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Teach them to eat: Complexities of Community Based Organization and Nutrition Education Initiatives in the Prevention of Chronic Disease

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TEACH THEM TO EAT: COMPLEXITIES OF COMMUNITY
BASED ORGANIZATION AND NUTRITION EDUCATION
INITIATIVES IN THE PREVENTION OF CHRONIC DISEASE

by

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B.A. University of Central Florida, 2011

A thesis submitted in partial fulfillment of the requirements
for the degree of Master of Arts
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ABSTRACT

This thesis examines how participants of an eight-week nutrition education class utilize disseminated information to manage chronic disease, as well as explores the challenges a community based nutrition education resource center faces in the arena of chronic disease prevention. Per the World Health Organization's Global Report on Diabetes, 422 million adults currently live with a diagnosis of type 2 diabetes, a four-fold increase since the 1980s. Within the U.S., approximately nine percent of the adult population suffers from diabetes, and obesity, a major contributor to the disease, afflicts nearly thirty-five percent. While medical professionals frame the controlling of chronic disease from a pathophysiological perspective by promoting self-care methods and using language rooted in personal responsibility for successful treatment plans, implementation of such strategies by patients is more nuanced. In Orlando, Florida, staff at a community based, non-profit, nutrition resource center, Hebni Nutrition Consultants Inc., has played a key role in advocating for African-American community health in Central Florida, educating clients about chronic disease prevention and management since their establishment in 1995. Using ethnographic methods of participant-observation and semi- structured interviews, this project explores the challenges the staff of Hebni face operating at the intersection of the public and private sectors, as well as how participants of Hebni's programming understand discourses of empowerment, neoliberal ideas of self-care, and individual versus collective identity, when navigating the biomedical world. This project contributes not only to the growing body of research surrounding health disparities in minority communities, but also how neoliberal policies have shifted responsibility of community health and wellbeing from the state and onto private organizations

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CHAPTER 1: INTRODUCTION

Chronic diet related illnesses, such as obesity, type 2 diabetes, and hypertension, are growing health disparities within minority populations, most notably within the African-American community. Many theories have been suggested to explain the upsurge of health inequalities including racial-genetic, behavior and lifestyle, socioeconomic status, and social-structural models (Dressler 1993; Hunt et al 2013). While the theorization of why increases are occurring can shed light on society's failures and marginalization of specific populations, it is also known that changing dietary patterns is the most effective way of controlling and reducing the prevalence of these chronic illnesses. For individuals suffering from chronic health issues, finding a realistic and tangible dietary solution at the present moment is most important.

In the American South, much of the traditional food consumed by African-American communities is known as “soul food”. Although high in fats and salts, contemporary soul food has strong historical roots. In a *Gastronomica – Journal of Critical Food Studies* article regarding the rethinking of traditional cooking, sociologist Kimberly Nettles (2007, 108) highlights the strong cultural and historical narratives surrounding the cuisine:

Contemporary memories of soul food or black southern cuisine linked to notions of family, love, and community— to the idea that black people, struggling under the yoke of slavery and the post-slavery experiences of sharecropping, Jim Crow racism, migration north, and discrimination could at least rely on the comforts of the traditional foods that solidified their relationships with one another in the face of adversity.

For many medical professionals, the cultural significance of soul food is either unknown or ignored for the simple fact that no matter how it is presented, these foods are incompatible with “healthy eating” regimens advocated by biomedicine. The framework in which dietary changes are presented to many minority patients by physicians in the U.S. has also been identified as

problematic. In a study on the effects of salt on health, Smith et al. (2006:197) concluded that Americans assign a moral value to foods, especially in the discussion of chronic disease prevention, and many negatively perceived foods are already attributed to minority populations by biomedical professionals. These associations are not the only ways through which African-Americans and other minorities are disadvantaged when preventing and treating chronic disease. Many of the strategies advocated for prevention embrace self-care methods, including ownership of disease and changes to dietary habits. However, because of the lack of understanding of medical practices and nutrition, the implementation of self-care methods may differ between physician and patient, causing medical professionals to view many patients as “noncompliant” (Ferzacca 2000; Hunt and Arar 2001; Smith et al. 2006).

After realizing the struggles of the African-American community to achieve better health, three African-American dieticians—Fabiola Demps Gaines, Ronice Weaver, and Ellareetha Carson—formed Hebni Nutrition Consultants, Inc., in Orlando, Florida, in 1995. Born and raised in Orlando, the three founders of Hebni saw changing foodscape and rise in chronic disease within the black community over the years. On their website, they explain that through educational programs and outreach, they aim to, “educate high-risk, culturally diverse populations about nutrition strategies to prevent diet-related diseases [...] Hebni’s programs serve African-American populations who may be at-risk for cardiovascular disease, cancer, diabetes and obesity.”¹ One of most significant contributions Hebni has made to community health was the establishment of the “Soul Food Pyramid.” Understanding the dietary habits of the southern black community, the founders created a dietary regiment that incorporated traditional soul food into the U.S. Department of Agriculture’s Food Pyramid. Two

¹ See website for Hebni Nutrition Consultants, Inc: <http://soulfoodpyramid.org>

of the founders, Fabiola Demps Gaines and Ronice Weaver, also authored the bestselling cookbook *The New Soul Food Cookbook for People with Diabetes* (2006), for the American Diabetes Association. It was the first cookbook that the American Diabetes Association published that was aimed specifically at African-Americans.

One of the most successful projects initiated by the organization is Project Oasis. This eight-week course is a comprehensive nutrition class offered free of charge to community members “willing to make changes to their lives,” as emphasized by Hebni staff. Since the course only meets once a week for 2 hours, instructors provide students with handouts containing easy to follow recipes and information about accessible food options. The instructors remain realistic about their expectations for the students. They explain that restricting one’s diet usually results in failure, and students will find the most success by portioning their meals and replacing unhealthy options for healthier ones. Since the class’s inception four years ago, Hebni instructors have offered this class multiple times a year and find that members of the community are still interested and engaged. The course may be held at locations that show interest to the organization, for example a church or community center. Stemming from this local advocacy and the questions raised by the continued health disparities for African-Americans, especially in the area of diabetes, my research questions crystallized around strategies for community health organizing in Eatonville, Florida.

Specifically, this research project examined how staff at Hebni Nutrition Consultants, Inc., navigate the challenges that grassroots non-profit organizations face working at the fringe of the public and private spheres in their mission to provide nutrition education and chronic disease-management methods to a predominantly African-American community. Using an

ethnographic approach, including interviews with participants from Hebni's nutrition education course, Project Oasis, I explored how these activists understood discourses of empowerment and individual versus collective identity, as well as implemented neoliberal self-care methods in their daily lives. Overall, I argue that as part of the "non-profit industrial complex," Hebni staff are bound to the neoliberal philosophies from which these non-profit organizations have emerged. However, Hebni's approach to education, community commitment, and diversification of funding sources allows for the creation of a social movement, more than a social service.

