with the increased emphasis on primary care is the additional need for specialist care for patients who are newly identified as needing these types of services. Specialty care is still much-needed to treat issues like cardiovascular and obstetrical problems. These services are not generally available in Immokalee; as of this writing, there are no full-time specialty physicians working in town. The local community health center does have the ability to offer some specialty services on a limited basis such as an infrequent visiting pediatric gastroenterologist and plans for a sleep specialist, plus they have a privately-run pharmacy with x-ray and lab on-site. Services noticeably missing in Immokalee include emergency or urgent care services, most specialist care, including local OB-GYN services (several local birthing centers have closed their doors, leaving only one birthing option about one hour away), a nursing home or other geriatric care facility, all other specialties not otherwise listed, and a variety of health care providers trained in languages other than English or Spanish. The closest specialists would be a few in Lehigh Acres (about 25 miles northwest of town), with many more options for care located in both Fort Myers (about 35 miles NW) and Naples (35 miles SW).

With all of the newly insured patients and many remaining uninsured altogether, the community health center in Immokalee has an increasing number of patients that require specialty care beyond the scope of the services they can provide in Immokalee. One nurse explained that to keep up with all of the new referrals, they expanded their ‘referral department’ to help connect their patients with specialists in surrounding cities:

> If somebody needs a specialist, they have to be referred out. We have recently expanded, quite a bit, our referral department, because used to be people would get referred to specialists, but since they didn’t have the money or the transportation or the language, they never went. But we have now 5 people who are working in our referral department, and we didn’t used to have any. And that’s all they do is make arrangements for specialist appointments and transportations for the people who are referred here, so that’s really good.
>
> Me: And that’s recent?
>
> Yeah, that’s within the past year or two … so that’s something. I think that was funded too federally, because we never used to have the money for something like that, so it must be more funding for that … … it’s hard to get referrals to specialists. If somebody is referred by the emergency room,

> theoretically at least, the specialist has to see them at least once, even if they don't have money. Whereas if its a private hospital, they don't have that rule. And, it doesn't always work, because a lot of times the specialist still wants money, but theoretically, they're supposed to be seen at least once if they have an emergency room referral (personal communication, January 29, 2015).

In a market-based health system like ours, specialty care is available in markets where their patients can pay – not rural, low-income areas like Immokalee. This opens up the additional problem of transporting people from Immokalee to specialists in surrounding cities.

Similarly, a physician assistant at a local emergency room said they often saw patients (especially uninsured patients) that needed specialty care. In those situations, they would provide a list of referrals to the patient and hope for them to follow up on their own, despite the challenges in doing so:

> I mean, we'll have patients that come in with a fracture, so, we'll x-ray them, we'll put on a splint, but we'll tell them, you need to follow up with an orthopedic surgeon. You know, we give them the names of two or three local surgeons, but they may or may not work on sliding scale or work on, you know, taking patients that don't have insurance and don't have the ability to pay. That kind of becomes a problem, you know, we refer them to the [local community health center], but then again, they are going to be in a long line of folks. You know, and then that's hard, because a lot of the, you know, the orthopedic surgeons are in private practice and they may not be able to afford to do a lot of charity care (personal communication, July 15, 2016).

Charity is ultimately the only option. When asked how people can receive care if they do not have health insurance or if they do not have the ability to pay, a nurse explained:

> Me: … you said sometimes people might not be able to afford [care]? …
>
> Often! [laughs] Sometimes even when they have Medicare. Like, there was a lady. Her medicines were 8 dollars. She only had 5 dollars. So we have a special fund, we were able to give her 4 dollars [sic] to cover the rest of her medicines.
>
> Me: What do they do if they can't afford [care]?

> We have a fund … and we can help people about 20 dollars every three months. That's money we raise ourselves through appeals to the staff, to clubs in Naples, and churches. It's like a separate little pool of money that we use in emergencies, but you can't depend on it because there is only a little bit of money there. Each person can only have a little bit.
>
> Me: So then the alternative would be the emergency room?
>
> Going without. … Because the emergency room won't buy you medicine. They only give you a prescription (personal communication, January 29, 2015).

Many patients thus end up relying on charitable care to obtain the resources they need – specialty care, medication, and other services that do not qualify as 'primary care' per se. In other words, rather than serving as just a stop-gap means to get people care, it serves a critical role in the provision of health services in Immokalee.

The lead health provider at one Naples-based charitable non-profit organization that patients may be referred to for additional specialty care explained to me that there was a significant amount of interest for their assistance in Immokalee. They would provide outreach through events at health fairs and the local school system. They would also receive referrals from a local hospital – a hospital which obtains a significant amount of grants, funding, and resources to care for the uninsured, while the non-profit operated on a shoestring budget. The particular services they offer – eye care -- requires a significant amount of expensive equipment, which they had to raise the funds for through local events appealing to wealthy Naples residents and through a grant obtained from a local community service group. The ninety-year-old physician I spoke with often found himself working many hours to keep the organization afloat, at once providing care in a busy clinic, conducting outreach events, and writing funding proposals.

Thus, Immokalee now has more referrals due to some increase in access to health coverage care as well as an increase in health needs associated with chronic health conditions. These needs cannot be fully met, however, as specialties are both unavailable locally and out of reach financially for many Immokalee residents due to our market-based system of offering care. This means that patients in Immokalee must either go without care, or depend on a relatively limited number of charitable services offered. These charitable organizations and health care providers offering charitable care are constrained financially, often severely so, further limiting the care that Immokalee residents can receive.

Lack of Health Providers

To offer health care, a facility must have health care providers willing to provide it in a location. As a rural health service environment with a large low-income, uninsured, non-English speaking immigrant population, Immokalee faces many challenges in attracting and keeping health providers. All of Immokalee is a Health Provider Shortage Area in primary care, mental care, and dental care as designated by HRSA, which means that the population-to-clinician ratio is greater than 3,500 patients to every 1 primary care provider, 5,000 to 1 for dental health care, and 30,000 to 1 for mental health care. The area also has a designated Medically Underserved Population, calculated using an index that takes into account the number of primary medical care physicians per 1,000 population, infant mortality rate, percentage of the population with incomes below the poverty level, and percentage of the population age 65 or over. This indicates that there is a high need for services that are not currently being met. There are a number of factors that influence the availability of health care in a particular place or to a particular group. In our market-based health care system, political and economic factors are key. For the most part, health facilities are located based on market factors, except where government gets involved to provide services in less economically-desirable areas. However, government care depends on state and federal funding to ensure equitable availability of care.

When I asked a group of administrators about hiring, they all laughed: “They’re always hiring!” (personal communication, April 8, 2016). This sentiment was echoed by a physician assistant from a local hospital:

> … there’s always a shortage of physicians and PA’s and advanced practice providers to be able to come in and provide the service. Being a smaller hospital, they may not be able to pay as well as the larger facilities, so I think that’s an issue. A lot of times, people will come in, stay for a short period of time, then move on to a different facility. A larger facility, obviously, has newer facilities, more resources, new equipment, so I think that is certainly a challenge (personal communication, July 15, 2016).

Similarly, a nursing administrator at a health care facility admitted:

> I think the last time HR looked, we have like a 21% leave rate, turnover rate, which is pretty good in this business, because there’s so many nursing jobs out there … and our pay, we can’t be as competitive with [a hospital in Naples] (personal communication, April 8, 2016).

The challenge of staying fully staffed and attracting quality talent to open positions in a resource-poor environment like Immokalee exists across most rural and urban areas in the United States. Newly graduated physicians are flocking to higher-paying specialty fields in the suburbs, rather than primary care practice in rural areas that offer lower pay and less community resources. Even health care providers themselves commented on how difficult it was to find and keep other health providers in Immokalee, especially ones able to offer culturally appropriate care to the population they serve – predominately low-income, non-English speaking immigrants. When I asked one nurse about a recently hired doctor that spoke Haitian Creole, he remarked that “He was hard to get” (personal communication, January 29, 2015). Several other providers expressed an interest and a need for additional Creole-speaking providers due to the increasing demand for health services by a growing Haitian population. One health educator stated that an important step in treating the entire community in Immokalee – not just the Spanish speakers – would require more hiring, especially staff that speak Creole:

> The first thing I would do, I would hire Creole speaking workers, ok? ... I would hire for specific positions. I would hire someone else too, to be there in the family department/care, or the dental, … not only that, I would hire an advocate that would give Haitian women and men a voice in terms of what [is available] to them, because I’m sure there’s a lot of things available to the Haitian community, but there’s no one there to tell them about it, you know? (personal communication, July 16, 2014)

Not only are there a limited number of physicians interested in working in Immokalee, but there are even fewer that are able to speak Creole or another local language.

Attracting and keeping health care providers has been an ongoing challenge in Immokalee, but additional changes associated with the Affordable Care Act that enable millions of additional Americans to receive coverage mean many more providers are needed. In Immokalee, where there is already a shortage of providers, many foresee the need for more nurses and so-called ‘mid-level providers’ (nurse practitioners and physician assistants) to fill in those gaps in physician coverage:

> …the theory was that the Affordable Care Act was going to allow people to have more access – whether it truly ends up that way, I don't know. I mean, I want people to have access to good health care – there's no, I mean, I wouldn't be in this profession if I didn't think that was important. How that gets done? I don't know. I think, you know, population is increasing and people understand health care better now than they did 40 or 50 years ago. There's obviously the retirement, you know, physicians, the way PAs and NPs are kind of positioning themselves is they want the primary care. It's kind of like the first step in the door…. they're kind of more the front line, I mean, serving as primary care, so I think that's kind of a mission of kind of PAs is to be able to take that role, because a lot of physicians are really not going into primary practice due to the reimbursements, funding, and salaries, they obviously want to go to the high-end specialties, so that's kind of where PAs are really taking the lead. And nurse practitioners as well (personal communication, July 15, 2016).

With a nationwide shortage of nurses and PAs, however, Immokalee's health providers are multiply challenged to fill these positions.

One nurse expressed that hiring changes had less to do with funding and more to do with administrative choices:

> We could use even more providers you know, to penetrate into the community because there's a lot of people, I'm sure that say that they don't come here and they don't get care of any kind and having more providers and more availability of appointments would help, but … historically, we're probably in a good situation relatively, compared to some times in the past. Compared to two years ago, we're much better now.
>
> Me: Why is what? From the stimulus money?
>
> Change of administration. More emphasis on getting nurse practitioners and mid-levels providers in here, so we can see more patients (personal communication, January 29, 2015).

So, administrators could take a more proactive approach to fill some of these gaps in care by working to attract health care providers, especially mid-level providers. When I asked several administrators what changes they would like to see in terms of funding and policy that would improve the work they did, they nearly all replied that additional staffing would be a top request. Training for health professionals that is low-cost and incentivizes working in rural health centers – such as more funding for the National Health Service Corps -- would help with staffing. A nurse administrator also suggested that local nurse training could be improved, since the local source of training did not include acute care (personal communication, April 8, 2016).

Another hiring trend that several providers noticed was in auxiliary staff like Medicaid eligibility workers:

> We can feel changes also with those Medicaid applications. They used to have people [at the health department], they hired two people to … help people when somebody call and then you don't have Medicaid, some people I refer them down there and they got Medicaid. They've changed their providers and they came here. Now, it is really difficult because they eliminate those positions. … It was like two months ago, two or three months [in early 2014] …. Yeah, it's this year that that happened, so it's become so difficult now, we don't know what to do. I tried to call for clients …. They don't have an ACCESS number, they don't know … how it used to be, when they deliver, they call here, the clinic and then they got the baby and all on Medicaid. They send them the baby's card. Now, I got clients, they got the baby, baby don't have Medicaid. One client, she has to go to see a cardiologist, and they don't have Medicaid … and she has to go back to Haiti and she went to another cardiologist. She doesn't have Medicaid …. We call and we couldn't, I don't know where to go, you know? What the best number to reach is. It's really difficult. I got other client, they got the baby and they say … 'Do they do an application at the hospital?' They say, no …. I still can't find some way … it's difficult, it's really, really difficult on the clients (personal communication, July 3, 2014).

When it is difficult to access Medicaid, it is difficult for providers to get reimbursed, which in turn places a financial strain on providers to low-income and uninsured patients.[3] However, another health provider said that they had increased funding to hire new "health care navigators" to enroll eligible uninsured people in the health care marketplace. This seems to indicate that perhaps the emphasis has shifted from enrolling people in Medicaid (a government-funded safety net program) to enrolling people in health insurance on the

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[3] On a personal note, having worked in Medicaid eligibility in Georgia in the past and also having received Medicaid while pregnant in Florida, there is a clear difference between case management now and ten years ago. Medicaid patients in Florida do not meet face-to-face with a case manager; instead, they have a toll-free number that they can use to speak with someone about their case, including claims. My claims after I had my child were often lost and I frequently was unable to connect to a person to speak about my eligibility paperwork or my claims. In contrast, when I was a Medicaid caseworker, I managed a caseload of over 400 families, met with them at least once a year, accepted their paperwork, and had a direct phone number where they could call with questions or concerns about their Medicaid eligibility. If I had not been proactive on my case (and knowledgeable about how the system worked), I would have not have received the full extent of benefits that I was eligible for – nor would the hospitals at which I received care have been adequately reimbursed for their services.

federal exchange (which allows health insurance companies to expand their list of consumers). Failure to expand Medicaid and reduced hiring of Medicaid eligibility workers means that people who need care might forego it, while putting the cost for care if they do seek it on the health care providers, often after long periods of time without care and potentially worse health conditions.

Discussion

Florida, especially rural, low-income communities like Immokalee, demonstrates the economic trends occurring across the American health care system and the impacts that this could have on the availability of care in the places that need it most. The increased marketization of health care means that all providers – for-profit or not – have had to adapt to the health care market or else get forced out. Even community health centers have had to enact corporate strategies of expanding partnering or merging to reduce the financial risk of providing care to populations that need increasingly expensive care but cannot afford to pay for it. For-profit health care ventures, while still a minority in the total number of hospitals in the US, have used mergers and acquisitions to expand their share of the market, including in ailing rural hospitals. All of this has been driven by changes in their finances, such as fluctuations in reimbursement for work done with low-income and/or uninsured populations. It is difficult to stay afloat with what several interviewees called a 'difficult' payer mix. Funding, whether through health insurance reimbursement or grants to help offset their costs of care, truly drives what health facilities are able to do, especially for those providers already operating within narrow budget margins. A look at a map of the availability of care in Figure 2 parallels a map of health care funding, which also parallels population income. Health care facilities locate in places where they can financially, which concentrates health facilities in communities like Naples that have plenty of money.

In the midst of all of this change, people's health care needs are shifting too. In southwest Florida, the average age of the population is high and rising due to the presence of wealthy retirees in the coastal areas, within the same county as Immokalee. Naples is an incredibly lucrative (and competitive) place to offer a variety of expensive health services –such as tertiary care -- to the wealthy elderly. Health care providers can earn much more money on one side of the county than on the other. The rising tide does not lift all ships, however, because the increasing availability of care in the wealthy coastal areas is out of reach for most people living in Immokalee due to barriers to accessibility. At the same time, chronic diseases are on the rise in both the wealthy, elderly coast and in the low-income rural community of Immokalee, though for different reasons. The latter are diagnosed with diseases associated with increasing age (diabetes, cardiovascular disease, musculoskeletal conditions) much earlier than they should, primarily as a result of poverty and lack of access to care. In addition, in states like Florida, years of rolling back social programs and stagnant wages mean that it is increasingly difficult for people to afford the things they need to maintain their health – not just health insurance, but healthy food, healthy places to live, and so on. The result is poorer health. Florida is in the top ten states for rates of diabetes, and one in three adults is hypertensive. In a state that did not expand Medicaid, people are unable to access the care they need. The rise of chronic diseases and their complications disproportionately impacts the facilities that diagnose and treat underinsured and uninsured patients, who may not have the money to pay for treatment until it becomes an urgent and advanced issue. All of the providers interviewed discussed the challenges of providing adequate care for the vast array of complex health problems faced by their patients.

Health care grows, expands, and contracts in different geographic areas depending on a number of ‘environmental’ (market) factors. Rather than assuring the health needs of everyone equitably, the health care markets ensures uneven development at every scale. The wealthy in Naples have an increasing array of health options, while Immokalee – with a population at high risk of poor health outcomes -- is effectively deemed to be insufficiently valuable for investment of adequate health resources. Health risks become even more geographically concentrated in areas of already-high risk through market forces. In other words, the rich get richer in resources, while the poor get poorer.

While the impacts of the Affordable Care Act are still speculative in the early years of its existence, there are a number of issues that we can anticipate. The Affordable Care Act has attempted to expand the pool of potential consumers for health insurance through the development of the health care marketplace, potentially allowing for more reimbursement (and thus financial stability) for services offered to the low-income and/or uninsured. However, the ACA also meant to expand Medicaid in every state to those in between 44% and 100% of the federal poverty level, with associated cuts in funding in hospitals in DSH payments. However, in states that did not expand Medicaid, hospitals will now face decreased funding for the work they do with the uninsured. Hospitals will likely have to increasingly take on a corporate approach to health care operations to stay afloat, or else face closures. Even community health centers, which have new sources of funding for the work they do, must adapt to the changing environment to be able to continue offering health services. In many ways, then, the Affordable Care Act helps to ensure the continued marketization of health care and the prevention of expanding services into rural areas, but done under the guise of increasing access to care.

Conclusions

In this complicated tangle of market-based, profit-driven health economics, we can see little change in low-income and/or uninsured people's ability to access needed health care. Health care is a different sort of service that nearly everyone will need at some point in their lives. However, we often treat it as a commodity and access to it comes down to whether not you can afford to pay for it or are eligible to receive assistance. Within this context, health care will not become available to the geographically and socially marginalized. As summed up by one local health care provider when asked the question about a law or policy change that he would recommend, who said "Short answer, it all comes down to money. More money, better resources, better care. The reality is, how do you get to that point?" (personal communication, July 15, 2016). That is the multi-billion dollar question. The reality is, neoliberal changes in health care – as furthered by policy, including the Affordable Care Act – keep Immokalee and other resource-poor areas without the resources they need to keep their populations healthy. In the next chapter, I explore the experiences of the health care providers that work in this type of health environment in order to identify some possible changes to the system that would benefit their work.