CHAPTER 2: LITERATURE REVIEW

Structural Violence

In December 2010, the U.S. Department of Health and Human Services launched *Healthy People 2020*, a multiyear, multidepartment, collaborative effort to promote health and prevent disease. The initiative contains more than 1,200 objectives focusing on broad structural issues such as: eliminating health disparities; addressing social determinants of health; improving access to quality health care; strengthening public health services; and improving the availability and dissemination of health-related information.² This plan aimed to be more comprehensive than its predecessor, *Healthy People 2010*, for which, “documented disparities have persisted for approximately 80% of the Healthy People 2010 objectives and have increased for an additional 13% of the objectives” (CDC MMWR 2013: 3). Health disparities, used interchangeably with health inequalities, refer to the differing health statuses of groups and are typically delineated by race, ethnicity, socioeconomic status, and gender.

Traditionally, responses to health disparities have focused on isolating and treating a specific pathology without fully contextualizing its prevalence within the cultural and socioeconomic specificities of given groups. World Health Organization shows that health disparities have intensified with globalization—as an expanding global economy allows transnational corporate interests to operate with minimal regulation, companies find loopholes within governments to safety laws, and economic and trade policies are quickly exacerbating health inequalities. Within anthropological research, it is noted that addressing the link between these issues and eroding health require new approaches, which “stem from the understanding that health disparities emerge from complex and multifaceted processes and

require collaboration across discipline. Thus, many of the contemporary explanatory frameworks aim to weave together elements of biology, geography, political, social, cultural, historical, and economic processes responsible for health” (Leatherman and Jernigan 2014,176).

Within African-American populations in the U.S., health inequalities, social suffering, and structural violence cannot be separated from one another. Social suffering, “addresses the intersection of medical and social problems”—racism, poverty, chronic illness, and “the ways in which society and its institutions unintentionally exacerbate social and health problems” (Farmer et. al 2013, 30). As a form of social suffering, structural violence acknowledges the historical context in which institutions systematically restrict groups from utilizing full agency.

Anthropologist Paul Farmer posits, “Erasing history is perhaps the most common explanatory sleight-of-hand relied upon by the architects of structural violence. Erasure or distortion of history is part of the process of desocialization necessary for the emergence of hegemonic accounts of what happened and why” (2013: 308). Although The Civil Rights Act of 1964 outlawed segregation within the U.S., it is still visible in neighborhoods throughout the country. Stark differences exist in health, socioeconomic status, and housing quality between African-Americans and their white counterparts, and the economic gap between blacks and whites changed little at the turn of the 21st century (Williams and Collins 2001: 116). Within the confines

Race and Neoliberalism

With health inequalities and the economic gap expanding between blacks and whites, it is important to understand the relationship between race and the dominant sociopolitical and economic ideology of neoliberalism. Anthropologists have historically engaged in conversations

and analysis of the construction and deconstruction of race as a social reality, rejecting race as biology. However, this does little to explain the very real experiences of racism felt by people of color (Harrison 1995). One explanation is exemplified by the perpetuation of the color blindness narrative—the belief that racism is obsolete as a result of the legal victories of the civil rights movement—and the discourse that now all individuals, regardless of color and sex, have same access to resources through which they can control their own destiny (Mullings 2004, 2005). This narrative is dangerous as it views racism as a historical phenomenon and, by denying its continual existence, reinforces white supremacy (Mullings 2004). Reflecting on Shanklin (1994), Harrison (1998) believes it is the responsibility of anthropologists to address the viewing of racial differences in the United States as a binary opposition between black and white “unselfconsciously.” The avoidance of a black/white dichotomy when speaking of race and racism tends to not only muddle, but inaccurately correlates, racism with structural issues like socioeconomic status. Without such a critical perspective, anthropologists are complicit in perpetuating the myth of color blindness. Leith Mullings argues that racism is more subtle now than in the past and “the most significant new feature is the transformation of practices and ideologies of racism to a configuration that flourishes without official support of legal and civic institutions” (2005: 677). However, while explicit state sanctioned violence against black bodies, like through laws that reinforced segregation and turned a blind eye to lynching, new forms of racialization, like the prison- industrial complex and voter suppression laws, are justified through discourses of personal responsibility.

This leads to a discussion of the neoliberal ideology. Margaret Thatcher famously stated there is “no such thing as society, only individual men and women...economics are the method...but the object is to change the soul,” thus laying the foundation of neoliberalism (Harvey 2005: 23). Neoliberals believe that a free market, free trade, small government, and privatization

of public sector services, enhances individual freedoms. Harvey writes, “While personal and individual freedom in the marketplace is guaranteed, each individual is held responsible and accountable for his or her own actions and well-being. This principle extends into the realms of welfare, education, health care, and even pensions” (2005: 65). Individual worth is placed on productivity and measured in terms of economics. It assumes individuals are rational actors and are not affected by outside influence. Within the conversation of race and racism, associating self-worth with monetary value works to actively rationalize inequality, delegitimize antiracist activities, and erase collective histories of struggle (Mullings 2005). Within this framework, the complex reality of racism is a top-down imposed hierarchy linked to structures of power (Mullings 2005).

CHAPTER 3: METHODOLOGY

This research is a long-term ethnographic study conducted over 26 months from June 2014 to September 2016 in the city of Orlando, Florida, and the town of Eatonville, Florida. My fieldwork was situated at the community organization Hebni Nutrition Consultant's Inc, and among the community participants who utilize Hebni's nutrition resources and services. Below I explain my research site selection and delineate project design.

Field Site Selection

The research site for this project is a community based nutrition resource center, Hebni Nutrition Consultants Inc., located on the outskirts of downtown Orlando, Florida. Through educational programs and outreach, Hebni's mission is to, "educate high-risk, culturally diverse populations about nutrition strategies to prevent diet-related diseases [...] Hebni's programs serve African-American populations who may be at-risk for cardiovascular disease, cancer, diabetes and obesity"². The strategic positioning of this facility places the Hebni organization in the middle of what the U.S. Department of Agriculture (USDA) deems "food desert" neighborhoods. Food deserts are low-access, low-income areas with a significant population of residents reside more than 1 mile from a supermarket in urban areas and more than 10 miles in rural areas. The USDA officially designates "food desert" areas based on census tracts delineated by the Census Bureau.⁵ Census tracts, as defined by the U.S. Census Bureau, "are small, relatively permanent statistical subdivisions of a county or equivalent entity that are

² This is 'About Us' section of official website http://soulfoodpyramid.org/?page_id=10

updated by local participants prior to each decennial census.”³ Fifteen zip codes in Central Florida fell under the USDA’s the definition, many predominately African-American, the target demographic for Hebni’s programs (Benwell-Lybarger 2012).

My research centered around one of the most successful programs developed by the organization, Project Oasis. This eight-week course is a comprehensive nutrition education curriculum offered free of charge, four times a year, to community members interested in adopting a healthier lifestyle to prevent chronic diet related diseases through changes in consumption practices. Since the course only meets once a week for two hours, Hebni instructors provide students with handouts containing easy to follow recipes and information about accessible food options.

Project Oasis is held at Hebni’s facility in Orlando on Monday nights. Per funding restrictions, once an individual has enrolled and completed a session, they are ineligible to reenroll for one full calendar year.

As part of an ongoing health initiative with Florida Hospital Diabetes Institute, Hebni conducts a second Project Oasis session on Tuesday nights at an alternative location, Healthy Eatonville Place (HEP), in Eatonville, Florida. Located approximately nine miles from Hebni’s facility, Eatonville is a historically African-American town with over 24% of the population diagnosed with type 2 diabetes. Established as a diabetes education and research center by Florida Hospital, HEP strives to encourage healthy lifestyles and disease management by offering classes and support groups free of charge.

The courses at the Orlando and Eatonville locations occur simultaneously. I attended the courses and became familiar with the course design and information. I also built rapport with

³ See: <https://www.census.gov/geo/maps-data/maps/2010tract.html>

Hebni's staff and the Project Oasis participants.

I discovered Hebni Nutrition Consultants, Inc. as I drove past their past their office on my way home from work in 2014. After researching Hebni, I contacted Fabiola Gaines, introduced myself, and discussed how I could contribute to the organization. When I first began my fieldwork, I became increasingly self-conscious of my positionality within the organization.

Although I am Hispanic and white, my outward white appearance and status as a researcher "studying" a black organization, sent me into a crisis. I became increasingly fearful that people would believe I viewed myself as a white savior, coming to "save" the black community. Although my intentions were never questioned and I was enthusiastically welcomed and embraced by both Hebni staff and Project Oasis participants, I continued to feel insecure, especially since my fieldwork began around the same time Black Lives Matter, conversations of police brutality and white supremacy gained national attention. I even considered throwing away my research project and leaving the anthropology program. However, I slowly began to reconcile my research and my identity. I was not there to change or influence the operations of the organization. While the women of Hebni took direct action within the community, I documented the struggles they faced as an organization, the struggles the participants faced navigating the biomedical world, and analyzed them from a critical perspective. Spending over two years doing fieldwork made me uncomfortably aware of my own biases, privilege, and issues within the Orlando community that never directly affected me. However, this made me realize one cannot tackle issues of inequalities without acknowledging topics that many white Americans may view as difficult because, by their mere existence, minority communities have always been uncomfortable and the victims of white privilege. Ignoring will not solve anything.

Research Design

In terms of data collection and methodological design, my project aimed to explore how both program creators and participants of Hebni's community based nutrition resource center view the organization's role in disease prevention and education dissemination within a local context. My specific research questions (RQ) were:

RQ1. What challenges do the staff of Hebni Nutrition Consultants Inc., face in their mission of reducing chronic diet related diseases within their community?

RQ2. How do class participants of Project Oasis utilize and implement course material in their objective to manage and prevent chronic disease?

As an ethnographic study, participant observation and semi-structured interviews were primary data collection methods for this research. I explored the organization's goals of disease prevention in the community with the following two perspectives in mind: (1) the perspective of dieticians coordinating the community education classes, and (2) the perspective of class participants (i.e., community members).

My data collection period at Hebni lasted 26 months (June 2014 - September 2016). I participated in a variety of the organization's activities, including Project Oasis. Additionally, I conducted over 300 hours of participant observation at Hebni. Participant observation in ethnographic research is a useful methodology because on-the-ground experience not only facilitates data collection in the form of fieldnotes, but it also calls for the continual reassessment of initial research questions. Listening to the perspectives of research participants helps the researcher be responsive to emerging and unforeseen research themes and findings, and provides rich data with which to contextualize interview narratives (DeWalt and DeWalt 2011:13).

Moreover, attending the two hour weekly Project Oasis classes not only exposed me to the same material and allowed me to share the experience with the class participants, it also allowed me to analyze how they interacted and responded to information given by the dieticians. I recorded my observations and notes in a field notebook which I later analyzed alongside the interview narratives.

I conducted semi-structured interviews with Hebni Nutrition Consultant's staff, as well as participants of the Project Oasis program. I carried out the interviews with Project Oasis participants at the conclusion of the eight-week course. My interview sample included: two Hebni staff members with whom I had formal interviews; five Hebni staff members with whom I had informal conversations; 15 Project Oasis participants with whom I conducted formal, in-depth interviews; and 30 Project Oasis participants with whom I had informal conversations.

During the interviews with Hebni's staff, I utilized a list of formal, open-ended questions to guide the interview in a forward motion, but allowed for an openness and flexibility to explore other ideas and themes that may arise (Kvale 1996: 125). The interviews lasted for approximately 20 minutes to one hour. I audio-recorded the interviews with participants who gave consent, and I took detailed notes during the interview session for those who did not. I transcribed recorded interviews in a Microsoft Word document and then coded for specific themes and subthemes, such as "funding constraints," "self-care methods," "collective versus individual responsibility," and "empowerment."

Participant Groups

Because I collected data with both the Hebni staff and the community members who participated in Hebni's programs, I delineate below the characteristics and methods for each of these samples.

Group 1: Project Oasis Class Participants

Participation in the semi-structured interviews for the community sample was limited to persons who officially registered and completed the eight-week Project Oasis course offered by Hebni, and were over the age of 18. During the first week of each Project Oasis session, I introduced myself and explained the premise of my research. During weeks two through six, I participated in the course, assisted staff members, and answered questions class participants had regarding my research, if questioned. At the beginning of the classes for weeks seven and eight, I reiterated my research needs and collected names and telephone numbers of class participants willing to participate in semi-structured interviews. Depending upon access to transportation and time constraints, I gave the interview participants the options of a face-to-face interview or phone interview.

Based on the participant's location, I conducted in-person interviews in the conference room or the project coordinator's office at Hebni's facility in Orlando or in a classroom at Healthy Eatonville Place. These locations offered the privacy needed for interviewing. In total, 15 interviews were conducted. Five participants chose in-person interviews and ten chose phone interviews. I gave a full explanation of my research and obtained informed consent (oral consent) before each interview began. Interview participants were not required to give any personal identifiers such as name, age, race, and current location. All participants were assigned

pseudonyms. Participants were not given remuneration.

Group 2: Hebni Nutrition Consultants Inc. Staff

After spending time with Hebni staff during the Project Oasis course, I verbally asked two staff members if they would participate in semi-structured interviews. Only persons employed by Hebni who had direct involvement with the Project Oasis course were eligible to participate.

Since all staff is over the age of 18, age was not a factor in eligibility. I gave a full explanation of my research and obtained oral consent before each interview began. I interviewed the Executive Director and co-founder of Hebni, Roniece Weaver; Director of Nutrition Programming and co-founder, Fabiola Gaines; and Project Coordinator, Glen Providence. These research participants gave their consent to use their real names, and they serve as what is known in ethnographic research as key informants. Interviewing carefully selected key informants can provide data about a particular cultural and knowledge domain within which these individuals can be considered experts because of their first-hand knowledge about the particular domain (Bernard 2002). In the case of this project, key informants from Hebni organization have first-hand knowledge of, and can provide insight about, the organization's goals, activities, and experiences. Participants were not given remuneration.

I secured the Institutional Research Board approval for my research via UCF's IRB review #SBE- 14-10758 (see Appendix A for IRB approval). Before launching my data collection, I also completed the CITI Training for research with human subjects.

Data analysis

Interviews conducted in-person at Hebni's facility were recorded and transcribed. The

verbatim transcripts from interviews were then coded and analyzed emerging categories of themes and patterns (Bernard 2002). The grounded theory approach was used throughout the coding and analysis process whereby I maintained flexibility and openness to allow previously unforeseen topics to emerge, thus closely “grounding” findings in the narrative data (Strauss and Corbin, 1998).

In the following chapters, I offer the results of my analysis organized into two sections with findings and arguments, following which I discuss my conclusions and consider the significance and contributions of this research to anthropology and public health.