"These were the unhealthiest of the unhealthiest: obesity, diabetes, hypertension, you know? They're train wrecks… The doctors … would get these train wrecks … and then they would turn around and get sued … and all they're trying to do is a good deed for the community…" (personal communication, April 8, 2016)

The US health care system is in a process of change, with impacts on every aspect of health care. Providing care in this type of environment has many challenges, as evidenced by the experience of a public health nurse from Naples, Florida that I interviewed in the early stages of this project. This nurse interacted with many immigrant patients through her work with refugees. During a phone interview, she spoke openly about providing care to the many different types of immigrants that she encountered. She told me that non-compliance with medical treatments was a major problem, especially for the Haitian population. Whereas their Cuban patients (the predominate immigrant group in the area) diligently followed directions provided by their health care providers, she stated that her Haitian patients often had problems following directions, taking medications as instructed, returning to doctor appointments, and just generally seemed to be less 'grateful' for the care they received. She expressed this as having "no idea what to do with them [Haitians]" (personal communication, May 2013). This was clearly a source of frustration for her in the work she did, because her job was to provide medical care, but she felt like her hands were tied when it came to ensuring that her patients followed up on their end of the care plan. The way she spoke about working with Haitian patients and the challenges she faced as a provider were an initial impetus for this dissertation project.

There is much to think about within her experiences of the provision of care to Haitian immigrants that are worth exploring in more detail in this chapter. First, the patient-provider relationship is expected to be one that is a transference of knowledge from the expert (the practitioner) to the sick and uneducated (the patient). When a provider's advice is not followed, it is explained as "non-compliance." Non-compliance is really a catch-all term for the many reasons that a person does not comply with the medical direction provided. However, from the perspective of the provider, it does not necessarily matter *why* they are non-compliant – just that they did not follow the treatment as prescribed, which often leads to a host of additional health problems that must then be addressed in future treatment plans. In addition, the conversation posits two different immigrant groups as being inherently different in terms of how they interact with the health care system. Not only does this gloss over *why* these differences may exist from a social determinants perspective, but it also suggests the possibility that pre-conceived notions of a group people may impact the way their provider interacts with them. Finally, it touches on the provision of charitable care and whether the patients should be 'grateful' for the care they receive or whether 'ungrateful' patients may be less deserving to care in the context of a market-driven health care system. I will review the literatures relating to each of these questions in further detail before exploring the provision of care from the perspective of health care workers in Immokalee – a rural farmworker community with a large number of very low-income, uninsured immigrants. Following a presentation of interview material obtained from 12 health care providers in a variety of roles in Immokalee, I argue that health care providers serve as the main point of tension between our politicized, market-driven health care system and the marginalized immigrant patients that require care, especially care for chronic conditions and prenatal health. At the same time, health care providers do not often have the tools they need to effectively understand their immigrant patients' complex needs.

Caring for Immigrants

An important axis of social difference that has significant implications for health is immigration status. The health of immigrants can best be understood by knowing that a person's health reflects where they live and where they are from (McLafferty and Chakrabarti 2009; cf. Basch et al 1994). What might appear initially as an individual factor affecting health might actually stem from structural issues, as when immigrants arrive with illnesses that have been controlled for years in the US but are still prevalent in their home country. Once they arrive, immigrants face additional barriers to good health. Immigrants are more likely to work in jobs that do not provide health insurance and they have lower rates of coverage overall when compared to native-born Americans regardless of immigration status (Derose et al 2007; Portes and Fernandez-Kelly 2012). They also may have limited English proficiency with which to access the health care system, they may live in segregated communities with limited health-promoting facilities, they may have limited financial resources to take advantage of preventative care, and they may face stigma and marginalization by the receiving country due to their immigration status and perceived cultural differences. Even in countries with universal health care, immigrants are less likely to use services and they receive poorer quality services than the native-born (Elliott and Gillie 1998). Many immigrants—whether documented or not—end up relying on health care safety nets and/or emergency services to receive care (Saint-Jean and Crandall 2005a). These issues are amplified along other axes of social difference, such as gender and race. For example, black men and women are more likely to suffer from several debilitating chronic illnesses such as high blood pressure and their mortality rates for diseases like cancer are significantly higher than for whites (Whiteis 1998). In a review of the literature by the Institute of Medicine, evidence overwhelmingly indicated that even when issues relating to access are controlled for, blacks receive lower quality health care than whites for reasons including health policies, racialized health practices, racial bias, and discrimination (Smedley 2012). Despite the existence of a "healthy immigrant effect," health of immigrants tends to worsen over time spent in the US (the "assimilation effect"), becoming similar to that of native-born Americans after 10-20 years in the US, especially for chronic diseases (Leclere et al 1994; McDonald and Kennedy 2004; Cunningham et al 2008). Another possible explanation is that barriers to health care access and lower service utilization by immigrants contribute to a lower reporting of health problems, making their health appear better than it actually is (McDonald and Kennedy 2004). Undocumented immigrants experience worse health than documented immigrants, and recent immigrants often have worse health than immigrants who have been in the U.S. for ten or more years. In addition, some immigrant groups have overall poorer health, attributed to the stress associated with migration itself and low occupational and socio-economic status in both their home country and the receiving country (Cunningham et al 2008).

Underlying discourses on immigration and the health system are ethical arguments surrounding immigrants and their "deservingness" of the decreasing funds for health care. Sargent and Larchanché (2011) call these issues "medical citizenship" or the "policies of entitlement that demarcate the rights of citizens and noncitizens" (p.348). Immigrants often face backlash in political discourse from those who see them as a drain on our economy, arriving in the US to use our health services and our welfare programs without contributing or assimilating. Because of the restructuring of the health care and immigration systems, citizenship is "increasingly defined as the civic duty of the individual to reduce his or her burden on society" (Ong 2003, p.12, citied in Horton 2004). In addition, unauthorized immigrants are excluded from the political process, lacking even the right to demand rights to health care, and these exclusions have embodied consequence (Willen 2012). Despite the trope of the needy and dependent immigrant, it has been shown consistently that immigrants tend to use services less than native-born Americans due to issues of access and structural inequality (Leclere et al 1994).

It is within this complex and contested environment that health care providers interact with immigrants in clinical and public health settings. Health care providers are at once bound by their jobs to provide high quality health care, regardless of social difference, at the same time that they have to negotiate neoliberal and anti-immigrant health law and policy. For this reason, the subjective experiences of health care providers working with low-income immigrant populations can provide insight into several aspects of health care delivery, including the challenges their patients face in receiving appropriate care, the challenges providers face working with low-income immigrants, and the challenges the health care system poses for those working in these types of communities. In the next section, I present the case of Immokalee, Florida and ten health care providers in various roles that work in the community. These providers share their experiences working "between a rock and a hard place" with a large immigrant population, especially with Haitian im/migrants. I will then explore some possible solutions to the challenges they mention.

Methods

To understand health care providers' experiences providing care to the Haitian population in Immokalee, I recruited ten providers in a variety of job who work with Immokalee's population. Health care providers were contacted directly using phone, email, and word-of-mouth between providers. The only requirement for these participants is that they were health care providers (broadly defined) that provided any type of health care in Immokalee. These are the same participants that were interviewed for Chapter 2.

A summary of the providers, their locations, and their job types is provided in Table 3, reproduced below.

Two of these providers agreed to discuss their experiences in non-formal settings without a list of questions. These conversations were annotated, rather than recorded. The remaining eight providers participated in one semi-structured interview lasting anywhere from 45-90 minutes. These semi-structured interviews covered a variety of topics, including service availability, institutional policies, challenges they face in their jobs, impacts of health care reform, and recommendations for change in the health system (Appendix A). Interview data was transcribed and then coded to identify themes within and across interview material. The data presented below represents the most common shared challenges they face in their jobs, as well as their individual recommendations to improve immigrant health care in Immokalee.

Table 3: Health Care Provider Research Participants by Position, Location, and Job Type

Position	**Location**	**Job Type**
Nurse	Public health department	Refugee health
Health educator	Public health department	Maternal health
Health educator	Public health department	Sexual health
Nurse	Primary care	Chronic disease
Physician	Charitable organization	Ophthalmology
Physician	Primary care	Adult health
Administrator	Primary care	As expected
Administrator	Primary care	Nursing
Administrator	Primary care	As expected
Physician assistant	Hospital	Emergency care

Provision Challenges in Immokalee

Interviews with health care providers indicated a number of “challenges” that they face in providing care in a largely low-income, immigrant farmworker community. While some of the problems they face are addressed in Chapter 2, this chapter will focus on the subjective experiences of health care providers as they interact with their patients, as well as their recommendations for how these issues could be better addressed in Immokalee and beyond.

Chronic Health Problems

As noted by many of the providers, the types of health issues that providers treat in Immokalee are often chronic and complex. In the Haitian population, these include high blood pressure, diabetes, and depression. Over and over again, providers noted that most of their adult Haitian patients had high blood pressure and/or diabetes that they couldn't get under control.

> Yeah, this is family practice. I see adults. I see everybody, Haitians, Hispanics, whites, African-Americans. So basically, what do we manage? We manage high blood pressure – anything that they come with. High blood pressure, diabetes, you know… (personal communication, May 21, 2015).

Another provider explains the conditions he saw in just one morning:

> Let me just give you an example. [looking at sign in sheet] Today, is a 64 year old woman who is going to turn 65 in May. We signed her up for—she got her Medicaid automatically, but we're working on her Medicare Part D, which is the access to subsidies for pharmacy medicines. And, there is another woman who is 65 but she never got her Medicare card so I had to send her to the Social Security office because it looks like they have the wrong address for her. The third woman I saw was also Haitian and she ran out of medicine for her blood pressure. There was some confusion about whether it had been ordered and sent to the pharmacy or not, so we checked in the record and with the pharmacy, and it was sent, there was some kind of a confusion, so she went and picked that up. The fourth one was also a Haitian woman and she was here for checking her sugar and blood pressure. She wasn't feeling well. Both of them—the blood pressure was good, the sugar was a little bit high, but she hadn't taken her medicine yet today. The fifth one was also a Haitian woman. She was here with a urinary tract infection, so we put her through a doctor and she got treatment. Then the next one was Mexican. The next one after that was a Haitian woman ...! [laughs] She was seen because she wanted to show me some of her documents. I think it might have been bills and statements from Medicare and we checked her blood pressure. It was a little high—she hadn't taken her medicine yet that day. Another Haitian woman was seen for the family planning class. She's pregnant. And so, that's been …

> Me: And that was just today?
>
> That was this morning. Let me see what we have this afternoon …. (personal communication, January 29, 2015)

This is consistent with the experiences of the researcher during community events and during interviews with Haitian women in Immokalee. At one health event coordinated by the Haitian Coalition of Collier County, roughly 9 out of every 10 adult Haitians that had their blood pressure checked had high numbers, and at one event, two people had readings so high that an ambulance was called. High blood pressure and diabetes require consistent treatment and ongoing monitoring to keep numbers under control – a challenge when a patient isn't accessing treatment or can't afford care. Untreated high blood pressure, for example, can lead to stroke – another condition that providers said they saw at higher rates among Haitians in Immokalee.

Untreated mental health conditions, especially depression, were also noted by several providers:

> One of the big problems that I see, especially with the Haitian women, is … I'm just going to come out and say it - abandonment by the family or social isolation, because a lot of them came and they left their kids over there, and a lot of them petitioned for their kids. If there kids are able to come in, usually they don't stay with the parents, they go off and get a job somewhere else and they kind of leave the parents here, and I've seen cases where kids have petitioned for their parents that, once the parents get here, they just sort of abandon them and leave them to their own luck and … so, that's a big problem because, when you get older, you need someone to help keep you straight, and a lot of those people don't have that. … We have a big behavioral health department here, but we don't have any … Haitian psychologists. That's … we're working on that need, it's …
>
> Me: That's interesting. Do you find Haitian women using the mental health services at all, even with a translator?
>
> Uh-uh. I've never heard about it (personal communication, January 29, 2015).

While this provider saw a social cause for the high rates of untreated depression in Immokalee's Haitian population, as well as a lack of services for this community, other providers explained this through cultural beliefs surrounding mental health:

> …after having the baby … Haitian women, they don't care too much about aftercare. So, mental health, it's not something they pay attention to …. If anything happens, they got another explanation, like people who got postpartum depression. It's like they got … a shock, you know, something like they got bad news and that's what they think made them like that (personal communication, July 3, 2014).

Regardless of how the high rates of chronic health conditions are explained, providers associated specific health conditions with the Haitian population, and these conditions are primarily chronic, complex, and often uncontrolled.

"Cultural" Differences

As discussed above, health care providers understand their patients' health and behaviors in different ways. Nearly all of the providers I spoke with saw a difference between "Haitians" (as a group) and other racial or ethnic groups in terms of their values, norms, and knowledges. For example, they are often seen as having different gender norms:

> If a woman comes in with her husband, her husband, I'll ask her the questions, he'll give the answer, and he'll get mad if I don't give the answer back to him, but try to talk directly to his wife or significant other. I've definitely noticed that. So typically now is, I'll look at both of them as I'm having the discussion, but I will say specifically to her, do you understand what I'm trying to tell? Now, a lot of times, he may be serving as the interpreter, so I don't know what information is then getting passed on, so, but that is something I have seen… I don't want to offend anybody, but I don't want to offend him by ignoring him. I don't want to get him upset, but I also need the patient to know and understand what we're trying to talk about (personal communication, July 15, 2016).
>
> … if you call them about, anything about their health, they will say, 'I have to ask my husband, and then after that I will give you an answer.' So, if the husband tells them not to participate…" (personal communication, July 3, 2014)

They are also understood as being opposed to testing and screening:

> I found it to be very easy to get a Hispanic person tested. Somewhat easy to get a Haitian person tested. But not very easy to get an African-American tested.
>
> > Me: Really? … Why do you think that is?

> I guess, I don't know. Maybe it's the mentality that they don't want to know. For the Haitians sometimes, it's because 'you gonna take too much blood out of me.' You know, a lot of it has to do with education, like not knowing that if I draw one tube of blood from you, you're not going to die, you know? You're going to produce more blood after that, you know? A lot of it has to do with education. And some of the people just don't want to know if they have anything.
>
> > Me: Do you find that a lot of Haitians don't want to know?
>
> Not because they don't want to know—it's mainly because … I don't want to give you my blood. I'm not sure if you're going to take it. I don't know if you're going to sell it, you know? And some say, that's too much blood. But some say too, I'll do it, I want to know …
>
> > Me: What about if somebody tests positive? Do you find people … are they resistant to getting treatment?
>
> [laughs] *YES*, which I still can't believe that! 'Cause me, if someone called and said, hey, you tested positive for something, I would run and find a clinic! But you find people that just don't care (personal communication, July 16, 2014).

Haitians are also seen as being especially religious:

> I mean, we have [a situation here] for our chronic patients that, you know, if they get into their teeth, then that's why they don't take their medication, because you know, they believe a lot of that voodoo and all that stuff, el [restev] so if someone who passed away who had diabetes, they think it was the meds… (personal communication, April 8, 2016)
>
> You tell a Haitian woman, ok, you need a Pap smear, you need a mammogram, she'll be like, my breast is fine. Nothing is wrong with it. I don't feel any problem, why should I go and do anything? I don't need anything. And deep down … part of this also is based on the … how should I put it? On the spiritual aspect of it. Those who believe in the spirits, other spirits like voodoo beliefs and all this, they think they will always be protected by those, the same way the Christians believe that God will protect me against anything. I have one lady who comes here – she has seizures. She's like, God will not allow me to have anything else. Anything else anybody could tell me, I will not believe it and I don't need medication for anything else. I'm just here for seizure medication. She has high blood pressure, she has high cholesterol, she has everything else. She will not even do lab work, because she says, *my* God, *my* Jesus that I'm serving, will

> not … so there's that perception. The first thing is, the first barrier is really a mentality (personal communication, May 21, 2015).

Several providers shared examples of Haitian cultural beliefs that diverged from western biomedical interpretations of illness and necessary treatment. Haitian providers often offered the most detailed and informed discussion of these cultural beliefs. For example, on pregnancy:

> Culturally, we see pregnant in a different way than people like the American people see pregnancy, you know? … I mean for you, as an American, as soon as you get pregnant, you wanna go to the doctor, start your prenatal care, right? Take your vitamins, do what you have to do. But for us, it might be like, no, I'll wait until I'm three months just so, you know? They might need someone to tell them, no, you don't wait three months, you know? 'For me, I couldn't, when I deliver, I want to be all in full clothes, I want to cover my baby.' For you, you might want to take your baby out after two days she was born! You know? These are all culture things. I'm not saying we need to change *that*, but you know? (personal communication, July 16, 2014)
>
> [Haitian] don't consider [pregnancy] a sickness so they go to doctors when they're sick, like you can't go to work. It's something serious, that's when you go to the doctor. … that's why a lot of them, they got prenatal care at the second and third trimester. Because you know, if they don't feel, you don't feel anything, they don't go to the doctor even if they know they're pregnant." (personal communication, July 3, 2014)

Many of the providers made essentializing statements about Haitians and their use of health care, or lack thereof. In the opening story, one public health nurse saw Haitians as being (as a whole) non-compliant and less "grateful" for the assistance they received compared with other groups, such as the Cuban population (personal communication, May 2013). Another provider that did not participate in this study kindly said that Haitian women were "ignorant," with a general lack of education about how to take care of their health (personal communication, May 2014). A nurse saw Haitians as being culturally more prone to seek services:

> I think the Haitians utilize them better than the Mexicans do, and the Guatemalans. I think so.
>
> > Me: Interesting. I wonder why that might be.