CHAPTER 4: HEBNI HISTORY AND GRANT DEVELOPMENT

In this chapter, I present the complex relationship between funding for nonprofit health work and the stigmatizing discourses of the health of minority groups, and demonstrate the problems that Hebni faces in navigating this challenging terrain. Specifically, the political and media discourses about the health of minority groups focuses on depictions of African-Americans as suffering disproportionately from obesity and diabetes. These depictions of minority groups, who might also experience being under-insured and other forms of structural disadvantage, are further linked with discussions of the so-called “disease burden” of these groups on the health system defined as the, “impact of a health problem as measured by prevalence, incidence, mortality, morbidity, extent of disability, financial cost, or other indicators” (Nation Institute of Health 2016).

On the global scale, the World Health Organization (WHO) includes diabetes in the top ten causes of the “global burden of disease,” showing a significant increase in diabetes in the last two decades (World Health Organization 2014). My research shows that because funding for community health programs is highly restricted and limited, Hebni activists are forced to adopt the fundraising strategies that reaffirm the same depictions of African-Americans as obese and a burden on the healthcare system in order to successfully secure funding for much needed community nutrition programs. The immediate need for funding on-the-ground programs might have the unintended result of deflecting attention from the underlying structural causes of these health problems.

On a more local scale, the Florida Department of Health is one of the many organizations across the country that, in conjunction with the Center for Disease Control (CDC), participates in a state-based telephone surveillance system to collect data on information regarding

individuals participating in preventative health practices as well as risk behaviors (Florida Department of Health, n.d.). In 2015, a County Chronic Disease Profile was created for Orange County, which is home to both Orlando and Eatonville (see Figure 1).

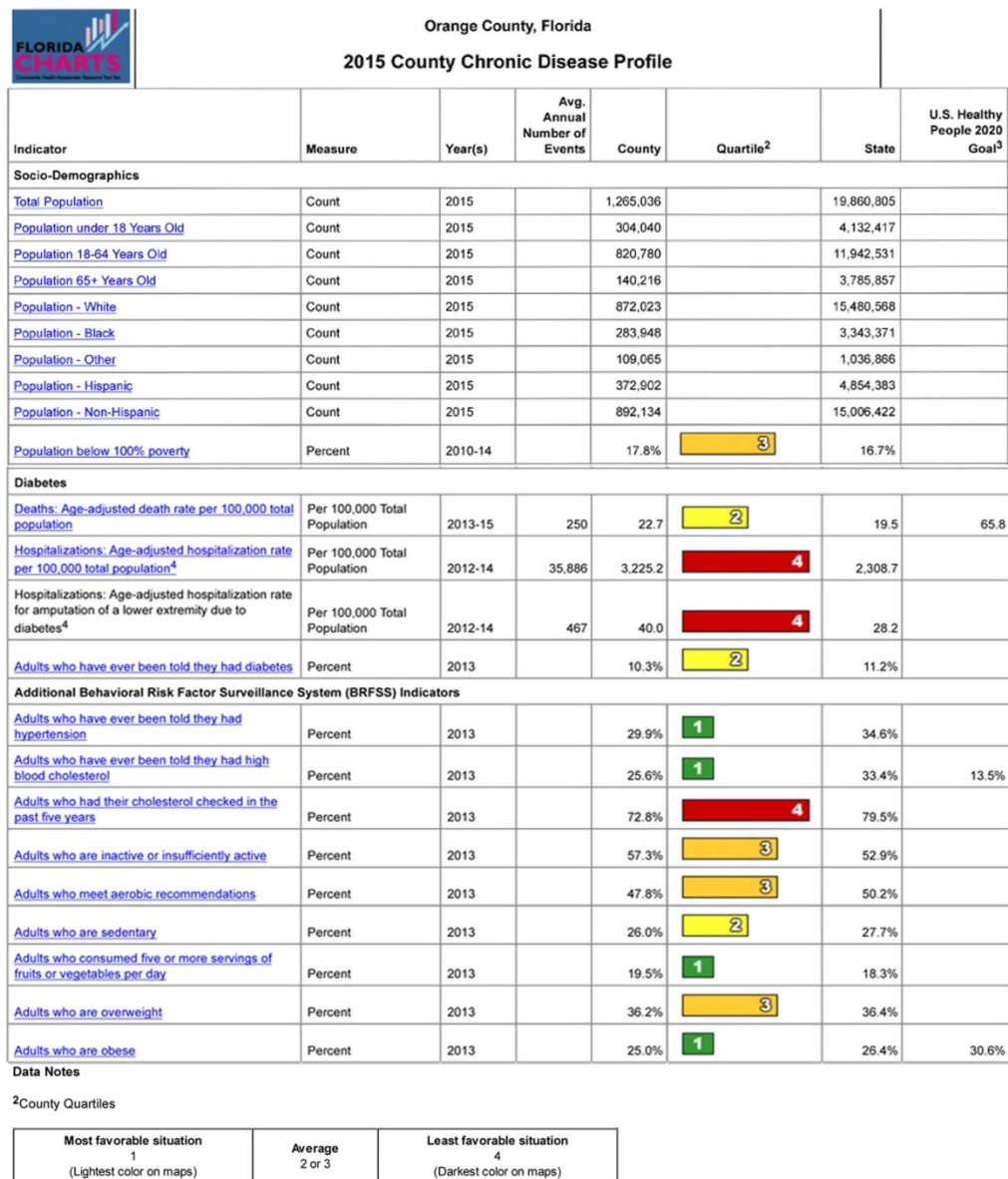


Figure 1. Orange County Florida 2015 Chronic Disease Profile (Florida Health 2016)

The series of health-related phone surveys, known as The Behavioral Risk Factor Surveillance System (BRFSS), reaches out to U.S. residents to collect data on health-related risk behaviors, chronic diseases, and implementation of preventative measures (CDC 2014). Health-related risk behaviors include: alcohol consumption, smoking, high cholesterol and blood pressure, use of illegal drugs, inactivity, and excess weight/obesity (CDC 2015). Such factors increase an individual's chances of developing a chronic disease. BRFSS informs health professionals of health trends and guides prevention and health promotion strategies, such as the creation of community and clinical programs that specialize in disease management. The data collected also appeals to the larger health care system by allowing physicians to educate patients about preventative measures which reduce overall medical costs. As a community program, Hebni uses the information collected, such as the fact that Orange County had higher rates of hospitalizations and amputations of lower extremities due to complications of diabetes than the overall Florida state average, to guide their program development and address issues in a practical way. When applying for funding and partnerships, Hebni understands that funders want the most pressing health-related issues addressed and utilize information of chronic disease provided by the Florida Department of Health.

Teaching People to Eat

The goal of the organization is simple, to teach people how to eat. Educating people about nutrition choices will allow them to see exactly how consumption practices directly impact their health. This was the mission of a business plan created by Hebni's three

founders, as they stood under a tree after a dietetics meeting in 1995. Fabiola recalls the dietetics meeting and the concerns she shared with her colleagues:

In the presentation they were asking a lot of questions that at that time had not been addressed by USDA or any, uh, programs in the state addressing how southerners eat. We were the only three black dietitians in Orlando. You have to remember that there are 17,000 registered dietitians in this country and only 2% are African-American. We decided to form a business and we would often say, 'Help Orlando lose weight and we would make millions of dollars!' But it never worked out that way because the people we needed to help, uh, couldn't pay us. And at that time I was a clinical dietitian at winter park hospital and I'm looking at predominately white hospital with more blacks dying at that hospital and it sort of perplexed me. Why are all these black people dying when it it a majority white hospital? And it was because of the chronic disease rates at that time that were not being address. So we decided to form a business and we applied to be a 501(c)(3) because we felt that a 501(c)(3) would have more people donating and giving us money to do things within the community. **[Interview with Fabiola, June 2015]**

Although Fabiola refers to Hebni as a business, the organization's 501(c)(3) status gives it the classification of a non-profit organization, or charitable organization, as defined by the IRS. Such organizations cannot benefit private interest, i.e., creator's friends, families, or private shareholders.⁴

From the organization's inception, the staff designed their programming and rhetoric around discourses of neoliberal ideas of self-care. These ideas include individuals recognizing and taking responsibility for their health, that health is directly related to the decisions they make, and only individuals have the ability to improve their situations. But, Hebni's position within the community became one of a mediator between patient and medical professionals. Whether realizing it or not, the organization adopted the responsibility of tending to the needs of a group of people society and medical professionals homogenized as "African-Americans".

⁴ See IRS Exemption Requirements – 501(c)(3) : <https://www.irs.gov/charities-non-profits/charitable-organizations/exemption-requirements-section-501-c-3-organizations>

Although the experiences of all African-Americans are not uniform, this collective “biological identity” is bolstered through systemic racism that is “embodied in the biology of racialized groups and individuals, and the embodied inequalities reinforce a racialized understanding of human biology” (Gravlee 2009:54). Nonetheless, as African-American women living in Orlando themselves, the three dietitians knew their experiences would resonate with their target audience, but addressing chronic diseases had to go beyond viewing them as pathologies. As Fabiola explains:

No one was addressing how minorities were eating and how these chronic disease rates were impacting our medical care at that time[...] We look at it holistically. Because you can't [just] address the diabetes and high blood pressure. You have to address how you gonna pay for this, my light bill, how I'm gonna deal with bad kids, how I'm gonna deal with bad relationships, so we just looked at the total person and address those issues and we became real popular in the community.
[Interview with Fabiola, June 2015]

This holistic approach confronts chronic disease as a product of social distress and individual everyday experiences, not just a medical issue (Mendenhall et al 2010). The women of Hebni are not the only organizers who acknowledge this missing component within mainstream medical discourse. In an article examining the “obesity epidemic” within the Latino community, Greenhalgh and Carney (2014) conclude that before addressing effective treatment for health problems, the narrative of blaming and shaming minorities for ‘dragging down’ American healthcare must be rectified. Through comradeship and shared experiences, empowerment programs, like those designed by Hebni, aim to reduce the stigma of illness within minority communities and demonstrate that these communities do not have to fall victim to the cultural and political narrative.

Organizations working outside the dominant paradigm must secure funding to

support alternative programming and daily operations, which is a constant battle between restrictions outlined by funding sources and listening and responding to their constituency.

“Sometimes you gotta go in the hood to get help”

Hebni moved into their current facility in 2006. Over the course of their 20 year history, they resided in various rental properties around Orlando, always outgrowing the location within a few years. When looking for a permanent location, Roniece and Fabiola had specific requirements: a central location near downtown in a predominantly black community; an existing building that people living in the community would recognize; and a place that would allow for future growth. They purchased an old black bookstore, where Fabiola remembers “buying books that actually had people that looked like me in them!” Renovations of the building came from donations and grants from the city. Roniece explains as follows:

Look at the exterior of this building. Even though...this was a community development block grant [we used] to do this. We are in an empowerment zone and sometimes you gotta go in the hood to get help. And sometimes it's good to stay in the hood. There are some people who are very wealthy and they bring their office to the hood because they get tax breaks and they get, uh, subsidies to do that. They takin' advantage of it. And believe me, I am too. Because city right now will give you—because my husband owns the building--they'll give you a façade grant. Because this building needs paintin'. [...] It's called façade grants. Because, I mean, Orlando is the City Beautiful. And that's their thing. But they want businesses to look up to speed too. And it's...it's better to invest money into the owner and help their stuff look good instead of going through code violations and saying... man, you spend too much time and effort penalizing people instead of helping people. **[Interview Roniece Weaver June 2015]**

The Community Development Block Grant Program (CDBG) is a community development initiative enacted by the U.S. Department of Housing and Urban Development in 1974. Annual money allocation is distributed as grants between states and local jurisdictions

deemed “non- entitlement” and “entitlement” communities. Emphasis is placed on the engagement of low or moderate income communities and populations through citizen participation, and activity must fulfill one of the national program objectives, including “benefiting low- and moderate-income persons, prevention or elimination of slums or blight, or address community development needs having a particular urgency because existing conditions pose a serious and immediate threat to the health or welfare of the community for which other funding is not available” (HUD, n.d.).

The City of Orlando has participated in and implemented various programs to revitalize distressed neighborhoods, focusing on citizen participation to determine what specific areas need. The Small Business Façade Program is an economic development program that provides interest free loans to help with costs relating to cosmetic building improvements in “commercial corridors, particularly in blighted areas” (City of Orlando 2013). The language used to promote these programs is one of empowerment; it calls on local commercial property owners to improve the appearance of their buildings to support the city’s viability. Revitalization of “blighted” areas is promoted by local politicians and law makers to encourage economic and social growth to underserved people.

Within recent years, Orlando local politics has centered around revitalization and development. The population is rapidly growing and the physical limits of the downtown area are expanding. One major development project currently underway is the construction of a new Major League Soccer stadium in the Parramore neighborhood—a historically black neighborhood, now designated food desert and one of the target areas of Hebni’s initiatives. From a business perspective, Roniece understands and appreciates the efforts for economic

development and growth within the city, but has serious concerns for the populations living within the boundaries of projected growth plans. The following excerpt from my interview with Roniece is worth reproducing here in its entirety because it illustrates well how race is at the heart of the boundary-making she describes:

Roniece: Now just to let you from a historical perspective, where is the railroad track?

Allison: It's the dividing of a neighborhood.

Roniece: It does. Always has. For years. If you drive around Orlando [...] Look at where the railroad track separates black from white. Go down Morse Avenue and cross over the railroad track. And within 30 seconds. It's like woosh.

Allison: Yeah the street that I live on the railroad track is must be...about three blocks. And it's incredible the difference

Roniece: It's everywhere. It's all over. It's not just Orlando. It's a railroad track. It's bridge. It's a water. It's everywhere [...] Railroad tracks. Any of those. Separates black from white. Back in the day and still to this day. Still to this day. And I think in my children's next generation. They will not understand the significance of what that railroad track meant

Allison: Yeah...and people today don't understand. They just say, "don't go to the other side of the tracks."

Roniece: Bingo!

Allison: They don't get it. And it's like, "what are you talking about?"

Roniece: It's a dividing line. That's your side. You stay over there. You best not be over here before the sun go down [...] And I don't care where you are in the world. That's the dividing line. And we startin' to see..and the problem with urban sprawl is that people started goin' out to the suburbs. But look at all the buildings that is coming back. Orlando is gonna run out of

space. And where they gonna go? To the other side of the railroad tracks.