> It’s just sort of a difference of temperament. I think that Guatemalans and [Mexicans] are a lot more stoic, they put up with things a lot more, whereas in Haiti, if you don’t yell and scream and be pushy, you won’t get anything because the scarcity is so overwhelming that you have to be assertive, you have to be very tough to get anything, so they have that mentality. Kind of like the Cubans in that way, they seek services more often than the Mexicans or the Guatemalans. The Mexicans and the Guatemalans are more patient, by temperament I think (personal communication, January 29, 2015).

These things were seen as being “cultural” and thus passed on from generation to generation:

> Now this is a generation, it’s like the old generation, the first generation of Haitians from Haiti. That’s the way they are. They are *set in their ways*, they are set in their ways, and it is very difficult to tell them to do anything else. And, you find this with the ladies as well as the men. The ladies seem to be even more entrenched in that mentality, because for me, it may be easier for man to man, I can tell a man hey, you know, this and that. They will listen to me maybe better, but you know … running the risk of sounding sexist, you know … women have made up their mind about certain things, and their feelings are not dictating that they need to change, they aren’t going to! (personal communication, May 21, 2015)
>
> …parents, grandparents particularly, they raise their kids in a way, traditional way… they’re very reluctant at the beginning and then after you do education, it takes a lot of time to educate, because it’s all … it’s a traditional, it’s a cultural thing, so it’s not easy to go away from it … if a Haitian client, they are by themselves, they don’t have any people from Haiti, they don’t have a mother, they don’t have a grandmother, they will get it … you don’t have to do much education with them because they go with that culture here. But if they got parents from Haiti, grandparents from Haiti, it’s a big, big challenge. It’s a big challenge. When that happens, you have to educate all of them” (personal communication, July 3, 2014)

In the eyes of many of the providers, it seems that culture is often seen as a barrier to the provision of timely, effective care for Haitians in Immokalee – a challenge that was difficult to overcome because it is something wholly part of a person’s being.

Funding Challenges

Chapter 2 discussed some of the changes in policy and funding impacting the work that organizations can do in Immokalee. Health care providers at these organizations often stated that they felt these changes, but with little understanding about exactly what was going on. Rather, they felt it in the work they were able to do with their patients:

> As Healthy Start, I don't know *exactly* how the funding is, but it is, it's changed. … Some things that we do is because they found … we have to do the services in a certain way so we can have to keep our funding (personal communication, July 3, 2014).

The same provider noticed other changes as well:

> [Medicaid has] become so difficult now, we don't know what to do. I tried to call for clients … They don't have an ACCESS number, they don't know [it], so when they … how it used to be, when they deliver, they call here, the clinic, and then they got the baby and all on Medicaid. They send them the baby's card. Now, I got clients, they got the baby, baby don't have Medicaid. One client, she has to go to see a cardiologist, and they don't have Medicaid so … she has to go back to Haiti and … to another cardiologist … I don't know where to go, you know? What the best number to reach is. It's really difficult (personal communication, July 3, 2014).

Similarly, a health educator noticed a reduction in chartable services available to which he could refer his clients:

> Yeah, especially at [a local health clinic], they had more programs for women, for people in general, especially people that are … low-income people, they have different types of specialists, different programs that would … let's say you have to go to a specialist for a GI or something, they had programs available where you can bring your proof of income and then they would get you in. They would get you to go see a specialist almost for free. The transportation would be provided. I think the only thing you had to do, you had to bring your own translator, but now… I don't see too many of those things, that stuff. Back in the days, they had a program here in town that could help you pay your bill—your electrical bill, your water bill, you know, once a month, once a year. I don't see that many programs here anymore.
>
> Me: Why do you think that might be?
>
> I mean, the economy, the … everything is, *money*. They don't have much funding so a lot of stuff had to close down due to fundings and stuff so … in terms of … and I think in a small community like this, these types of agencies or organizations are … I'm saying there's not any more. But now, what I see now, I see more organizations just giving food, you know, food and clothes and canned food and you know, bag of food. I've seen more of those than companies that cater more to health care. I mean that's my opinion and that's what I've seen from the time that I was here, like maybe

> 2005, 2003, 2004, we had more community-based organizations, non-profits, that would cater to the community (personal communication, July 16, 2014).

But not all changes in funding have brought challenges. In fact, the local health facility said that they were able to use new streams of funding for programs that they had previously not been able to afford. However, nearly all of the providers indicated that they saw how changes in funding impacted the work that they did on a daily basis – and things were often changing.

Non-Compliance with Medication

Another consistent challenge they face is trying to get people to take medicine at the correct time and dosage, or the issue of 'compliance.'

> You give them those pills, they are going to take it for a few days, few days they won't take it, I have to sit down and explain to them, if you don't take it on a consistent basis because the medication has to reach what is called a steady state, so the dosage has to be at a certain level to produce a certain effect in your bloodstream. So I had to sit down and explain to them, if you take it today, you know, that [lack of] compliance of medication is not doing anything. You may as well not take it at all. So, if you're going to take it some day and you're skipping days, don't take it. Just wait for your death! [laughs] I'm not saying that really, but … [laughs] but I mean you may as well not take it, because what happens is, when they come here, they see the other providers, they will say, do you take your medication? Yes, I take my medication. I will not stay there. I will say, do you take your medication? Yes, I take my medication. Are you sure? I mean, … it be a little bit, you know, like I'm doubting of everybody but, are you sure you take your medication? Yes, I take my medication. Do you take it every day, twice a day, or three times a day as you're supposed to? Wellllllll … I think, someone tell me, I'll take it. I say, listen, you're an adult, I'm an adult. I can see your results. If you're taking this medication every day, you will not … Well, look, I skip sometimes, ok? [laughs] And they own to it, but … what happens? They complaining that we give them too many medications. But if you come to the doctor, you say you're taking your medication, and you're still not controlled, ok the medication is not enough. I increase the dosage or add more. And that's why, sometimes when I see patients, they end up with so many, even my head spins. I have to sit down and *cut* some them, throw away some of them, because they are not taking their medication and the more you're giving them, the more noncompliant they are going to become (personal communication, May 21, 2015).

The reasons for this non-compliance varied across providers, from cultural to financial. Haitian health care providers tended to have a more comprehensive understanding of the factors that contribute to non-compliance. For example, one provider explained:

> I've seen it. I've seen it—a lot of men, Haitian men and women who've had stroke and I know it has to do with diabetes or high blood pressure. Because a lot of them do not take the medication the way they're supposed to and I can tell you, I promise you that they have the medication, they picked it up. They don't have that education or one-on-one couch saying, this is how you take this. You take one today, one at ten, one at two, one at five, everyday ….
>
> They don't take [medication] regularly. I mean, we have this older lady, she's like 70 years old. We used to help her. Actually, we started to set up a pill box for her. Even when we did a pill box, she still didn't get it. So she has to have someone that's there, at her age, to say, here's the medication. Take it. … And she cannot read the bottle, another thing. Some of them don't how to read. They don't know how to take the medication and then most of the time, when you go to the clinic, they just give you the prescription. You go buy it. They can't really explain it to you. So the language barrier is a big thing too. It's a big thing too.
>
>> Me: So there's not a pharmacy in Immokalee that would print it in Creole?
>
> No! There's no such thing. I mean, the clinic down there, they have Creole speaking person, but it's not enough. Once you go home, you forget about it. And not only that, the importance of taking this medication too. Because you know, you find some that even *share* this medication to someone else that has high blood pressure [laughs]. You know what I mean? … Yeah, the language is huge. I met this guy … I used to work down there. They had come up with this new pill bottle where you just press the two sides and the head popped open. I went to the bathroom. I seen this Haitian guy try to open this thing with his mouth, with his teeth, like fight with it. And I'm like, no, no, that's not how you do it. Just press the two sides! Boom. He was so shocked, like so surprised! Man, how did you do that, that's magic! But they didn't explain it to him in the pharmacy how to open it. They did that so everybody could open it—an easy way to open it, but someone has to explain to you how to do it. … Some of the older people really grabbed the bottle and twist it so they came up with a new one. And then, at the pharmacy they have a big poster that has it on there, how to step-by-step. But this poor guy don't know how to read Creole, English, none of that stuff. He's not going to read that or even the picture. Not going to pay attention to it. So, someone had to tell him, look, this medication, you push the two sides, boom, it opens. And the same thing for my mother. My mother has high cholesterol. She had the same type of bottle. When she

> got it, I made sure I went home and explained it to her because she doesn't read English (personal communication, July 16, 2014).

As the provider explains, this is a challenge relating to a combination of funding, knowledge, language, and communication. Similarly, another Haitian health provider told me two heart-wrenching stories that are commonplace in Immokalee:

> You have depression. You have marital problems. You have … you know, life skills problems. So people are not able to, you know, manage the stress in their lives and they invite more stress when they cannot manage, they cannot manage themself properly. They invite more stress. Like, let me give you an example. I saw a lady recently, not Haitian, but I saw a lady and she had some – I mean, she's diabetic, she's big, and she's still gaining weight. Her diabetes is totally uncontrolled, but she's untreated for a type of insulin. One of them she's taking about 200 units a day. Another one, she's taking three times a day before meals. Another one she's injecting once a day. Because she has high blood pressure, she has … and so, her life is spinning out of control because she's married, I mean she's separated with three kids. Her daughter is separated, her daughter has three kids and the boyfriend kicked the daughter out, so she had to take you know, daughter in with three kids and she's going from here to there. You know, daughters not working. So, I look at this and I'm like, ok, she's here for me to say something about her medical situation, but there's nothing you can do with that medical situation if those issues are not dealt with. … So we see a lot of this here, especially in the Haitian community. Like this morning, I saw a lady, amputee, one-foot amputee, and she has no insurance, diabetic, heart issues, cardiac, heart disease with a pacemaker, and absolutely no insurance. She's been in this country, she came to this country with a green card, yet due to her health issues, she has never worked. … Her fasting blood sugar was 268. … She gets a sliding scale, but the other issue was she was at 100%. She was self-pay at 100%. I have to stop and ask, why? And the moment that I see this, I left the room and called case management – please help me with this, what's going on here? Because nothing, I mean, it's not going to get better. She can't even – we put her on Lantus. Lantus is very expensive. She cannot even afford the Lantus. You see what I mean? So what these people end up doing is they *ration* out, they *ration* their medication (personal communication, May 21, 2015).

These providers showed a particularly thorough understanding of the many reasons that someone may not take their medication as indicated. Regardless of the reasons why, however, all of the providers expressed that non-compliance was an ongoing issue with their Haitian patients.

Transient Population

Providers listed several other challenges that they faced working with a primarily low-income, non-English speaking immigrant population, mostly notably that a low-income farmworker population that may or may not be authorized to be in the United States tends to move around a lot:

> The emergency room is not the best place to come in all the time. You want to see the same person over and over. Granted, if it's a transient community, a migrant community, they'll probably not be around to see the same provider … (personal communication, July 15, 2016)
>
> One of the big issues that is a barrier for us is telephone numbers. They'll have a telephone number that's good today, and when we go a month later, its shut off, so that is a big issue. Every time you come in, we're trying to get a good address, good phone number (personal communication, April 8, 2016).
>
> You find some people that do not give you the correct address, or they're working and you can't get to them, because once we get a positive pregnant woman [for certain STDs], we have like 24 hours to get them to get treated. And you know, we only work 8 hours, so you know? That can be a little hard, but you find the clinic actually, once they get tested positive, they look for them too, but a lot of times, they can't find them, and they're … not like me that go out and find the people, they call them. Like me, I go out to the house and stuff, so we kind of like, work together real well, but as a pregnant woman, we have to find them as fast as we … They move and maybe someone failed to update the information. Phone disconnected. You know, all that stuff? It's not like they don't want to be contacted. You find some of the young women—like young, young little girls—they don't want their parents to know. That could be an issue. But as far as adults, it's not that they give the wrong address, it's just … sometime, they don't update their address, sometimes they work. They tell you, oh, I work out of town, I can't make it today (personal communication, July 16, 2014).

This is particularly challenging in light of the fact that many of the health issues that the Haitian population are at higher risk for are chronic diseases that require consistent and ongoing treatment.

Overcoming the Challenges

Despite the issues that providers see as being barriers to their ability to care for Haitian immigrants in Immokalee, all of them have chosen to work with this population in a town that is predominately low-income and non-English-speaking. They often spoke of how they strive to provide better care to their patients through a variety of tactics and strategies. When I asked them what recommendations they had to improve health care for their patients, they offered several thoughtful suggestions ranging from changes that take place within the patient interaction to those that would need to happen at a policy level.

Education

Most providers saw education as being a key component of improving their patients' health. For some, education was a way to overcome culture as a barrier to care. For others, education was part of an effort to create more informed consumers.

> I take time to educate someone, especially Haitian, every chance that I get. It could be anything. It doesn't even have to do with my job. If it's something that I'm hearing wrong that I know the right answer, I take the time to say, hey, no, that's not how that goes. You do it that way, that way, that way. You know, there's a lot of misconceptions about things, like this guy one time I was talking to him trying to offer him a test and he's like, ok, now you're going to get my blood, one tube of blood. Once you're done with it, if you check that I don't have HIV, you're going to sell it. One tube of blood, right? … I'm like, one little tube of blood. I'm trying to explain to him, if I were to get your blood—not selling it. If I was to get it to donate to other people, there's a process for that. I would have you sign papers, I would have to do a little interview with you to see what your height, your weight, your this, your that, you know? Just to make sure you are a donor, you can donate blood, because not everybody can donate blood, you know what I mean? So, I take the time to explain to him, educate him about the blood, about what one little tube can do, what it cannot do. This one tube cannot save someone's life, just one little tube of blood, the size of this pen like this, you know? It's just that every chance that I get, even if its HIV, if it's any STD, if its politics, if its whatever … if I have the knowledge, I take the time to educate you just so you don't make the same mistake (personal communication, July 16, 2014).

However, every discussion of education was focused on educating Haitian patients, who are generally seen as lacking knowledge about what they need to do for their health. No one mentioned their own need to learn more about their Haitian patients.

Building Trust

Several providers thought that a lack of trust was part of what kept a perceived distance between providers and their Haitian patients: “Once you create a trust with them, you’ve got a long-lasting relationship with them” (personal communication, July 3, 2014). This is also true for Haitian health providers:

> Like, some Haitians would be afraid to talk to you because you’re Haitian, just like you said, they think you might be saying it to some people. But there’s a way to calm that … you know? You have to make sure that you explain the confidentiality part of it, you know … in a way that you make them understand this is between me and you, and you know also tell them a little about you, how long you been doing this, just so you know that they know they can trust you. And I’ve been doing this forever here. If it was an issue, I don’t think I’d be here still, but you find that there, you find that’s true. Sometimes, certain Haitians that I know, I would rather somebody else talk to them, like another coworker who are either Hispanic or Caucasian. Talk to them just so, to take myself out of the equation. … But sometimes, you find some of them that feel more comfortable because you’re telling them in their *own* language, you know? They feel more comfortable: oh, I didn’t know, it’s nice that we have a Haitian here that can tell me in my own language. They feel comfortable. I think me, I would feel comfortable too if someone talked to me in my mother’s language, the language I’ve learned ever since I was a kid, because I’ll be honest with you, sometimes I get tongue-tied in English [laughs]. You know, but … it’s just, they feel more comfortable, most of them. But you find some that, I’m not sure if he’s not going to tell on me! But you have to set that … the boundaries. You have to tell them, in an honest voice, that this is my job. This is what I do, this is what I cannot do, you know? And then after that, you know … I mean, I’ve got people that actually the first time, they didn’t want to talk to me. And I told them, we start to get to know each other, and then it’s all good (personal communication, July 3, 2014).

This idea forms the basis of the push to get more Haitian providers in the local health clinic – they are seen as being more effective providers with the Haitian population, not only because they can speak the language, but also because they are expected to have a better understanding of how Haitians think. The assumption is that Haitians can communicate better with Haitians, which allows for a deeper relationship between provider and patient.

Outreach and Communication

Beyond the provider-patient relationship, several providers expressed the need for greater outreach and involvement with the Haitian population in Immokalee:

> I'm sure there's a lot of things available to the Haitian community, but there's no one there to tell them about it, you know? The newspaper, it might be in there, but ok, imagine, let's say we're going to do like fair here. Like for this community. How many Haitians do you think are going to show up? A small amount because… Imagine we do like a big health fair here for everyone to come. You see that a few Haitians show up because no one tells them about it. It's not in Creole, you know? It's either in English or Spanish—I don't have a problem with that. But you know … And I'm sure there are people here that would help translate this for free, you know what I mean? I'm one of them, but its like we don't have this voice that would go out and say, hey, we're going to have this fair. You need to show up, you need to come. There will be food, there will be free stuff, there will be health checks, you know, all of that! (personal communication, July 16, 2014)

Not only is there a need for more outreach, but this requires better communication:

> Please try to do things more verbally, instead of giving a whole bunch of pamphlets in Creole. That's another issue too. A lot of these people don't read. They don't read, even if you give it to them, they aren't going to read it. Instead of putting things on paper, maybe try to train some people, young folks that would do more like, one-on-one. Come to this table, sit down, let me teach you how to do this, instead of you know… they aren't going to do it. More like verbal pictures, you know, if you're going to do pamphlets, put big pictures in it, you know … 'cause most of those older Haitians, they are the ones that are really in need for that and they don't read. … Yeah and you know one of the things too, a lot of those pamphlets, the Creole is *so wrong* in it, I'm telling you, because—its not their fault, because they just go to Google Translate, put that, you know … it doesn't make sense! I've seen a lot of them. Some of them be like, man! Who did this? [laughs] (personal communication, July 16, 2014)

Another provider explained that working to overcome linguistic issues was key for compliance as well:

> You have the majority of these people who cannot read and write. Other thing they don't, people here don't understand is, if somebody doesn't know how to read or write, whether you write it in Creole or not, they're not going to be able to read it. Even in Creole, they can't read. So, we try to translate everything in Creole, but only the generation who are coming out of Haiti right now can read Creole, because Creole is being taught in Haiti right now.