Allison: Yeah, and that is kinda what is happening now downtown. Kinda where, uh, CityView...

Roniece: They call it gentrification [...] They say it's not, Baby it is. What happened with CityView is a very good example. "Oh it's uh, it's affordable. It's for everybody!" Okay, year one the rent is as low as it can get. Year two...woops. Rent hike, I can't afford this. Then get the hell out. It's a game.

Allison: And now with that stadium going in...are they redoing Central over there? Is that the road they are redoing over there?

Roniece: They are redoing Church Street.

Allison: Ah, Church Street. Okay.

Roniece: I think in my position here, I have an advantage. Everything is gonna get spruced up around here which I do think is a good thing, but I do have a concern about who they pushin' out and where they gonna go. When you see, and I won't call the man's name, but when I heard a gentleman in a position of power say, 'I do not want to drive through the hood to get to the stadium.' I'm talking about a very powerful man in this neighborhood, in Orlando, that's why you seein' this change in this community. Go down three blocks and when you start seein' apartments boarded up, what we call the projects, where did those people go? Where did they go?

Allison: Nobody asks these questions though...

Roniece: Nobody has the guts to ask. If they do, the thing is, it is economic development, it does bring jobs, it does bring mixed development and new things to Orlando. We can't keep living in the 50s, because that is when those things was built, it is eventually gonna get torn down but you displace...in the 50s, in the 60s, in the 70s all those boarded up apartments were professional black families. Teachers, principals. They ended up now becoming the projects but that's where they lived. They lived in Parramore first. But then urban sprawl, then urban sprawl wasn't as great. But that's where they lived. They were professional working people. Not thugs, drug dealers, baby mama drama folks sittin' round watchin' *The Young and the Restless* all day, that's not who lived there in the 50s and 60s.

Allison: So, what changed?

Roniece: They made more money.

Me: So, they moved?

Roniece: So, they moved out and those places became vacant. And then those places became public housing.

The areas Roniece refers to as “empowerment zones” are legally titled “enterprise zones” by the City of Orlando. Businesses within these areas are offered special benefits such as tax incentives, to create economic and social opportunities for surrounding neighborhoods. Roniece’s use of “empowerment” instead of “enterprise,” whether intentional or not, reinforces the notion that business and capital are ultimate forms of power, as espoused by neoliberalism. By this logic, the wealth brought into the community through businesses will fix the inequalities that persist. Many of these businesses are also recipients of community block and façade grants. How and if these grants directly benefit the intended communities is beyond the scope of this research. However, my interest in Roniece’s narrative relates to how grants to entice community development through business ventures relate to Foucault’s concept of governmentality. Michel Foucault defined governmentality as the way in which the state, or governing body, exercises power over its constituency. Foucault, when speaking of government writes “One governs things...I do not think this is a matter of opposing things to men but rather of showing that what government has to do with is not territory but rather a sort of complex composed of men and things” (Foucault 1991:93). With respect to community development grants, the governing body attempts to control the relationship of the community and the physical environment by enticing individuals to conform to a specific standard. This is a form of aesthetic governmentality.

While studying government initiatives to reform slums in Delhi, India, geographer D.

Asher Ghertner (2010:207) termed “aesthetic governmentality” to describe the state’s mission to establish a dominant “aesthetic order” through carefully manufactured programs that benefit the individual and compel residents to reconstruct how they view their “sense of self and place” for the greater good of the community. With regards to Orlando, policymakers entice community organizations and businesses to participate in revitalization and development promotions under the notion that they will help promote the economy. At the same time, such programs force members of the community to acknowledge they are part of the “problem,” and the grant funding provides guidelines for self-reform (Lawrence-Zúñiga 2015:146). Policy makers have a hand in how they wish the outcome of that process to look. These issues do not go unnoticed by people within the community. In my interview with Roniece, she explicitly states her conflicted feelings of how taking advantage of incentives for her business will affect the surrounding community in the long term.

Follow the money and follow the trends

Establishing the mission of Hebni was easy, but strategizing how to disseminate nutrition information, while emphasizing its inextricable relationship with personal health, in a public arena would be a testament of the strength of the organization. One of the first programs to reach a wide audience was *Sisters: Take Charge of Your Health*. Fabiola recounts how, if Hebni wanted to have an impact on the eating habits of the African-American community, they needed to target the women first “We needed to start with the females,” she stated, “because we felt she is the nutritionist of the family.” Reaching out to friends, family, and church groups, *Sisters: Take Charge of Your Health* grew from 200 participants during

the first year in 1996 to 1,500 participants by the last year in 2012. The program consisted of various workshops that addressed health from a holistic perspective. It covered topics ranging from nutrition education and cooking demonstrations to car repair tips and HIV awareness. Fabiola argued that the success solidified Hebni's name and credibility within the community:

That's how we got our name out in the community...Uh, cause the *Sisters: Take Charge* and then we started doing grant programs. Applying for grants, and uh, and we just, uh, I consider us the gate keeper for nutrition in this community because if you want to do anything with nutrition and especially in the minority community, you have to come through us. **[Interview with Fabiola, June 2015]**

As part of the African-American community, as well as dieticians, the women of Hebni looked at health trends within minority populations and focused on those issues. One of the most influential projects on a national scale was the development of the Soul Food Pyramid, a direct response to the U.S. Department of Agriculture's food pyramid created in 1992. Hebni created a dietary regiment that took into consideration the eating habits of black southerners:

And our soul food pyramid was different from the USDA because we took the high fat meats and put them at the top. Ya know, pig feet, chittlins, ham hocks, uh neck bones. Things that we eat as a tradition and wanted to show that those foods were fats and not protein sources. So, our pyramid took off like gang busters when we first introduced it to the world because it was addressing issues that were not before. **[Interview Fabiola June 2015]**

Not only did the soul food pyramid provide insight into the proliferation of health disparities plaguing African-Americans, but it also conveniently fit under the hot topic of self-improvement through health promotion strategies such as nutrition education.

When we first formed the nonprofit, nutrition education materials was the big buzz word at the time. So, we created the soul food pyramid and my counterparts – white or black— said wow. I finally got something that I can use and give to a client to bridge the gap on nutrition education. That was the first buzzword. Then diabetes became the

buzzword word in nutrition education. **[Interview with Roniece. June 2015]**

Following the trends and melding nutrition education and diabetes prevention, the organization designed Project Oasis, a free eight-week comprehensive nutrition education course. Heart of Florida United Way released a request for proposals to fund programs “that focus on long-term solutions to community issues in education, income and health” (United Way 2015). Focusing on prevention will save money spent on intervention. United Way CEO emphasizes such measures as, not only beneficial to the community, but also economically sensible. The course was designed around concepts of prevention and received the initial funding. However, not only has competition for funding increased, but the overall funding has reduced. After not receiving funding from United Way to continue the program, Hebni needed to find another source of financial backing. While discussing funding requirements, Fabiola observed, “Funding has, uh, reduced so much the last five years. It’s very competitive. Small nonprofits are really having to struggle to compete with universities and large nonprofits.”