> And they have education for adults and all this right now. They are trying to get it, there. Some people can write a whole letter in Creole right now. It's only now, but this whole generation that's here right now, the majority of them can't read. So the majority of them, whether you put it in Creole or English or whatever [laughs], they can't read it. So we need to develop a system, sometimes you could use two bars, that means they know they have to take it twice a day. Or you write a 2 on it, and its twice a day. One bar, that means once a day (personal communication, May 21, 2015).

In addition, the church is understood as being a central part of the lives of the Haitian population in Immokalee. One Haitian health professional explained to me that this was an important strategy to disseminate information about resources and to gain participation from this community: "If you've got five minutes, something to do a campaign in the church, that's where you'll find, you will reach all of the community, the Haitian community (personal communication, July 3, 2014). Again, this requires the commitment of a person to do outreach within the Haitian community.

Creating Health Advocates

Haitians need advocates in the local health system – people who can serve as a voice for the needs of the Haitian population and who can help them gain access to the types of services they need:

> And I think also, Haitian practitioners, they should also be … when I say involved more, try more to be like they make, like one, it's like they work together to help the Haitian community, so that way Haitians, they don't have, the first provider, they should look at when they have should be a Haitian, because they understand your language, they understand, they know your culture and everything, they should be the first one so they should work … together and work with the Haitian population and try to provide better services and better customer service too and understanding for the Haitian community (personal communication, July 3, 2014).
>
> One thing, the first thing I would do, I would hire Creole speaking workers, ok? … here in particular. Not a worker that would just work, like say, I would hire for specific positions. I wouldn't just throw someone in this environment that, oh you come here, you come there. I would hire someone specifically, let's say, HIV specifically, working with the HIV [doctor], which they have for her at the clinic, they have Creole speaker for that, but I would hire someone else too, to be there in the family department/care, or the dental, so this person can provide … not only that, I would hire an

> advocate that would give Haitian women and men a voice in terms of what [is available] to them (personal communication, July 16, 2014).

This would require people who can speak Haitian Creole, primarily Haitians, who can serve as community health workers with the Haitian population. As of 2016, there were plans to hire someone as a Haitian *promontora* at one of the local clinics to do exactly that.

Even broader still, several providers indicated the importance of building the capacity of Haitians to become "self-reliant" and serve as their own health advocates in the health care system:

> I would think we need to have that woman, Haitian women, not involved like, *understand* the importance of care and educate them to seek for health and then to advocate for themselves, because it's really important that they do that, because sometimes you might have the problem that needs care, you don't have the care you deserve, the care you need, just because you don't have somebody to advocate for you, so they need to advocate for themselves. And they need to know what they want and what they should expect, because most of the people, they don't know what to expect. I used to be like that, but I'm just trying to make, because I know somewhat what to expect, because they just tell them, "take this" and you take this and you don't … ask questions, you just take it. So, they need to advocate for themselves (personal communication, July 3, 2014).

When I asked the above provider how they can advocate for themselves, she responded:

> They need to ask questions. You need to know what to expect, what to expect from health care. If you got a disease, you need to look up about what … so you know, you know what questions to ask. If they give them what it is for, what impact it can do to other, I got other diseases, I got other kinds of sickness, how can that impact this? And how should I feel after? What can happen? If I see that, what should I do? (personal communication, July 3, 2014).

It isn't just about patients serving as advocates, but Haitians working to improve their community as well:

> But you know, in another way too, I'm not going to put the blame on everybody else, but us Haitians too, we need to step up and start creating things like, nonprofit organizations that would cater to Haitians, you know? (personal communication, July 16, 2014).
>
> We need to come to your churches in search of, you know, educate people and motivate people to take their medications if they don't understand

> something. But they need a sort of an organization to go to them when they have a problem. There's none right now, as far as I'm concerned, that's very responsive to this. So … there needs to, there needs to be a better way … this population … they need some leaders in the community to stand up for them and say something. Because that's the way it works. If you're not stating your needs, nobody cares! So, if nobody is taking the time to state the needs of the community, so basically, they go unanswered (personal communication, May 21, 2015).

In other words, advocacy is needed at multiple levels to effectively serve the needs of the Haitian population, in health care and beyond.

Expanding Access

One health care provider mentioned the need to work at the policy level to improve health care for their Haitian patients:

> If they would expand Medicaid, that would cover almost everybody.… Which they could possibly do, you never know. That would solve … more than half of the problems with Haitian women. 'Cause most of 'em do have residency. It's not like the Mexicans, where so many of them are undocumented. Almost all of the Haitians are documented, so they could benefit (personal communication, January 29, 2015).

Because so many of their patients – Haitian and otherwise – are low-income, they would qualify for health care assistance if Medicaid was expanded in the state of Florida. As discussed in Chapter 1, this is a contentious subject in the state. However, as this provider notes, it would significantly benefit the Haitian population in Immokalee, many of whom do not currently qualify for assistance.

D**iscussion**

Health care providers in Immokalee are acutely aware of the challenges they face in providing care to Haitians in Immokalee. As a predominately low-income, im/migrant, non-English-speaking population, Haitians have difficulty accessing the care they need – a point that I will return to in Chapter 4. These barriers to health care access impact compliance, which serves to construct a group's deservingness to care. The health care system (usually unwittingly) participates in the construction of different immigrant groups as being more or less deserving of care. As seen in the opening story, an inability to access care may be construed as being less grateful and thus less deserving of limited health care resources offered by providers. In many ways, health care providers serve as the main point of tension between our politicized, market-driven health care system and the marginalized immigrant patients that require care. At the same time, health care providers do not often have the tools they need to effectively understand their immigrant patients' complex needs – not just at a biological level, but at a socio-economic level as well. Research has shown that immigrants have different health needs and health 'risks' than the native-born; however, the ways in which the health care providers understand these different needs and risks are often explained through a focus on supposed biological differences or cultural differences. In the rest of this chapter, I will discuss the problematic idea of building "cultural competency" for health care providers – a concept that attempts to supplant strictly biological understandings of health differences (which have gendered, racialized, and/or nativistic undertones) with one that attributes the challenges providers face as being due to cultural difference. I argue that the cultural competency approach glosses over very real social and economic challenges that essentializes Haitian patients and makes them seem more challenging to contact, interact with, and treat.

As discussed in the review of literature on immigrant health at the start of this chapter, research suggests that the health needs of immigrants are not currently being met. Within a period of approximately ten years living in the US, their overall health declines to match that of the native-born. They are at higher risk of certain health issues, they face higher barriers to the accessibility of care, and they utilize services at lower rates than their American-born counterparts – and these issues are compounded by gender, race, and socio-economic status. These challenges mean that Immokalee's immigrant patients are at higher risk for certain health conditions, especially those associated with poverty, while also being less likely to obtain the care they need. As the health care providers in Immokalee were very much aware, their Haitian patients were less likely to be compliant with prescribed treatments, especially medications. Non-compliance – the failure of a patient to implement a plan of care created by a health provider – is an important issue in our health system because of both its potential negative impacts on the health of the patient, as well as the strain it puts on the already-limited financial resources of community health centers (Vermiere et al 2001). The idea of 'non-compliance' implies that the patient is at fault.

Many of the providers I spoke with saw non-compliance in this way – it didn't seem to matter exactly why their Haitian patients didn't comply with their treatment plan, especially their medication plan – just that they didn't seem to ever follow directions.

In an effort to understand the needs and challenges of immigrant patients, there has been a move toward providing 'cultural competency' training for health care providers in medical and nursing schools. Cultural competency is the capacity of a provider to function effectively within a culturally-diverse health care setting. The idea behind this push for cultural awareness is that culture is a barrier to care for immigrants, and with a better understanding of the cultural differences that exist between patient and provider, clinicians can provide improved care with better outcomes and compliance to treatments. This training is most often provided as part of health care training, though this is still a relatively new topic within medical curriculums. When it is taught, it often narrowly focuses on culture as a technical skill that can be obtained similar to other scientific knowledge and exhibited through an "easily demonstrable mastery of a finite body of knowledge" (Tervalon and Murray-Garcia 1998; Kleinman and Benson 2006).

Unfortunately, there are a number of limitations of the cultural competency approach to health care provision. For one, without care, this approach often fails victim to an essentializing logic that can be seen in the following excerpt:

> In order to work with Haitians, one needs to understand the influence of religion and history on the Haitian psyche and their belief in voodoo made this history possible. It also helps to be aware of some essential characteristics of the psychological make-up of the Haitian people. … Many Haitians use therapy the same way that they use medical services. They begin treatment in a time of crisis and stop treatment when the issues are resolved. The concept of a long-term insight-oriented therapy is foreign. Seldom will Haitians remain in treatment once symptoms have been alleviated. Haitians may stop treatment abruptly, but return several years later if a new crisis emerges. Clinicians should not interpret abrupt terminations as therapeutic failures or breaches in the relationship (DesRosiers and St. Fleurose 2002, p520).

Though the (Haitian-American) authors sometimes use the qualifier "many" (not all) Haitians in several places here, broad statements about Haitian behavior are made as well. A unified "Haitian psyche" is assumed. Stopping treatments abruptly is explained as a result of cultural inclination alone. In addition, clinicians are advised to attribute abrupt terminations to these cultural behaviors as well, rather than looking for clinical or interpersonal reasons for the end of treatment.

While the intention of this type of educational material for clinicians is to provide guidance is handling Haitian patients with different knowledges of health and medicine, it inadvertently separates culture from the many other factors that shape patient behavior. Cultural competency often conflates "race and ethnicity; [does] not acknowledge diversity within groups; may inadvertently place blame on a patient's culture; often emphasize cultural differences, thereby obscuring structural power imbalances; and finally, fail[s] to recognize biomedicine as a cultural system itself" (Carpenter-Song et al 2007). In addition, "Culture is inseparable from economic, political, religious, psychological, and biological conditions … Cultural processes frequently differ within the same ethnic or social group because of differences in age cohort, gender, political association, class, religion, ethnicity, and even personality" (Kleinman and Benson 2006, p1674). Cultural competency, by teaching monolithic "cultures" and marking them as different from Western (and often white, middle-class) culture, glosses over the fact that all cultures are amalgamations of a globalizing world (Duffy 2001). It sets up culture as a problem that must be overcome, which circumscribes the solutions available to health providers in overcoming the challenges they encounter when they work with immigrant patients.

The health care providers that I spoke with in Immokalee frequently spoke of the challenges in dealing with 'Haitians' as a group with a shared culture. Haitians were variously described as noncompliant, ungrateful, ignorant, uneducated, pushy, unhealthy 'train wrecks' that did everything they could to avoid paying for care. There was clearly an element of frustration that these providers felt toward the Haitian population. These providers work daily with a large immigrant population, in a challenging health care environment, so they were open with me about their frustrations when they were unable to fully meet the needs of their Haitian patients. They have clearly all been trained to consider cultural differences that their patients may have, especially when there are so many "cultures" in Immokalee. However, many providers seemed to blame the poor health care outcomes of Haitians on the fact that these patients were Haitian, rather than on socio-economic factors that limit their patients' ability to receive care, obtain medications, and follow prescribed treatments. In the interviews I conducted, some of the most essentializing statements about Haitian culture and identity came from Haitians themselves. This may be because as health care providers working in a diverse health system, they are often approached by non-Haitians to serve as both cultural brokers and as people who can explain Haitian culture. At the same time, these Haitian health providers were also much more likely to understand non-cultural factors influencing health and compliance. As discussed in Chapter 4, Haitian women in Immokalee face a number of barriers to receiving the care that they need, including a lack of financial resources, limited transportation options, and language differences. Once these factors are accounted for in the health behaviors of Haitian women, how much of their non-compliance can really be attributed to cultural differences?

So how do we improve health care for Immokalee's immigrant patients? The recommendations offered by health care providers give us a good start from a clinical perspective, but we can go further. As indicated by the providers themselves, we have to change the provider-patient relationship toward one focused on education and trust-building. However, education here cannot be a paternalistic activity – it must become a truly 'culturally competent' care that is patient-driven, providing options for patients to make their own decisions about their care. This type of health environment would include all of the following: a culturally and linguistically diverse staff that is reflective of the population served (Anderson et al 2003); socially-aware training about cultural beliefs providers may encounter working in their community (Kleinman and Sung 1979; Anderson 2003), or what I will call a "socio-cultural competency"; resources and facilities that reflect the knowledges, languages, and populations served (Anderson 2003; Tervalon and Murray-Garcia 1998); integration of culturally-specific forms of care (Leininger 1997; Narayanasamy and White 2005); patient-focused interviewing and care (Tervalon and Murray-Garcia 1998); and community-based care and advocacy (Tervalon and Murray-Garcia 1998). Beyond the health care setting, a culturally competent care would also need to incorporate marginalized knowledges into the construction of health science and into the development of policies and practices in order to change institution-level discrimination (LeVar 1998, cited in Narayanasamy and White 2005). These new understandings of culture should be rooted in transformative education for providers that emphasizes personal reflexivity and personal growth (Duffy 2001). All of this would help to build trust between providers and their patients. Put together, providers need a “social competency” that would enable them to work across social categories and classifications to provide care that incorporates a range of social differences, from socio-economic to cultural.

We also have to create the necessary resources for Haitian patients to receive the care they need. This includes creating materials in Haitian Creole and for illiterate audiences and conducting outreach activities in places that Haitians live, work, and worship. At this point, there has been very little engagement with the Haitian population in Immokalee by health care providers. While there are outreach events, such as the annual Migrant Expo, these have primarily been targeted at the Spanish-speaking immigrants. However, at one health fair event for Haitians held in Immokalee, over 200 Creole-speaking people attended. Clearly, there is a need and an interest in Haitian-specific events that is not being met by just hoping they show up at events for all immigrant groups.

We have to create advocates for Haitian health in Immokalee, both in the clinic and beyond. All of the Haitian health care providers I spoke with worked in their daily lives to improve the health of Haitians in Collier County by serving as cultural brokers for their patients within the health system. As some providers explained, however, it has to go beyond the providers to the patients themselves. Enabling Haitian patients to take control of their own health means that they should be provided the knowledge and resources needed to lead the decision-making process. They may need to be shown how to ask questions, but also how to access and maximize resources that may be available to them.

Any changes that happen in the local health environment are limited by political and economic factors that prevent Haitians from being able to obtain the resources they need to maintain their health, from health care to income and education. As one health provider indicated, expanding health care access through an extension of Medicaid to low-income adults would benefit many Haitians in Immokalee. But in Immokalee, where extensive charitable care is available, a lack of primary health care is not the primary problem. Rather, poverty wages, poor housing, and a general lack of resources work to put Haitians at higher risk of poor health. A failure to understand the socio-economic realities of Haitian patients’ lives is a severe limitation of non-Haitian health care providers. Even if health care access was provided to everyone, they would face a number of challenges in their daily lives that are associated with poor health outcomes. To truly improve health in

Immokalee, policy changes are needed across the board for immigrants, from wage increases in agricultural work to funding for public transportation.

Conclusion

Immokalee's health care providers often find themselves between a rock and a hard place. They work with populations that face many difficulties in maintaining their health, from low-wages to a lack of needed services. This produces a range of complex, chronic conditions that require extended treatment – treatment that relies on compliance for effectiveness. However, the socio-economic status of their patients makes compliance a challenge. How do we understand this compliance? Is it a matter of cultural difference, where the patient has alternate understandings of a health issue and thus does not follow through with a prescribed treatment? Or is it that a patient lacks the power and resources to get the care they may need, regardless of the cultural knowledges that underlie their understanding of their health? As we will see in Chapter 4, it appears that the latter may be the more likely scenario. However, the way in which the health provider understands their patient's behavior has important implications for the patient-provider relationship and potentially for the patient's ability to access the care they need. Providers must be given the training and tools they need to understand their immigrant patients' complex health needs. By equipping providers with a "social competency," we can give them the skills they need to work across a variety of social differences they face in their work with low-income, non-English-speaking, immigrant patients.

4 / Utilization and Accessibility / *Haitian Women Navigate the Health Care System*

“Mwen konnen depi ou pa nan sante fok ou we dokte. / I know when you are not in good health, you have to see the doctor.” (personal communication, 2015)

Haitian immigrant women in Immokalee fall into multiple “target population” classifications for federal health care research because they are low-income, immigrant, and rural. Since the enactment of the Affordable Care Act and the changes it ushered into the health care system in an attempt to improve the health of disadvantaged populations, there has been increasing political and academic interest in identifying populations that face barriers to health care access and the impacts on patterns of service utilization. In this chapter, I identify some patterns of service utilization among Haitian immigrant women living in Immokalee and consider their barriers to health care as they attempt to navigate the changing, challenging health care landscape presented in the first three chapters. While numerous studies have previously identified barriers to health care for “target populations,” this chapter investigates the specific barriers to a case study population – Haitian immigrant women -- within the context of broader political and economic changes in the American health care system. Using in-depth, semi-structured interviews, Haitian women provide information on where they receive care and why, the challenges they face in trying to obtain care in a fragmented health care landscape, and recommendations for how the area can improve care. I argue that geography can contribute to a more complex understanding of health and health care than is currently found in the literature by contextualizing health care accessibility within the broader social, economic, and political processes that impact immigrant women—processes which are inherently spatial. This has implications beyond the case study population for rural immigrant care more broadly.