Measuring success of programming differs between funders and program organizers. The sessions of Project Oasis for 2015-2016 were funded by the Florida Department of Health through the Closing the Gap grant. Florida Health requires quantitative data collection throughout the course. When I asked what information is requested, Fabiola responded, “Girl, don’t get me get started with all the stuff the State of Florida wants and what they gonna do with it, we have no idea. They want the pre/post data, they want hemoglobin A1C data, they want cholesterol data, and that’s it. And we do a consumption survey on our own.” But Fabiola and Roniece have a different perspective on determining the success of their program:

We have pre and posttest. And a questionnaire allows us to analyze the success. And

the questionnaire is like, “did you gain any knowledge” or whatever from the program. Also, we look at our attendance rate. Our attendance rate for the course for 8 weeks has been 98%. We figured if they didn’t like the class they wouldn’t be coming. We were really shocked with the rate of attendees we have weekly. The reason I feel that we are so successful with our projects is because we are actually looking at the people we are serving. So many programs come into our community and they stay for x amount of time and they leave and take everything with them when they go. It’s just a grant project where as we are in the community and that’s why this building is so important because people can walk in at any time and get service. And you know we (pauses) in our early years we were just workin’, workin’, workin’ for nothing. And when I talk to young people I tell them the importance of volunteerism, because when you work for nothing, you reap the benefits later. And it’s so important that you give back. See most African- Americans in my era, I was fortunate enough to go to college but a lot of us wasn’t. And my parents instilled in me, you’re fortunate enough to go to college and get a degree but you gotta give back to your community. And this is part of the give back. And it ends up being something I love to do. And it works out. **[Interview with Fabiola, June 2015]**

While decreases in cholesterol, blood pressure, hemoglobin A1Cs, and weight are important to organizers, they are not the only factors that contribute to success. Community participation, accessibility, and sustainability are integral to success. Nonetheless, fulfilling quotas set by

fundors to continue receiving money to keep Project Oasis free is necessary. Taking on the responsibility of improving the health of the community, Hebni challenges participants to “take charge and make changes to their lives.” This framing isn’t unique to Hebni, and it is through this neoliberal discourse of self-care that victims are blamed for structural situations out of their control

The latest project funded by grants from the Department of Health is the Fresh Stop Mobile Market. Part of the trend of farmer’s market buses popping up in cities around America to serve food deserts with fresh produce, The Fresh Stop Mobile Market is modeled

after the (failed) Fresh Moves Bus program in Chicago. Like Project Oasis, the goal of the Fresh Stop Bus is to increase fruit and vegetable consumption in vulnerable communities to diminish, prevent, and educate its members about chronic diseases. The Fresh Stop Bus itself is a renovated public Lynx bus, but getting it up and running was fraught with difficulties. To keep the funding, Hebni must collect 900 signatures of people who get on the bus as proof that the project is successful:

Roniece: The paperwork is this thick. I swear to god. Every month what [we] sends to them, and now with the bus, we have to collect 900 signatures of people who get on that dang fresh stop bus and if we don't have those signatures to show proof that they got on that bus, we get dinged. Give them 899 signatures and you will get dinged. They have found...and the problem is --people not me—but others who got funding went to China, went to Hawaii. They messed over that money so bad.

Allison: Yeah. And now it's even tighter for funding projects now, so I can only imagine.

Roniece: Oh yeah and it's harder. You gotta be new, different and edgy. And that bus was an edgy piece for us and, um, we had a site visit back in October. When she came and, um, her boss said, "Henbi has always been the brightest star for the Department of Health. Y'all always doing something different and it has an impact on the community." And I said you know what? What you do is penalize people who do good. And I sent an email to them and I was pissed off. And it took me a month later to call her and she said, "I knew you was mad because I could tell by the tone of your email." I said, "You penalize people for doing good...Your penalty is gonna make me cheat because you won't let me do my job." So I tell you what they did even worse with the grant that we did get submitted, it was written for African-Americans. The bus is multicultural. So if I go into a Hispanic neighborhood, those signatures don't count. If I go to Bithlo to a trailer park, those signatures don't count. If I go around here--George is a white guy that comin' to our nutrition class—those signatures don't count. So you want me to run around wit a clip board and say, "Y'all white folks you can't sign this. The Department of Health only wants black people to sign this." Cause I said that's how stupid you look to people. That's discrimination too. Y'all better straighten this out. Y'all wrote this. Your attorneys wrote this. Y'all got the attorneys now tellin' people how to manage

health of the community. And they don't give a rats ass about the repercussions or how it look. For example: we were supposed to do a class in September and we were supposed to do it in conjunction wit Orlando Hospital--Orlando Health. The [main contact] went on maternity leave, they didn't care when we did it. So because we didn't do it in September, they ain't gonna pay us. But we got two classes lined up for January and April. Still the same two classes. They said, "Oh no we ain't gonna give you no money because you didn't do it in September like you said you was." And I said okay, okay.

Allison: It's so much red tape.

Roniece: The red tape is like...fuck this. I don't wanna do this.**Allison:** Oh my gosh. So, what did they wind up doing with the bus then? Is it still just African-American signatures only?

Roniece: They finally, after I gave them a black woman's sermon about it, they finally rewrote a template of that page of the contract and said that Roniece is serving multiple, uh, ethnic communities and her signatures will come from Hispanic, African- American, uh Dominican, Puerto Rican, mixed cultures.

The example of the bus demonstrates the state's neoliberal ideologies of passing responsibility of community health onto private organizations and use of language that reinforces negative stereotypes of minority communities. The 900 African-American signatures desired by the funders also reinforce racial stereotypes and structural violence towards marginalized populations. They must work within the boundaries and rhetoric provided by the current biomedical system for funding. Strategies advocated for disease prevention embrace neoliberal self-care methods, including taking ownership of one's health through changes to dietary habits.

These findings raise questions about the long-term work of such critical organizations as Hebni, which simultaneously provide much needed benefits to the local community but at a potential cost of missing the opportunity to contest the neoliberal self-care methods and models

that are the main culprits behind limited funding for social services.. In a political climate in which the critical value of public services is appreciated, Hebni's advocates are positioned well to inform on both health and food for the creation of policies based on first hand experiences and needs as understood from grassroots work in these communities.

In the next chapter I will explore how participants of Hebni's programs, specifically the Project Oasis program, understand the nature of chronic illnesses and how information from the classes is utilized on an individual basis.

CHAPTER 5: EMPOWER ONE, EMPOWER ALL

In this chapter, I explore how information provided in the Project Oasis course is utilized by participants. Using narratives collected during interviews, I will discuss three main themes: (1) empowerment discourses, (2) individual versus. collective identity, and (3) neoliberal ideas of “self.”

Structuring of Project Oasis

As mentioned in the previous chapter on nonprofit funding, Project Oasis is an eight-week comprehensive nutrition education course offered by Hebni Nutrition Consultants Inc. The sessions are conducted four times a year at two different locations: Hebni’s main facility outside of downtown Orlando, and a remote location at Healthy Eatonville Place (HEP), a diabetes education and research center in Eatonville, Florida. Established in 1887, Eatonville has a prominent position in U.S. history as the first town founded and governed by freed African-Americans. Presently, Eatonville is not only a designated food desert but, as revealed in a study conducted by health advocacy group Healthy Central Florida, has a diabetes rate of approximately 25%—almost three times the national average (Florida Hospital 2015). In response to this health crisis, Eatonville residents, town leaders, and local health organizations collaborated to create HEP. Florida Hospital, a key player in the formation of HEP and major funder, views the center as, “a ‘place of trust’ empowering residents to live healthier – and better...Its mission: Identify individuals who may be undiagnosed, help those with the disease better manage their condition and encourage healthier lifestyles to prevent the disease altogether” (Florida Hospital 2015). Having such a prominent role as the “gatekeepers of nutrition” within

the African-American community in Orlando, administration at HEP frequently consulted Hebni staff on issues surrounding engagement strategies to attract community members to their facility. After forming a partnership and securing additional funding, Hebni agreed to organize Project Oasis sessions concurrently with sessions at their Orlando facility.