Im/Migrant Women’s Health Care Access and Utilization of Health Services

Geographers have much to contribute to the study of health inequalities. Not only do differences in health experiences and health outcomes fall along lines of social difference, but these experiences must be understood in terms of their context (Kearns 1993). As Smith and Easterlow (2005) succinctly put it, “Geography clearly matters for health. The question is, how?” (p.174). While the existence of health inequalities along axes of social difference is well documented, there has (still) been relatively little engagement with the geographies of health disparities (Hayes 1999). Rosenberg (1998) observes that medical geography has yet to become an inclusive medical geography, sensitive to issues of social difference in issues of health and health care. There are a few notable exceptions, primarily from feminist geographers seeking to explore the subjectivities of gendered, racialized experiences of health. Parr (2004) calls for additional research on the intersectionality of gender, race, immigration, and other axes of social difference to counter claims that geography is genderless and colorblind.

Gender, race, and immigration status have significance in the study of health because they allow us to see the power relations within the health care system that affect one’s control over their own health. In terms of gender, we know that women’s experiences of health and health care are different from men’s experiences, not necessarily due to physiological differences in needs, but because of social and cultural norms and different political and economic opportunities. Women tend to live longer than men, but they also tend to suffer from more illness (Rosenberg and Wilson 2000); they tend to use health services more often (Rosenberg and Hanlon 1996, Dyck 2003); they are more likely to find employment in the lowest paying jobs that provide less financial resources to maintain their health (McDonough and Walters 2001); they often experience gender bias in the doctor’s office; and they may let their own health needs suffer in order to take care of family members that may be sick when they have limited financial resources to take of everyone (Young 1999).

Race is another social category that needs additional study by medical geographers, not because it reflects actual biological difference, but because it is a social construct with very real consequences for people’s daily lives. In the United States, there are several troubling trends in black health. For example, black men and women are more likely to suffer from several debilitating chronic illnesses such as high blood pressure and their mortality rates for diseases like cancer are significantly higher than for whites (Whiteis 1998). Williams and Mohammed (2009) found that despite an overall decrease in infant mortality rates in the U.S., the gap between black and white infants has actually grown significantly wider since 1950. In a review of the literature by the Institute of Medicine, evidence overwhelmingly indicated that even when issues relating to access are controlled for, blacks receive lower quality health care than whites for reasons including health policies, racialized health practices, racial bias, and discrimination (Smedley 2012). In other words, racism is still deeply engrained in the institutions of our society, including in public health policy, and discrimination has continued even if individual racism has declined (Williams and Mohammed 2009). This discrimination is reflected spatially through racialized housing segregation that locates a larger proportion of blacks than whites in areas with limited health care facilities. Dunn and Dyck (2000) have noted that many of the health differences between "races" can be accounted for by these sorts of socio-economic circumstances. By studying differential health outcomes and access for a "minority" group in the U.S., we can begin to see how often invisible social forces like institutional racism and discrimination have an impact on the health of people with darker skin tones.

In addition, we cannot investigate the health effects of one social difference in isolation from other markers of social difference—we must look at how various axes of difference interact to inhibit or promote the health of individuals and populations. In geography, Dyck (1995) notes that though there has been increasing interest on intersectionality and health, there has been relatively little work on the health needs and behaviors of black women. Gender and race, as social constructs with material consequences for health, certainly affect black women's use of health care services in unique and important ways. Aside from the excess burdens faced by women because they are women and black people because they are black, black women face additional obstacles in the attainment and maintenance of their health. Poverty rates amongst black women are worse than for black men and any white group (Rosenberg and Wilson 2000). Black women living in poor areas face a number of structural barriers, including poor housing, lack of prenatal services, and exposure to environmental toxins (Grady and McLafferty 2007). These areas may also face physician shortages and low rates of insurance due to poor employment opportunities. All of this requires an intersectional approach to health disparities and the structural inequalities that act on multiple scales concurrently (Smedley 2012).

An important axis of social difference that has significant implications for health is immigration status. Immigrant health—often compounded by gender, race, and class--is a surprisingly under-researched topic in geography given the discipline's interest in spatial mobility, globalization, and transnationalism (McLafferty and Chakrabarti 2009). The number of immigrants in the US has doubled over the last forty years to about 40 million, or 13% of the population (Pew Hispanic Center 2013). Immigrants not only move across borders, but also from one context and health system to another (Sargent and Larchanché 2011). Their health can best be understood by knowing that a person's health reflects where they live and where they are from (McLafferty and Chakrabarti 2009; cf. Basch et al 1994). What might appear initially as an individual factor affecting health might actually stem from structural issues, as when immigrants arrive with illnesses that have been controlled for years in the US but are still prevalent in their home country. In addition, the geopolitical environment and the rights that women are afforded in various countries differ across space and shape health inequality (Moss 2002). Once they arrive, immigrants face additional barriers to good health. Immigrants are more likely to work in jobs that do not provide health insurance and they have lower rates of coverage overall when compared to native-born Americans regardless of immigration status (Derose et al 2007; Portes and Fernandez-Kelly 2012). They also may have limited English proficiency with which to access the health care system, they may live in segregated communities with limited health-promoting facilities, they may have limited financial resources to take advantage of things like preventative care, and they may face stigma and marginalization by the receiving country due to their immigration status and perceived cultural differences. Even in countries with universal health care, immigrants are less likely to use services and they receive poorer quality services than the native-born (Elliott and Gillie 1998). Many immigrants—whether documented or not—end up relying on health care safety nets and/or emergency services to receive care (Saint-Jean and Crandall 2005b).

Interestingly, one of the main themes in the work that has been done on immigrant health is what has been termed the "healthy immigrant" effect. Quantitative studies comparing foreign-born and native-born Americans and Canadians indicate that immigrants tend to be in better health than the rest of the population, including lower overall mortality rates and much lower rates of certain diseases (McDonald and Kennedy

2004; Antecol and Bedard 2006; Cunningham et al 2008). However, the health of immigrants worsens over time the time they spend in the US (the “assimilation effect”), becoming similar to that of native-born Americans after 10-20 years in the US, especially for chronic diseases (Leclere et al 1994; McDonald and Kennedy 2004; Cunningham et al 2008). One possible explanation for this phenomenon is that migration may be health-selective, with healthy people more willing and able to migrate than people with chronic or acute health problems (McDonald and Kennedy 2004; see Smyth 2008 for a review of this literature). Another explanation--one that this project will investigate--is that barriers to health care access and lower service utilization by immigrants contribute to a lower reporting of health problems, making their health appear better than it actually is (McDonald and Kennedy 2004). While this work is interesting in the investigation of disease etiology and health promotion, it masks the heterogeneity of health in immigrants by lumping them all into one category despite differences in socio-economic status, country of birth, and experiences prior to immigration (Antecol and Bedard 2006). They also tend to conflate the terms “immigrant” and “race’ (Dunn and Dyck 2000; Elliott and Gillie 1998). There are certainly differences in health care access between a professional immigrant who arrives with a job offer that includes full medical benefits, a refugee fleeing dire political circumstances at home who is given temporary health benefits under a federal program in their new country, and an undocumented immigrant who is ineligible to receive health benefits and are thus limited to local free clinics. As a result, undocumented immigrants experience worse health than documented immigrants, and recent immigrations often have worse health than immigrants who have been in the U.S. for ten or more years. In addition, some immigrant groups have overall poorer health, attributed to the stress associated with migration itself and low occupational status in both their home country and the receiving country (Cunningham et al 2008). Williams and Mohammed (2009) call for research that will assist the health care system and its patients in taking account of factors like anti-immigrant sentiments and discrimination that may differentially affect access to health services for immigrants.

I will now turn to the case of Haitian women in Immokalee to examine their utilization of health services and the barriers to their ability to access care, keeping a critical perspective on the fact that they are at once poor, black, female, and immigrant in a rural community with a changing health care environment.

Haitian Women in Immokalee: A Case Study

Haitians are the largest group of Caribbean immigrants in the United States and that number has been growing quickly. Though there has been an increase in the number of Haitians arriving in the U.S. since the January 12, 2010 Haitian earthquake, Haitians have a long history of immigration to and from the United States. These immigrants have often had to flee from political corruption and violence in Haiti, as well as deleterious economic conditions (often provoked by the U.S.) that have crippled the Haitian economy and sent thousands of Haitians abroad looking for work. As a result, many Haitian immigrants arrive in the U.S. with limited financial resources and often with the goal of returning home to Haiti when political conditions improve (Basch et al 1994). Though many Haitians are authorized to be in the U.S. through the traditional routes of citizenship, there are thousands here under Temporary Protected Status and thousands more that have outstayed their visas and have become “undocumented.”

Unfortunately, health data specifically on Haitian immigrants is lacking, at least partially because they are usually lumped into the category “blacks” or sometimes “non-native blacks.” The relatively small amount of work that has been done is based primarily in the three cities with the largest Haitian population: Miami (specifically Little Haiti), New York, and Boston. In one recent qualitative study on the health beliefs and service utilization of Haitian immigrants living in Boston, Allen et al (2013) found that Haitians face unique barriers to health care access, including language differences, an unfamiliarity of preventative medicine and the American health care system, concerns about the safety of Western biomedicine compared to traditional herbal remedies, and mistrust of the public health system and the U.S. government more broadly. The authors also note that the high cost of health care and the prevalence of poverty in the Haitian community was a consistent theme in their focus groups, with participants stating that it was a significant barrier to good health. Interestingly, this study noted that many Haitians in Boston were not enrolled in the Massachusetts health plan (the model for the Affordable Care Act) because they were worried that it might cause problems with their immigration status. In fact, many

Haitians—authorized and undocumented—expressed fears of deportation; many also said that undocumented Haitians would probably not use the system at all because of fear of being caught. In another Boston study, Ryan et al (2004) discovered similar barriers to health care access, including fear of deportation, language barriers, too few Creole-speaking health care providers, long waits, impersonal care, and cultural fatalism. In Miami's Little Haiti community, surveys and focus groups conducted by the Haitian Neighborhood Center, Sant La collaborative (2004) indicate that the primary barrier to health care access for Haitian immigrants was "no insurance" (75% of respondents), followed by "high costs." They also found that many Haitians were unaware of what health services they were eligible to receive, stating that they preferred to use self-care, including herbal remedies, unless they were in an emergency situation or, importantly, if they were pregnant. Their findings were organized into three categories of barriers to access: primary barriers (financial), secondary barriers (structural), and tertiary barriers (cultural). Also in Miami, Saint-Jean and Crandall (2005a, 2005b), using quantitative surveys, discovered that only half of the respondents had any type of health coverage, correlating with level of education, income, citizenship status, length of residence in the U.S., English proficiency, and gender. They also found that many Haitians avoid the health care system due to their lack of legal immigration status. The authors conclude that this community faces serious access challenges that may explain negative health outcomes in the Haitian community. All of the above authors call for additional research on this important and yet understudied population, specifically stating the need for additional qualitative studies that can speak more specifically to the observations they made.

Methods

This research is based on the interview data gathered during conversations with Haitian immigrant women in Immokalee on their experiences of health care. Thirty Haitian women were recruited for participation using a combination of flyers and word-of-mouth study advertisement. To be eligible to participant, women had to be at least 18 years old, born in Haiti, and currently living or working in Immokalee. Participants received a small incentive for their participation in one semi-structured interview in the location of their choice. After discussing the study and the IRB documentation with the researcher and a

Haitian Creole-speaking research assistant, participants completed demographic information, summed up in Table 4 below. Additional demographic information can be found in Appendix C.

Because many Haitian immigrants are unable to read in either English or Haitian Creole, the vast majority of the participants were recruited by word-of-mouth and outreach by the researcher and research assistant. One participant would tell us about a friend or neighbor that would qualify, or neighbors would ask us to participate if they saw us do an interview with someone they knew.

Table 4: Demographic Information for Haitian Women Participating in the Study

Age	Range: 18-78 Mean: 49 Median: 44
Total Annual Household Income	50% reported <$10,000/year
Highest Level of Education	30% had never attended formal schooling 64% had completed only through junior high
Length of Time in the US	Range: 3 months – 35 years Mean: 12 years Median: 8 years
English Proficiency	93% speak English poorly or not at all
US Citizen?	62% No
Health Insurance Type	53% none, 43% public program
Employment	None (17), packinghouse (8), fields (3)
Common Health Conditions	Hypertension (13), diabetes (9), chronic pain (8), pregnancy (6), stress/depression (5)

To obtain utilization information, my initial plans were to have women provide spatial information using maps; however, plans were changed when I realized that many women would not be able to read or understand a map of the region. Instead, spatial information about health care utilization was obtained through verbal description of the places where the women had received care and the ways they got there (car, bus, walk, etc). In addition, women were asked a series of questions pertaining to health care utilization, barriers to access, health care activities, and recommendations for change, with opportunities to steer the conversation as they saw fit (Appendix B). Interviews were conducted in Haitian Creole and English using an interpreter who served as both a translator and a cultural broker. Though I initially intended for these interviews to be done solo, my research assistant and I found that many women felt more comfortable interviewing with a friend or family member present or participating as well. Three of the interviews had a male present in the room who answered some of the questions in place of the participant. Five interviews were done with two participants, where one person's responses often mimicked or played off of the other person's responses. One interview was done with three young women, who agreed to participate on the condition that they could all be there. It was done with a variety of onlookers as well, who would periodically contribute to the conversation. I found the messiness of these interviews acceptable and even preferable to one-on-one interviews because the increased comfort level of the participants would potentially provide more candid responses than one-on-one interviewing.

For analysis, I annotated each interview using the English translations to find themes across all participants. This generalization of the interview material was done partially to protect the identities of the women who agreed to participate, at least a few of whom expressed an interest in not being located. In addition, there were many similarities between the experiences of the women, and so the researcher chose to analyze the interview material at a high level to provide the opportunity for them to speak in a collective voice, rather than as individual, subjective experiences. A focus on subjectivities, while important, often overlooks the collective effects of social, political, economic, and social forces that shape immigrant experiences (cf. Hall 1997). This approach to data fit well with the goal of the researcher to find general recommendations for local medical facilities, politicians, and planners. This information is supported by some transcription and translation of interview material from Haitian Creole when needed.

Utilization

The primary source of health care in Immokalee is a network of non-profit health care facilities that are classified as both a community health center and a federally qualified health center. This network offers general/family practice, pediatrics, women's care, dental care, and mental health services, as well as several on-site services including a pharmacy and a laboratory. In addition, there are a small number of other private providers not affiliated with the community health center that offer family medicine. There are no specialists in Immokalee as of this writing; however, the small planned community Ave Maria 8 miles south of Immokalee offers limited OB-GYN services (but no contraception). There are no hospitals located in Immokalee; the closest is a small, for-profit hospital located 30-40 minutes north-northwest of Immokalee in Lehigh Acres. This facility houses a 24-hour emergency department, a critical care unit, and a range of clinical departments, such as primary care, cardiology, neuroscience, oncology, orthopedics, and more. The most frequently utilized hospital – a large, private, not-for-profit hospital – is located in Naples, 45-60 minutes southwest. It is part of a system with two hospitals (700+ beds) and a variety of medical institutes that offer a comprehensive array of services, including a birth center, surgery, and emergency services.

Figure 3 shows the most common locations where the women interviewed for this project obtained health services and their routes for getting to those locations. The vast majority of the women we interviewed (26 out of 30, or 87%) had gone to the local health clinic at least once, and often used it as their source of primary health care. They often took advantage of the clinic bus to get there, or they drove there, usually in a family member's car. Only one woman tried to walk to the clinic, which is located in the northern part of Immokalee on a busy road. All but one of the women were aware of the types of services they could or could not access at the clinic.

Figure 4 shows the most common locations and routes for health care utilization beyond Immokalee. More than half of the women interviewed had to utilize hospital services at some point since they had arrived in Immokalee for treatment for acute or chronic conditions. Nearly all of the women utilizing hospital care went to the emergency room in North Naples, even though it is further away than the hospital in Lehigh Acres. For emergent conditions, they either called an ambulance or got a friend or family member to drive them. With both modes of transportation, the routes follow slow-moving and windy roads cutting through undeveloped tracts of swamp, taking at least an hour one-way. In one notable exception, a woman in labor took two buses (for a total of 2-3 hours of time) to get to the hospital when she went into labor. She made it to the hospital before her baby was born, but she was in severe pain on the bus on the way there with her husband (personal communication, May 2014).

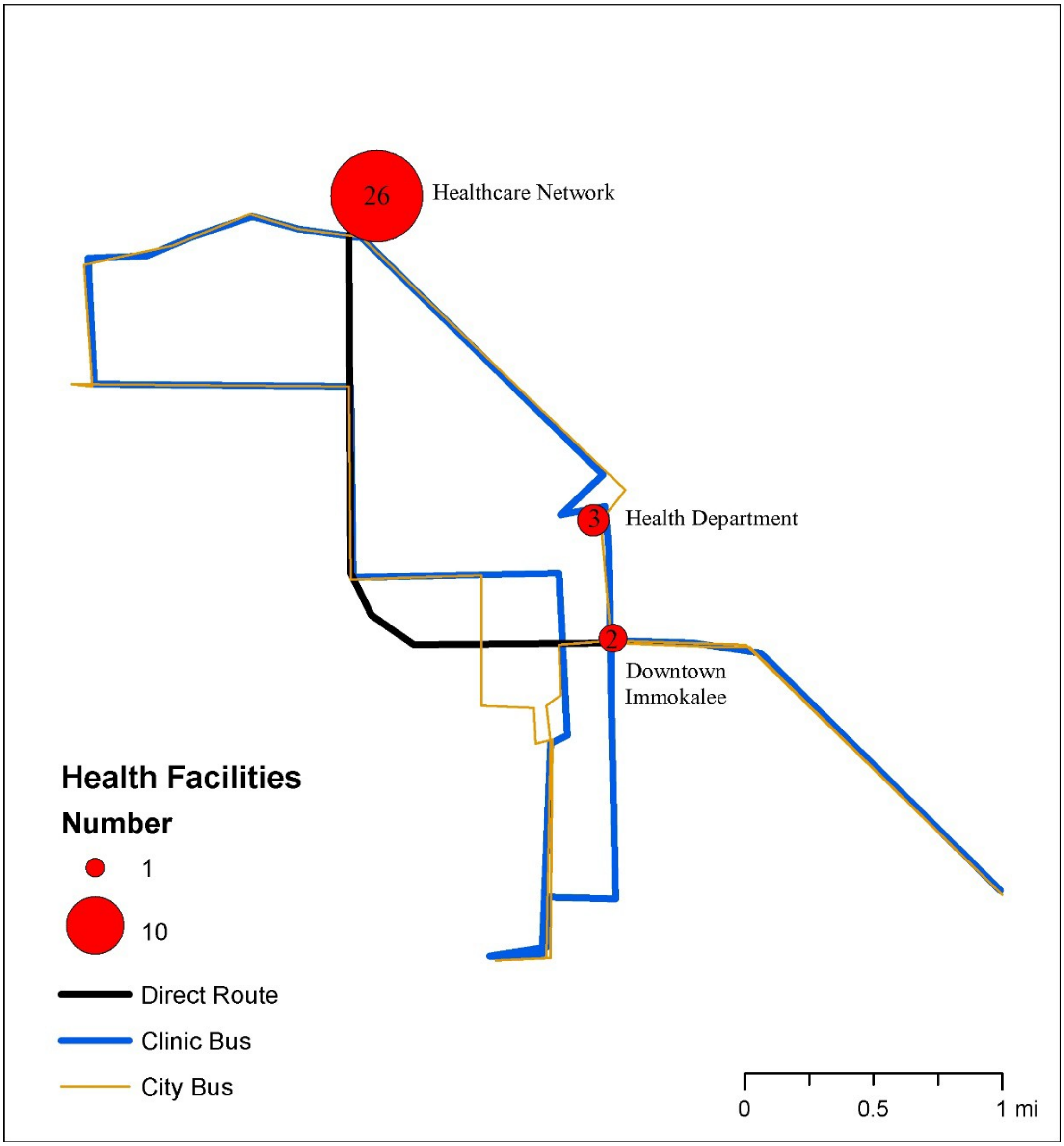

Figure 3: Utilization of Health Care Services by Research Participants in Immokalee, including paths of travel and modes of transportation.

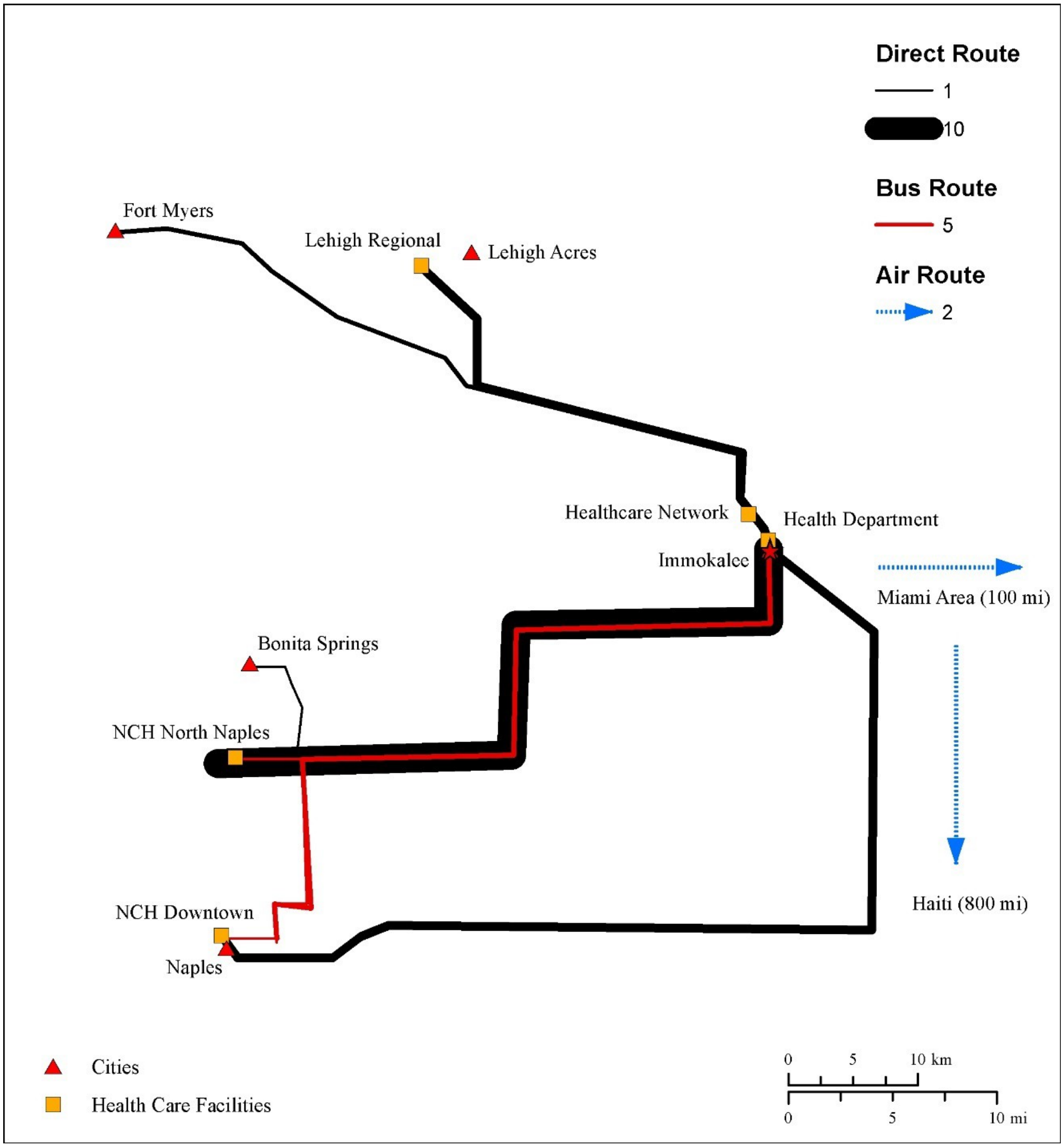

Figure 4: Utilization of Health Care Services by Research Participants in Southwest Florida, including paths of travel and modes of transportation.

Other non-emergent services, such as specialist care, were accessed by small numbers of women. These services are located in Naples, Lehigh Acres, and Fort Myers, and they are difficult to reach without access to a car. The few people that were able to see specialists in the locations either had a family member drive them or they paid someone (usually $60-$120) to drive them. Many women said they were referred to specialists in these places, but had not been able to afford to get there and so are not represented on the map above. One woman had to travel via helicopter to receive serious emergency care twice in the Miami area because her issues were outside the scope of the hospital in Naples.

In at least two cases, women admitted that they would sometimes travel back to Haiti to receive health care because it was more affordable than trying to receive care in the United States.

Accessibility

Clearly, geographic location remains an important factor in the access to and utilization of health care in Immokalee. However, the role of geographic distance may be overshadowed by other social factors that influence health care utilization by Haitian immigrant women in Immokalee. Haitian women expressed a number of *barriers* to accessibility of care that they had to navigate in order to obtain health services. Not only do these barriers help us to think about the relationship between health and socio-spatial processes, but they also provide a clear list of possible interventions that academics, clinicians, planners, and policy makers can implement to improve accessibility. I found that the primary barriers these women face fall into three main categories:

Financial Barriers

The most significant barrier to Haitian women's health care access in Immokalee is money. Nearly all of the women interviewed expressed significant challenges in financing their health care needs, with the exception of a few women who had Medicaid or Medicare coverage. Eight of the 30 women admitted that they did not have money to pay for care they needed, so they just did not utilize it when needed. Three of these women said they used plant-based remedies they obtained from their gardens or when they went back to Haiti. Shockingly, two women found it less expensive to fly to Haiti to receive care than to go to the Naples hospital for their needs. However, several of these women expressed that they were suffering because they could not afford the care they needed:

> *Si'w pa gen kob, si'w pa gen Medicaid; le'l al la yo bo'w yon conprime apre sa ou vin lakay ou wa'p soufri.*
>
> If you do not have money, if you do not have Medicaid; when you go over there they give you some pills and after that you come to your home to suffer (personal communication, 2016).

In addition, some of the women attempted to receive care even if they could not afford it, especially in emergency situations. They knew they could go the hospital to receive care and then deal with the bills later. However, eight of the 30 women had unpaid medical bills. One woman interviewed, living in a one-bedroom apartment with four other family members, brought me copies of all of her bills from the local clinic. They were past due and she was very upset that she could not afford to pay them. The largest bill was $99, which the letter stated had gone to collections (personal communication, 2014). Another woman, when faced with an emergency room bill for more $10,000 told us her response to her situation: "*Mwen di ki kote map jwen kob pou'm peye'l* / I said, Where am I going to find money to pay it?" (personal communication, 2016).

Nine of the women interviewed said it was difficult to afford medications. For example, one woman, depressed and in pain, said she had several prescriptions that she was given, but she could only try to afford to take the ones for hypertension and diabetes that would keep her alive. The other medications, such as for her pain, went unfilled, and she could not afford food to take with the medications she did have. She made very little money in her packinghouse job, and the money she makes goes to support her family in Immokalee and in Haiti – the latter of which she said would die without the remittances she sends for food (personal communication, 2016). Low-income individuals such as this woman are eligible for a sliding scale fee at the local clinic, paying as little as $20 at the local clinic; however, they would not receive assistance when paying for "extra" services that had to obtain outside of the clinic, such as medication. At least two women said they had to use free alternatives:

> Gende le si mwen pa gen lanje pou'm achte medikman, mwen bouyi fey, mwen achte fey mwen, mwen bouyi. Mwen pa achte fey non, mwen mache nan lari ya mwen cheche fey ki ka bon pou tansyon pou'm desann li.

> Sometimes if I don't have money to buy medications, I boil leaves, I buy leaves and I boil them. I don't buy leaves, I walk in the streets and I look for leaves that are for blood pressure to lower it (personal communication, 2016).

Though having public health insurance (Medicaid or Medicare) seemed to provide some security for the 13 women in the study who were eligible for it, three of those women discussed their inability to afford their share of the bills left over after payment by their insurance. One woman had thousands of dollars of medical bills despite her Medicaid coverage, though she was unsure why these were not paid by the insurer (personal communication, 2016).

Nine women of the 30 saw the problem as stemming from a lack of employment opportunities in Immokalee. One woman, in heavily accented English, spoke about the need for jobs for over ten minutes:

> Nobody down here don't got no job. No, no job. You got packing house, you go, you work. People make 3 hour days, 5 hour days; that's it. It can't help you. It can't. Why down here, people don't put jobs down here [for] people [to] work? People love work. Haitian people not lazy people, Haitian people like job[s]. Love it. Well! Haitian people come leave [a] long way to come [to the] states to fill for job (personal communication, 2016).

This sentiment was echoed by many women – they desperately wanted to work, but could not find a job aside from part-time, low-wage labor:

> When you don't have a job, you can't afford to get the care you need. *Depi pa gen travay, pa gen anyen, sante'w pa bon*. / As long as there is no jobs, there is nothing, your health is not good (personal communication, 2016).

Transportation

Immokalee is a rural, inland town that is relatively isolated from surrounding towns, and we can see from the map above that utilization of services tends to be concentrated in the immediate Immokalee area at the local clinic, with significant use of the hospital in northern Naples. Few services, especially non-emergent specialist care, are accessed in surrounding cities. The only health care option in Immokalee is a nonprofit that offers primary care services. While most women had utilized this clinic, many expressed some difficulty in getting to the facility. Because few had access to a car without paying the owner money for gas, they relied on either the clinic bus or the city bus to get there. However, there is only one clinic bus and it drives "slow" and has to "make a lot of stops."

There are no specialists in Immokalee, and several of the women said they were referred to care outside of Immokalee. While the distance kept some women from going to the referred specialist at all, a few attempted to make the trip by paying a friend or family member to drive them the 45 minute trip to Lehigh, the 1+ hour trip to Naples or Fort Myers, or beyond. One woman had to pay $100 for each trip to a downtown Naples hospital, and she had to go five times in a short period of time (personal communication, 2015). Another woman told me she had to take her child all the way to Port Charlotte for care (65 miles northwest, not pictured in the map), which cost her close to $160 for gas and a co-payment (personal communication, 2016). These are expenses on top of any costs they have to pay to be seen at the health care facility itself.

Twenty of the 30 women had at some point needed to access services at a hospital for needs beyond the scope of the local clinic. This was a problem for all of the women I spoke with, because they have to travel around an hour to reach the nearest hospitals in either Lehigh Acres (NNW) or Naples (SE). Because many women do not have a car, they needed to either pay someone to drive them to the hospital, or they take the bus. Unfortunately, it takes two buses to go from anywhere near Immokalee to anywhere near the hospital (see map for routes). As just one example, one woman with a six-week-old baby explained that she was able to receive good prenatal care at the local clinic, but she was considered a high-risk pregnancy because she had both preeclampsia and gestational diabetes—both of which are common amongst pregnant Haitian women in Immokalee. Her classification as high-risk prevented her from delivering her baby with the midwife at the clinic—instead, she had to deliver with an obstetrician at the hospital an hour away. When she went into labor early, she and her husband took two buses to get to the hospital, which she stated took about three hours (personal communication, 2014)

Inability to Get an Appointment

Six of the 30 women said they had difficulty getting an appointment at the local clinic, forcing them to either wait extended periods of time to receive care or to go to the emergency room for the care they needed. One woman said she was not able to get an appointment for a couple of months (personal communication, 2015). Another woman said that once when she was sick, the appointment was for so long in the future that she could not wait:

> *Wi, klinik la, mwen kon ale wi. Le'w ale, le'w pa gen randevou yo fe'w pedi twop tan. Ki fe'm te pi pa'l landan dri. Ma'l nan mwa Avril, petit mwen cheche'm nan parking nan mene'm nan dokte. Yo voye'm jous nan Me, yo ta kite'm mouri. Jous nan Me, sa'w di? Et sake fe pitit mwen rete mwen, li di kom bezwen yo vin cheche'm. Kounya lopital mwen soti la. Ko'm bezwen yo vin cheche mwen. Petit sa mene'm bay li, li mene'm Fort Myers*.
>
> Yes, the clinic, I used to go. When you go, when you don't have an appointment, they make you lose too much time. Which make me not go often. I went in the month of April, my child picked me up from the parking lot and brought me to the doctor. They sent me (scheduled me) all the way in May, they would let me die. All the way in May, what do you say? And that's why my child made me stop, he/she told me when I need [to go to the doctor] they will come pick me up. I came from the hospital [doctor's appointment] right now. When I need, they come pick me up. This child bring me to them, they bring me to Fort Myers (personal communication, 2015).

A third woman had heard of someone who was sent home because they could not get an appointment and that person died because of it (personal communication, 2016). All six women said that if they need an appointment for something urgent or bothersome, they needed to be seen that day instead of having to come back, especially when it is so difficult for them to get to the clinic. A few also said that it is difficult for them to have to wait all day at the clinic with the hopes of being seen – that when you don't feel well or you are pregnant, you can't just sit there without food and in discomfort:

> Especially for kids, they take a lot of time. For me, if I'm pregnant, they do that two times but I talk. *Yo te fè'm sa yon premye fwa dezyèm fwa mwen te joure yo. Mwen te sispekt yo*. I'm serious. So *mwen chita anndan* for 40, 45 minute. Okay, *mwen gen yon timoun nan vant mwen, mwen grangou. Si nou di mwen vini ak pa manje pa bwe, nap ban'm sevis, nou paka kite'm chita pou paket tan. So mwen la pou'm pran appentman bone mwen pa gentan pran anyen. So ya kite'm chita nan chanm nan pou* 30, 45 minute. I don't like it.
>
> Especially for kids, they take a lot of time. For me, if I'm pregnant, they do that two times but I talk. They did that to me a first time but the second time

> I cursed[4] them. I suspected them. I'm serious. So I sat inside for 40,45 minutes . Okay, I have a child in my stomach, I'm hungry. If you tell me to come and don't eat, don't drink, you'll give me services, you can't let me sit for a lot of time. So I'm here for an early appointment, I wasn't able to eat anything. So they'll let me sit in a room for 30, 45 minutes; I don't like it (personal communication, 2015).

Several women admitted that if they were unable to get an appointment at the clinic, they found a way to go to the emergency room in Naples instead. They either called an ambulance to pick them up, or called a family member or friend to pick them up and drive them to the hospital. At the hospital, they would at least be seen for their issue that same day.

Social Distance

A final barrier to health care for Haitian immigrant women in Immokalee is what I broadly refer to as social distance, which includes linguistic, cultural, educational, and social differences between themselves and their providers. The number of women who expressed facing this type of barrier was surprisingly low considering the literature on the subject. Nearly all of the women had gone to the clinic at least once, and nearly all of these women expressed having only positive experiences at the local health facilities, regardless of the background of their health care providers. This seems to suggest that the *acceptability* of the clinic is relatively high among the Haitian women I interviewed and that lack of trust (found throughout the literature) is minimal. Only 3 women stated they had language barriers due to a lack of a translator present in a medical encounter. Part of this may be that Haitian women said they often attended doctor's appointments with a friend or family member who can translate English for them. A few said they communicated without assistance, using Haitian Creole and hand gestures to explain their health needs (especially at the hospital). For example, one woman that had to deliver her baby unexpectedly one night at the hospital did not have a Creole speaker to help translate, so she interacted with the workers in her English, which she rated as fair to poor.

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[4] According to my research assistant, "curse" is the direct translation, but based on the context of the use of the word, it implies that she was probably being very direct to get her point across.

However, at least two women gave the indication that they did not fully understand the information they were given at the clinic. In one notable example, a woman tells us she thought she was pregnant but didn't know. She later tells us she had some tests done at the clinic and they gave her medicine to make her feel better. She shows us the paperwork, which clearly states in English that she is pregnant and that they gave her a prenatal vitamin (personal communication, 2015). This seems to indicate that, for at least some women, they may not know if they fully understand something being communicated to them. In other words, they don't know what they don't know.

Discussion

In our market-oriented health care system, health insurance is your ticket to receiving care. However, Haitian immigrant women in Immokalee either stay home to raise their children and/or they are severely underemployed in part-time agricultural jobs that pay below minimum wage. Neither of these employment scenarios would typically offer health care benefits, and women cannot afford to purchase their own insurance on little to no pay. If they absolutely need emergency health care, they can get it by finding a way to go to the hospital, but they do so knowing that they will most likely not be able to pay for any bills they receive later. Some women are able to qualify for health insurance coverage, primarily through either Emergency Medicaid for Pregnant Women for all documented immigrants, Emergency Medicaid for all immigrants, or through Medicare once citizen immigrants turn 65. This provides some security in the event of an illness, but not complete security for all of the women in this study. In addition, the politics of immigrant health care in Florida and nationally has made it increasingly difficult for immigrants to receive assistance with health care, whether or not they are documented. The state failed to expand Medicaid with the enactment of the Affordable Care Act – an expansion that could have potentially provided health coverage to several women in the study. Instead, uninsured women are limited to using the nonprofit clinic, which they nearly all agreed provides good care for the most part, but they still have to pay using a sliding scale that may be out of reach for women living in households with five or six people living on less than $10,000 a year. The sliding scale also applies only to clinic services and does not assist them when they need non-clinic services, such as medication.

For the older participants, an inability to afford medication was a significant source of concern and illness. For a majority of the women interviewed, however, it is difficult to access the care they need, and they must wait for an issue to become urgent before they can justify the expenses of seeking care.

Financial issues aside, Immokalee faces many of the same challenges as other rural areas in the United States. Local health facilities have a difficult time attracting physicians, particularly specialists, when providers can work in nearby cities for greater pay and better access to amenities. As a result, Haitian women have difficulty getting appointments on short notice for urgent issues or for chronic health problems. Emergency care is no substitute for the ability to access ongoing treatment with a primary care provider. A trip to the emergency room is not only more expensive, but does not provide the continuity of care that is often needed by patients with chronic, ongoing health problems like hypertension, diabetes, pregnancy, and pain management.

If they need urgent, emergency, or specialist care, they have to travel long distances, which is difficult without a car or the money to pay someone to take you. In Collier County, the Collier Area Transit (CAT) system runs a bus (#19) between Golden Gate (east of Naples) and Immokalee, but you would have to take another bus from a stop on Collier Boulevard (bus #27) to reach the NCH North Naples on Immokalee Rd, or two buses to reach NCH Downtown Naples. This process takes hours. There is no direct bus connection between Immokalee and Leigh Acres, though at roughly 25 miles, technically Lehigh (and its health facilities) are closer to Immokalee than Naples. To see a specialist in Lehigh or Fort Myers, you would still have to go through Naples, taking at minimum four buses and 5+ hours of travel time. The going rate to pay someone to drive you to any of these towns for care is prohibitive for most of these women as well. There were rumors a few years ago that the CEO of the local clinic and one of the largest developers in Collier County were researching if it would be feasible to put a hospital or urgent care facility in Immokalee or nearby Ave Maria. No one seems to know what happened to this project, though an urgent care facility was built on Immokalee Road, close to the NCH North Naples hospital.

The acceptability of the local clinic appears to be high. The women interviewed have figured out a way to “make it work” by taking English-speaking friends or family members with them to appointments to readily serve as translators in case one is not available. Other women found they were without a translator at the hospital, but they still felt they received good care and mostly understood any information that was given to them. This may be a case of not knowing what they don't know they need to know, but it also seems that they make the best of the care they have available to them. Many of the women were outright thankful and said they liked/loved (*renmen*) the health care system, the clinic, the United States – essentially, they seemed happy with whatever they could get. I did not hear anything about mistrust in their health care providers, despite that being a recurring theme in the literature for Haitian immigrants in the United States. The vast majority of experiences shared were overtly positive and thankful that they could receive some sort of health care, in comparison to Haiti where you are not seen if you do not have money.

The most concerning issue in the interviews was that nearly half of the women interviewed had hypertension and about a third were diabetic, yet faced significant barriers to health care accessibility. This is a potentially dangerous situation to be in. All of the women I spoke with said they were interested in receiving health care. It is often assumed by health providers that immigrant patients have alternative modes of care that they seek in place of biomedical modalities; however, I did not find this to be the case with the women I interviewed. The three women who said they sought out alternative medicines (*fey* / leaves) did so because they are unable to afford biomedical treatments for their ailments. This is not to say that traditional medicine does not exist in Immokalee; rather, some of the women appear to use traditional medicines and biomedical treatments in combination, but can't often afford the latter. In addition, many of the people expressed a knowledge of preventative medicine and tried to follow preventative behaviors to stay healthy: watch the foods you eat, get exercise, visit the doctor, take medicines as indicated. But in nearly all of these cases, they had trouble following these prescriptions for a healthy lifestyle due to financial and physical limitations. If you cannot afford food, or pay for medicine, it is hard to maintain your health. If you have severe pain or an ongoing, untreated health issues, it is hard to maintain your health. The stress of being unable to maintain a healthy, able working body was enough to cause depression among the five women I interviewed that shared information about their mental health, though that number is certainly higher. For example, one woman explained how the doctor's approach to reducing stress didn't work out for her:

> *Te gen yon moun ki te vini nan klinik la yo fe'l pale ansanm ave mwen. Li di se mwen ki ka trete tet mwen. Et li te voye mwen, li di'm; chita bo lari gade machin, al nan shop, al pale ... Sante'm pat bon, mwen pat kapab. Et mwen kon ouvri pot la vreman map gade machin kap kouri, men mwen pat ka pledi mache paske le a mwen pat bon ditou. Mwen pat santi'm te bon. Apre, li fin voye'm nan li di se mwen ki ka trete tet mwen. Bon, mwen rete la, depi'm pa pi mal. Men le a, mwen te gen pwoblem anyway. Paske le sa, ti kob yo voye ban mwen et te pou'm peye kay bill mwen, mwen pat gen kob nan men mwen. Tout bagay sa yo te nan ... konsa. Le fini, mwen pat gen memwa. M pat gen memwa. Apre, gende fwa yo kon ouvri mizik nan kay la pou mwen yo di'm enjoy. Le'm tande telefon sonnen, epi bye yo di'm enjoy epi yo ouvri mizik. Le ti travay la vin bagay map fe ti kob, mwen pap pi mal anko.*
>
> There was a person that came to the clinic and they had them talk with me. They said that I am the one that can treat myself. And they sent me, they said; sit by the road and watch cars, go to the store, go talk ... My health was not good, I couldn't. And I would open the door and actually watch cars that are driving, but I couldn't keep walking because the time wasn't good for me at all. I wasn't in good health. After, they finished sending me, they said I am the one that can treat myself. So, I stay here as long as I'm not worse. But at that time, I had problems anyway. Because at that time, the little money they sent me was for me to pay my house bill, I didn't have money in my hand. All of these things ... like that. Also, I didn't have memory. I didn't have memory. Sometimes, they turn on music in the house for me and they tell me enjoy. When I hear the phone ring, then bye, they tell me enjoy and they turn on music. When the little work comes, I will make a little money, I okay again.

Recent research suggests that rates of chronic disease may be found at higher rates in marginalized communities, even if lifestyle factors are controlled for, suggesting that stress itself is a risk factor for chronic disease through biological pathways still unknown (Mendenhall 2016). This could explain the surprisingly high rates of chronic illness among Haitians in Immokalee.

The traditional approach is to funnel more and more money at health care delivery, rather than addressing the social determinants of health – particularly poverty -- which would have a bigger impact on health outcomes. This is true within the population involved in this study, one which is multiply marginalized as poor, black, immigrant, female, non-

English speaking, and rural. For all of the interest in decreasing health disparities among target populations, addressing problems that lie solely within health care is only part of the battle. This research, like much other research on poverty, suggests that the real problems that people face in their day to day lives must be fixed at a more fundamental level (social, political, economic) before health disparities are reduced. A health facility could be highly acceptable and relatively affordable, but this doesn't address the broader social determinants of health that hinder people from being able to maintain their health. This is especially true for places with large populations of marginalized people – rural or urban, poor, and/or with large im/migrant populations – which serves to further concentrate poor health in these places of "high risk."

Recommendations

None of these four major barriers to care for Haitian immigrant women are unusual. In fact, these are the same barriers that come up over and over again in research on immigrants and/or people living in rural areas. But the identification of these barriers is important because not only does this project provide a geographic understanding of how difficulties in accessing care affect the spatial patterns of health care use, but they also provide a basis to make recommendations specific to Haitian immigrant women's health care access in Immokalee. When I asked the study participants about what things could be changed to help support their health in Immokalee, most of the women had difficulty thinking in terms of community-level changes that were needed. Several women said to ask the doctors – the most educated people – what could be done to improve women's health. When pressed to think about health more broadly than just health care, they came up several ideas relating to health care delivery, planning, and policy that I detail and add to below.

Health Care Delivery

Though health care delivery is only part of the equation in trying to improve the health of Haitian women in Immokalee, it could be a relatively easy-to-identify fix. Some possible solutions include:

- Greater availability of appointments: Many of the women interviewed had experienced difficulty obtaining an appointment for a health care issue, especially one they considered to be urgent. This led to a large number of the women interviewed seeking care at an emergency room at greater cost and with less continuity of care. Rather than trying to get in more patients in an hour, the local health facility could hire additional health care providers or extend hours. This would allow for a greater number of patients to be seen in a day without sacrificing the quality of care that patients expect. One research participant also suggested the possibility of a doctor making house calls for the elderly, who often live on a limited income and do not have the ability to drive.

- Construction of an urgent care facility: An urgent care facility would help fill in the gaps that the clinic does not provide. Many women felt their health needs were urgent, but were unable to obtain an appointment at the local clinic within an acceptable amount of time. In addition, all of the women in the study had to utilize the hospital in Naples at some point for either themselves or their children, and all of them expressed frustration at the difficulty making the trip. An urgent care center located in Immokalee could provide some of these services, however, more needs to be known about exactly how this sort of center would be funded—especially when most of its clients would be uninsured and low-income.

- Increased preventative services and health education: Many of the chronic conditions that Haitian women deal with can be controlled with a combination of preventative care and health education. Free outreach events offered by the health department or local clinic should be targeted to the needs and interests of Haitians, rather than immigrants more generally, because the needs of the relatively small number of Haitians are often overshadowed by the needs of Spanish-speaking migrants in Immokalee. The Haitian women I spoke with were particularly interested in preventative education, because they could (and do) use that knowledge to avoid having to spend a lot of money on their health.

- Additional Creole-speaking health care providers: While the number of women who suggested this was smaller than expected, the addition of additional Creole-speaking providers would only be viewed as positive among the women interviewed. From these conversations, it seems that the most effective place for these providers would be in the local pharmacies and in clinics in Naples and Fort Myers that receive patients from Immokalee.

Planning

Planning is a relatively underutilized means to improve health, especially for marginalized communities like those found in Immokalee. Planners and policymakers often feel they must choose between economic development and healthy environments in rural places: “With consistently lower average income and accumulated wealth in rural areas, economic development is even more likely to trump healthy design” (Hartley 2004, p.1677) – that is, if formal planning even takes place. However, planning can be an effective way to address the social determinants of health in ways that are specific to local needs.

- Better transportation: It may be difficult to attract additional doctors and specialists to Immokalee without state or federal policy action, so an immediate focus on improving transportation within and between Immokalee and surrounding towns is an effective start. A second clinic bus would speed up transportation to the clinic. In addition, the city of Immokalee currently has two bus lines that circle the town and two lines that run to Naples. One line is a new “express” service from the new casino in Immokalee to the wealthy South Naples area, with no stops near businesses or services in Naples. This route is really not meant to serve the low-income residents of Immokalee. The second line runs down a relatively undeveloped road to the transportation center, where riders can catch another bus that goes to the hospital. One major improvement would be to reroute this second line to go past several key locations in Naples, including the North Naples Hospital, on the way to the transportation center, or to create a third route that runs through North Naples. The creation of a Lee County route from Immokalee to Lehigh Acres (similar to the LinC route already connecting the bus systems in Lee and Collier Counties) would provide quicker access to health facilities in Lehigh Acres and Fort Myers as well.

- Additional affordable housing: Though none of the participants specifically mentioned the high cost of housing, local news reports have suggested that affordable housing remains an issue for everyone in Immokalee, especially those who don’t make enough money to support their health. Rent is a necessary expenditure. With the wages paid in the agricultural labor found in Immokalee, most workers can only afford to live in substandard housing, sometimes lacking sanitation, windows, or even electricity. They overcome this problem by living with a large number of people and cutting back on needed health services. Additional affordable housing developments would help provide a minimum standard of living for the growing numbers of these workers.

Policy

Long-term solutions to some of the challenges that Haitian women face in Immokalee could come in the form of policy change. Though there are certainly limitations to relying on policy change to improve health (namely, that is takes a long time, if it happens at all), the following policy actions would result in significant improvements in health and health care for marginalized populations like the one involved in this study:

- Expansion of Medicaid: Florida was one of the states that refused to expand Medicaid with the Affordable Care Act. Doing so would greatly improve access to health care for Haitian women in Florida, many of whom currently fall into the coverage gap. Providing health insurance coverage to these women would also allow for the clinics and hospitals in which they obtain care to receive reimbursement for the services that they are already rendering, but not getting paid for.

- Immigration reform: All attempts at immigration reform should revisit the issue of waiting periods for federal assistance, including programs like

Medicaid. Considering that about half of Haitians in Immokalee have been in the U.S. for five years or less, the five-year waiting period is a major barrier to their receipt of care.

- More and better jobs: Almost a third of the women interviewed were desperately seeking work to afford to live. While some efforts have been made to encourage job growth in Immokalee through the construction of a casino in town, it is questionable how much this business decision will impact the population of the Immokalee. Most of the women I interviewed that worked were in the packinghouses or the fields. Currently, the average income of crop workers in between $10,000 and $12,500 for individuals and $15-17,500 for a family, which is below the federal poverty line, and housing conditions for workers are notoriously poor. The packinghouses pay slightly more, but still at or below minimum wage. This contributes to the poverty and poor health many of these women endure. Policy action needs to be taken to ensure that farm labor (both in the fields and in the packinghouses) can earn wages that can actually support themselves and their families, regardless of immigration status.

Conclusions

Haitian immigrant women in Immokalee face a number of barriers to their access of health care stemming from both the fragmented health care landscape and everyday challenges of life in the United States for low-income, non-English-speaking immigrants. While the Affordable Care Act attempted to provide additional health care access for low-income people with the Medicaid expansion, this study – and many others – suggests that even if the United States achieved universal health care, other barriers to health would persist. Other determinants of health, especially income, shape the health of Haitian women, and they have had to try to support their health in a challenging health care environment with limited incomes. When all of this is considered, the radical transformations necessary to truly improve health for marginalized communities seem nothing short of utopian, but arguably, it is a worthwhile goal that can be used to advocate for the comprehensive changes that are needed to address health disparities. Medical geography provides us with a lens to understand that health and health care are much broader than we have historically understood them to be, made up of a broad range of biological, environmental, and social factors. To effect change in spatial patterns of health and disease, we need an equally broad range of biological, environmental, and (importantly) social interventions. We have to think broader than just throwing money at health care, and instead redirect our efforts to effective health care delivery, planning, and policy actions at the local, state, and federal levels.

Conclusions / *Making Change in Health (Care)*

"The idea that some lives matter less is the root of all that is wrong with the world" (Paul Farmer)

This project has provided a case study of the health care environment in Immokalee, Florida – a rural farmworker community in southwest Florida that presents a number of challenges for the predominately foreign-born population that lives there. The presence of these challenges indicates the intersection of political, economic, and social processes that have produced a complex and inequitable environment in which Haitian immigrant women seek to maintain their health. In many ways, this project was a structural one, analyzing how Haitian women and their health care providers navigate a complex health system that is constantly in flux while seemingly also lacking the power to shape the system in a way that supports immigrant health. However, there is no one person or group that is directly responsible for the challenges that exist in immigrant health care. This system is clearly unsustainable for all of the parties involved – politicians and health facilities, health care providers, and the patients themselves. Immigrants across the US must contend with federal anti-immigrant policies; health care facilities and public health departments serving rural, low-income, and/or uninsured persons face funding challenges; and health care providers have a limited set of skills when it comes to diseases of poverty. Though changes at the local level may have some impact on the health care environment, they cannot address the bigger issues of poverty and disempowerment that prevent Haitian immigrant women (and others) in Immokalee from living a life of good health.

Spatially, we can see these processes written onto a map as the concentration of risk and poor health in certain communities, or what Schulz et al (2002) have termed the "spatial determinants of risk." Through policy and planning decisions, wealth and power become concentrated in some areas, just as poverty and disenfranchisement become concentrated in other areas – the latter of which are much more likely to contain a disproportionate concentration of marginalized groups, like immigrants. The places often lack access to a variety of resources, which further serves to produce health disparities by reducing health. In Immokalee, where the limited employment opportunities are usually in low-wage, physically demanding agricultural jobs, one’s health is absolutely necessary to be able to make a living. Working in low-wage jobs often means poorer housing, lack of transportation, lack of quality education, exposure to environmental contaminants, and a host of other living conditions that hinder health. In addition, poverty and agricultural employment often mean a lack of health insurance – the primary way in which Americans can access health care. As all of these issues occur in the context of unsustainable changes in health policy and economics that move services toward wealthier areas, people are less able to get the health care they need in places with large uninsured populations like Immokalee. For too many people I interviewed in Immokalee, reduced health leads to greater poverty, which leads to worse health, which leads again to more poverty, and so on, in a downward spiral. At the root of all of this seems to be a lack of agreement that the lives of the socially disadvantaged matter, or that everyone is ‘deserving’ of good health.

In 2015, the American Public Health Association released a report entitled “Better Health Through Equity: Case Studies in Reframing Public Health Work.” The report provides case reports of several public health agencies and organizations that have successfully shifted their work from a focus on health disparities (a measurement of the differences in health outcomes between groups) toward an agenda of health equity. Health equity is the absence of health disparities between groups with differential access to power, which requires us to address the “causes of the causes” of poor health (Braveman and Gottlieb 2014). Health equity is fundamentally a matter of social justice, and the populations that face greater health inequities also face a number of related challenges to their livelihoods – low wages, lack of access to quality education, unsafe housing, toxic environments – as well as political disempowerment to address these issues. The women of Immokalee that I interviewed are multiply marginalized – black, immigrant, low-income, female, non-English speaking. The intersections of these axes of social difference help to produce and shape the experiences of these women in Immokalee. So how do you work toward health equity with a population that is (arguably) disenfranchised from the ability to enact change? In the APHA report, they present a series of lessons that agencies and organizations can take from the APHA’s Better Health in Equity project. These lessons include:

- Acknowledging that equity is more than any one single intervention;

- Partnering needs to happen across sectors, including housing, education, and employment;
- Being mindful of the role that government and public policy have played in perpetuating health inequity; and,
- Gaining community participation at every step of the process (APHA 2015).

From an organizational perspective, these approaches to public health work are a good start toward action that is multifaceted and inclusive. However, from this list, how do we write change into the landscape and build health equity into the structure of our society? In Chapter 4, I detailed two possible approaches that agencies, activists, and others can use to re-design the environments that we live in -- policy and planning – that are worth revisiting.

Current policy approaches do not go far enough. In 2018, we are still, eight years after the passage of the ACA, debating whether people should have a right to health care, including those who cannot afford to pay for care. From the very beginning of the construction of the ACA, certain groups were barred from receiving assistance, while others were limited in the types of assistance they could receive and when. Rather than overhauling the financing of the health system to something more sustainable, the changes associated with the ACA were laid on top of the already existing mess of a health system – a system that does not work for the people that need it the most. Our current health system starts from the assumption that health care is, and should be, a commodity, and this is writ large into the health care landscape across the United States through the need for community health centers, the decline of hospitals, the rise of the suburban specialist, the decline in trust in American health care, and so on. It is difficult to imagine a way to harness the political system itself to make changes in health care, when special interests abound and creativity is in short supply. Policy takes a long time to change, but in the same way, any movement toward a more effective, equitable health system would take some time to roll back as well. An incremental approach to policy change in the health system (such as seen with the ACA) could produce some small material gains for marginalized people, at least until larger scale changes are able to succeed in our political climate. At the same time, though, incrementalism arguably helped to create the piecemeal, unsustainable system that we see today.

We can only make political changes by shifting the discourse that we use to talk about immigrants and health care. Not all damaging discourse about immigrants has been from anti-immigrant politicians. The concept of deservingness has been employed by those in academia, health care, and social services to argue *for* immigrant access as well. In Viladrich's (2012) excellent discussion of the scholarly frames utilized in research articles to support the inclusion of undocumented immigrants into the health care system, she lists four primary frames: the "cost-saving" and the "effortful immigrant" argument, the "surveillance" frame, the "maternalistic" frame, and the "chilling" frame. All of these frames provide limited (and limiting) moral justifications for providing health care to undocumented persons, but they highlight the myriad ways in which the concept of deservingness has been mobilized for different causes. As Clark (2008) notes, even the pro-access narratives can serve to undermine their own arguments for immigrant inclusion by, for example, portraying immigrants as dangerous or diseased – or by distinguishing between working (deserving) and non-working (undeserving) immigrants. We need to steer the conversation toward a "social justice" frame that says that everyone, including immigrants regardless of status, has a right to health care – and that the only way for all people to truly have equitable access to care is to move toward universal health care access.

But we have to go further than addressing just health care policy if we want to make it easier for people to live healthy lives. Much of the struggle I witnessed in Immokalee came not from the ability to access health care, but from their inability to afford to live. Agricultural work pays less than minimum wage. Housing is expensive in Immokalee, so people may live with 5 or 6 people sharing a one-bedroom apartment in order to lessen the burden of rent. Food is expensive, especially when you are not able to find work and you are ineligible to receive government assistance. Addressing the socioeconomic inequities faced disproportionately by people of color, immigrants, and women is the ultimate key to health, because health and wealth are inseparable. This is, of course, the social determinants of health model that public health uses to convey the interactions between the social, political, economic, and biological conditions in which we seek to maintain our health. This framework gives us a way to understand all of the possible sites for intervention in a particular health problem – and policy changes could go a long way to improve the material conditions in which people live. As suggested in Chapter 4, increased wages for agricultural labor, better working conditions, increased access to health resources, and sane approaches to immigration reform could have a greater impact on overall health for Haitian women in Immokalee, and arguably for other marginalized groups as well, than just throwing money at health problems, often too late.

Using the social determinants of health model also shows us how planning can help to create environments that are more supportive of health. Immokalee is a rural, isolated community that lacks many of the resources and amenities that people need to live long, healthy lives. How can we re-design places like Immokalee so that they are more health-promoting? Policy is the foundation, but what else can be done? There are exciting collaborations beginning between public health and planning, and the professional organizations for both fields have new research groups dedicated to the overlap between them. The American Planning Association has produced several reports outlining how to incorporate public health into planning decisions. Areas of public health that can be addressed through planning include active living (active transportation, recreation), emergency preparedness (climate change, infectious disease), environmental health conditions, access to healthy food and clean water, accessibility to health and human services, and mental health (housing quality, green spaces, security) (APA nd). In a review of city plans, the report found that places did well in their planning for things like active living, but most places were "very weak" in the way they approached accessibility to health and human services, as well as mental health issues. This is certainly true in rural, unincorporated places like Immokalee – where plans exist, they fail to address accessibility and mental health, but most often, there are no plans. As Hartley (2004) states:

> We are accustomed to think of urban space as 'designed' and rural space as 'natural,' yet the same policies that create sprawl and unhealthy urban spaces also are at work in rural communities, which forces planners to choose between economic development and healthy environments. With consistently lower average income and accumulated wealth in rural areas, economic development is even more likely to trump healthy design (p.1677).

In combination with policy change, thoughtful planning would provide opportunities for people in Immokalee to live healthier lives. Re-routing transportation routes so that people can access hospital services, building affordable housing, creating safe green spaces and gardens – these things become semi-permanent parts of the landscape. While these changes aren’t enough, they happen at the local level and provide an extra layer of support for entire communities, rather than just focusing on health care and the individual.

The health care providers and the Haitian women I interviewed “make it work.” They are resilient in the face of the challenges they face. Health providers advocate for their patients and provide quality care to their patients despite the problems in our health system. Haitian women do the best they can suffer through the pain when they can and find the money they need when they must see a doctor. Interestingly, none of the study participants felt strongly about any particular changes that could be made to improve the health of Immokalee’s residents. Most people did not know what could be done. Perhaps the most important change that could be made is to encourage community empowerment – however that community may be defined. Many of Immokalee’s residents are marginalized in the political process due to citizenship status. Creating a collective voice through local advocacy organizations and increased political involvement open up the possibility of improving not only health, but every aspect of life for immigrants trying to live in the United States.

Appendix A: List of Potential Interview Questions for Health Care Providers

Background

- Tell me a little about your job.
- How long have you been working with women in Immokalee?
- Tell me about the history and mission of the organization.
- How does the organization fit into the broader health system in Immokalee and/or southwest Florida?

Funding and Availability

- What sorts of issues has the organization had to contend with over time in terms of the broader patterns we see in healthcare (rising costs, issues with quality, physician shortages in certain areas, etc)?
- How has the scope of the organization's work changed since it began operations?
- Tell me a little about the issue of rising health care costs as they relate to your organization. How has your organization responded? How could you respond?
- How has the Affordable Care Act impacted the work that you do in Immokalee?
- Has Florida's non-participation in Medicaid expansion impacted your work?
- Do you think that state or federal politics impacts the work you do in any way?

The Haitian Community

- What policies does your organization have in regards to uninsured and/or undocumented patients? Have these changed over time?
- What documentation do you require to receive treatment?
- What types of services do you offer to Haitian women?
- What sorts of challenges do you face providing care to Haitian women?
- How does your organization accommodate Haitian immigrants?
- How have you attempted to reach out to the Haitian immigrant community?
- What other options for care are available to Haitian women in Immokalee?
- What are some of the gaps in care that immigrant women might face in Immokalee? Have these gaps been discussed by providers in southwest Florida?

Future

- What does the organization hope to do moving forward?
- If you could make any recommendations for improving healthcare in Florida or nationally, what would they be?
- If you could advocate for any law or policy changes at the local/state/federal levels that would make your job easier or more effective, what might they be?

Appendix B: List of Potential Interview Questions for Haitian Women

Personal

- Tell me about yourself. [Where were you born? When did you come to the US? How long have you been in Immokalee? Are you employed?]
- How would you describe your overall health?
- What types of things do you need to do to stay healthy?
- Have you been to see a doctor in the U.S.?
- Who do you go when you need help or information on your health? [Health department? Health fairs?]
- Where do you go for health care? [For primary care? Emergency care? Mental health? Prescriptions? Substance abuse? / How do you get there?]
- What types of health issues would you go to a doctor for?
- What is your experience like? [Do the doctors at the clinics you go to understand your health needs? / Are there language interpretation services available? / Are services located in convenient locations?]
- What problems do you face when you need to go to a clinic for health care?
- Are you covered by any kind of health insurance, or some other kind of health care plan? What kind of plan is it?
- IF UNINSURED: What happens if you need care? [What hospitals do they go to? / What happens if they can’t pay the bill?]
- Can you think of a time when you needed health care or advice but did not receive it?
- What kinds of health services do you need that you do not currently have access to?

Prenatal Care [if applicable]

- Have you been pregnant in the United States? How was your overall health during your pregnancy?
- Did you receive prenatal care? If so, where did you go and why?

- Do you remember when you first went to see the doctor?
- Have you ever delivered a child in the United States? Where did you deliver and why?

Haiti

- Did you ever visit the doctor in Haiti?
- How would you compare your experiences of the healthcare system in Haiti versus the United States?
- What has your experience with the American health system been like? Overall, what is your opinion on the American health care system?

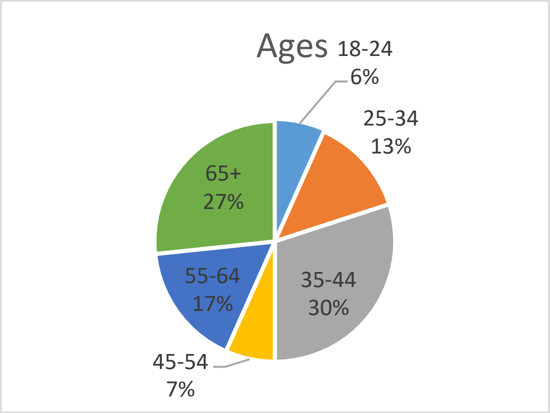
Discrimination

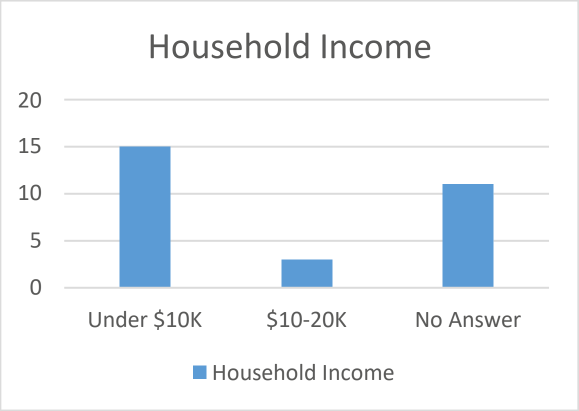
- Have you ever experienced any prejudice or discrimination in your own life because of your skin color, being a woman, or immigrant status? [In health care? Has it affected your health?]

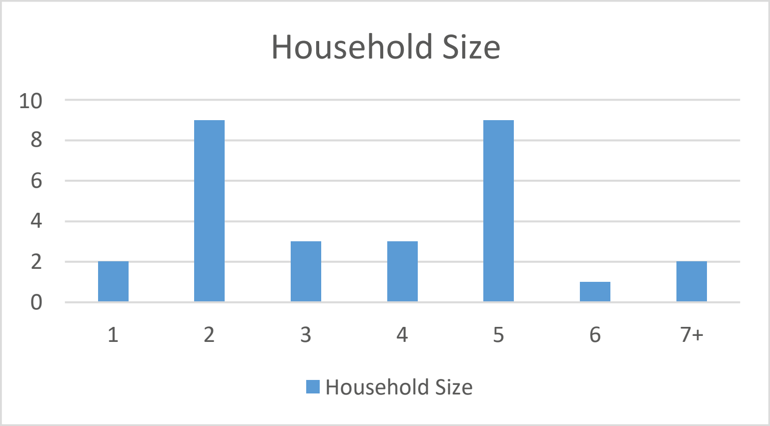
Haitian Health in General

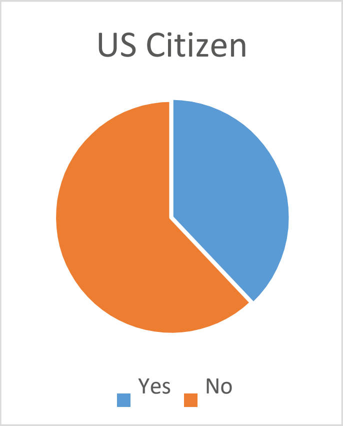
- What are major health issues you see in the Haitian community in Immokalee, especially among women? [Are there transportation, language translation, cultural or other issues? Health may include things that are not strictly medical like violence prevention, AIDS education, etc.]
- How could the clinics improve their services for Haitian women?
- In my report for local politicians, planners, and physicians, I will be making recommendations on how to improve services for Haitian women. What suggestions do you have that you feel should be included in this report?

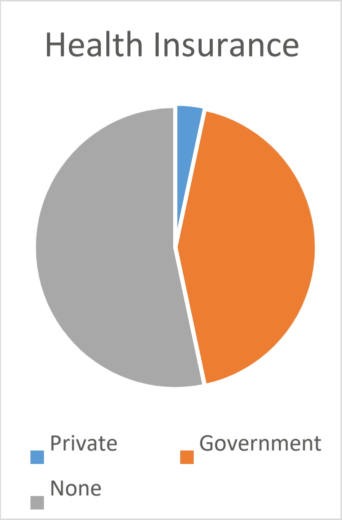
Appendix C: Demographic Information on Haitian Women Study Participants

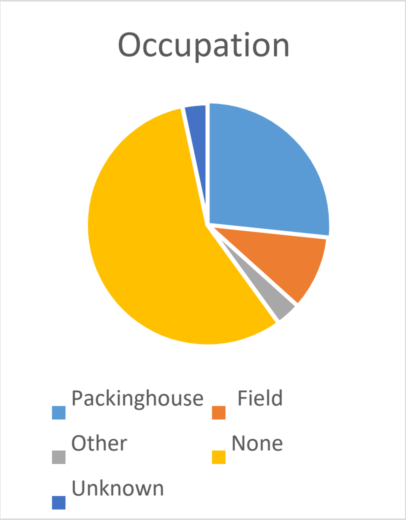


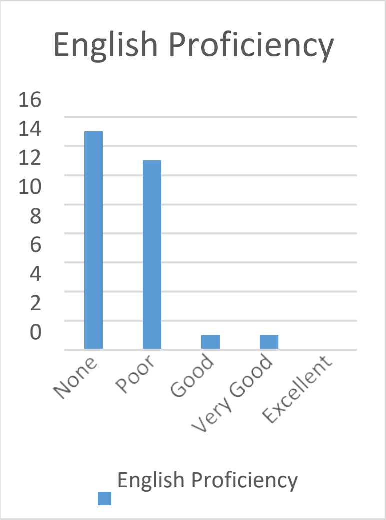


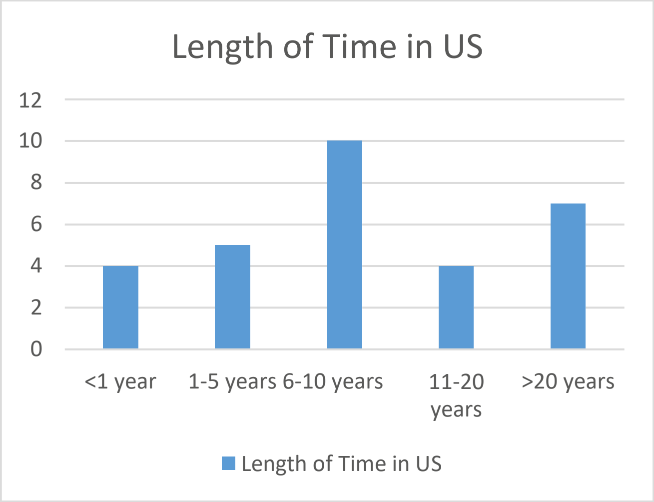


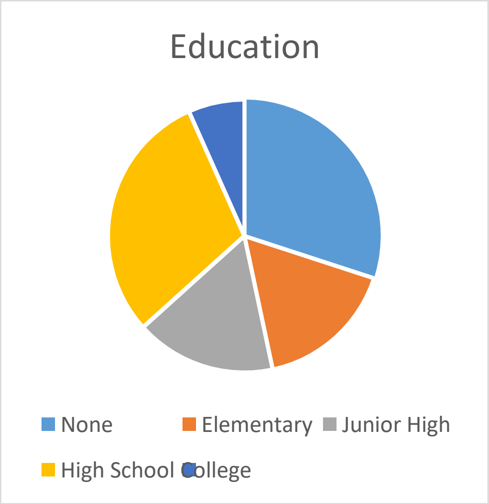









Length of Time in US
12
10
8
6
4
2
0
<1 year
1-5 years
6-10 years
11-20 years
>20 years
Length of Time in US


Education
None
Elementary
Junior High
High School
College

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