Having conducted this regimented course for the past five years, Fabiola has perfected a script for each week. Her oratory toolbox includes: key phrases, staple anecdotes, and witty retorts for questions and complaints she already knows will arise. The ease at which she conducts the class allows for a playfulness in her teaching method that creates a sense of comfort among the participants. One woman, Eartha commented, “I really learned a lot. The kindness. How she was kind to everybody. No, I didn’t feel inferior because some people have a way to talk to you to make you feel like, ya know, I have this education. I have this and that, and you don’t know. I know more than you. But it wasn’t like that at all. It was very people friendly. And I appreciated that.” Fabiola’s approach to nutrition is simple: teach them to eat. Giving people the tools and information that allows them to make informed decisions to take control of their health is the main task. This is a clear example of self-care espoused by neoliberalism. As a diabetic herself, and unapologetic lover of Godiva Chocolate Cheesecake from the Cheesecake Factory, Fabiola is realistic in her expectations and wants participants to create sustainable, lifelong habits. Depriving oneself of specific foods is not part of her rhetoric.

To give participants a visual guide of what a balanced meal consists of, Hebni created “The Soul Food Plate.” The Soul Food plate is an adaptation of the U.S. Department of Agriculture’s (USDA) MyPlate, the nutrition guide rolled out in 2011 to replace the Food Pyramid. The Soul Food Plate demonstrates how to incorporate aspects of Soul Food, infamously known for having a high fat, salt, and cholesterol content, and staple southern

foods, such as collard greens, sweet potatoes, and cornbread, into a balanced meal.

Recognizing strong cultural ties to community, belonging, and a shared history, Fabiola emphasizes that traditional foods do not need to be eliminated, but certain ingredients can be replaced using healthier options. Louise, a single mother of four who wanted her entire family to adopt new eating habits, made a small, yet significant change using this advice:

Pigeon peas was the way I got my kids to start eating brown rice. What I did was I tried different brown rices until we found one that they liked and they liked this one brown rice so much that, this one time, I was really tryin' to stretch. I was really low on money and we had to buy some white rice and [my daughter] said, "no mommy I don't like white rice." And I was shocked, so now I'm like, "I can't go buy white rice because she don't like it anymore". So, when your child doesn't like it anymore, that's a good sign. I used something they liked. **[Participant Observation, May 2016]**

To keep participants engaged with information and encourage them to continue on the journey to a healthy lifestyle, small gifts are distributed as incentives at the end of each class. One particularly popular gift is the portion control plate. The eight-inch plate is divided into three sections, each with a specific food group designation: half the plate used for fruits and vegetables, one quarter of the plate for proteins, and the remaining quarter for the grains. As if on cue, groans fill the room as Fabiola announces that the appropriate portion of protein for a meal should fit in the quarter section. Unfazed, Fabiola taps the protein section of the plate and reaffirms her stance on portion control:

If you can get a four-piece of Popeye's chicken in this little pocket right here, you can have it. You can't go high, you have to stay within the ridge. You can take it off the bone, but it got to fit right here. I did not say you could not have fried chicken, did I? I did not say you could not have fried fish, did I? All I said was it got to fit in here. That's all I said. I'm not taking anything away from you. I'm just restricting your portion size. **[Participant Observation, February 2016]**

The carefully selected language used by Hebni resonates with a form of informed disease prevention education referred to as "patient empowerment," a method that views patients as

responsible actors in taking control of their own healthcare. This approach, a form of neoliberal self-care, is rooted in empowerment philosophy, which assumes that for optimal individual health, people must not only alter personal behaviors, but social situations and institutions that influence their lives (Anderson et al. 1991; Lee et al. 2016). Patient empowerment juxtaposes the compliance-based approach to disease management, which views the expertise of healthcare professionals' as authority. This positionality creates a situation where the provider becomes the primary decision maker in a patient's self-care regimen, striving to bring the patient into compliance with recommendations. In a study evaluating the efficacy of training experienced diabetes educators to adopt a patient-centered philosophy of empowerment, Anderson et al. argues, "the patient empowerment approach to diabetes patient education seeks to maximize the self-care knowledge, skills, self-awareness, and sense of personal autonomy of patients to enable them to take charge of their own diabetes care...in consultation with health-care professionals, they can select and achieve their own goals for diabetes care" (1991, 585). This is the driving philosophy behind Project Oasis.

"You did me a disservice"

Feeling frustrated after an annual checkup with her primary care doctor, Mary, an African-American woman in her early fifties, confided in a fellow church member about her health concerns. Mary recalls, "I said, 'Ya know, I need to do better with my health, and due to me havin' the twins, I gotta learn how to implement some exercising and eating right because I went to the doctor and I'm not happy with what was, well what he had shared with me, and I just need some help.'" Although she has two grown sons who no longer live with her, she is currently

raising her two-year-old twin grandchildren. She believes that to keep them healthy, she must lead by example, and their presence has urged her to reconsider lifestyle choices.

Over the past few years, Mary has battled with her weight and admitted that her doctor—who has since retired and sold his practice—had explained the correlation between weight, blood work, and disease: “He had said, ‘I want you to be careful about your weight because your blood work, ya know, because you could be...’ but I didn’t take it seriously.” She did take it seriously after her annual blood work this year:

I came back in for the reading of the results and she said, “Uh oh, your HbA1c is 6.7. You’re a diabetic.” I said, “Oh really?” And she said, “Oh yes, and we are going to prescribe you some medication.” And I looked at her and I said, “No, you’re not. I’m gonna lose the weight.” I think she did me a disservice. Because she should have educated me on the side effects of diabetes. She should have said, “Mary, your health is very important to me. I need to share the complications, the side effects of diabetes.” I’m not a health care professional. You don’t just prescribe a person medicine and say, “Oh you take this pill and you know...” No. Educate me on how to do better. Long term. Not a short term by giving me a pill because by you not educating me, you’re doing me a disservice. I was in denial. Very much in denial. I was saying, “I do not have no diabetes. This lady is crazy.” You know? But I am not ignorant of the fact, of the changes taking place in my body. I knew something was going on. **[Interview with Mary September 2016]**

Mary’s experience demonstrates a disconnect between the ideas patients and doctors have regarding the treatment of chronic disease. Research taking a critical look at the doctor-patient divide in long-term treatment using explanatory models note that the lenses through which each party views chronic disease management conflict with one another. The goals and treatments provided by medical professionals are grounded within a clinical context, whereas patients measure treatment feasibility based on impact within a social domain and day to day life (Hunt and Arar 2000; Lazarus 1988; Loewe and Freeman 2000; Mendenhall et al 2010). Mary believed that the immediate use of medication after her diagnosis would only provide a short-term solution, but becoming educated and taking ownership of her diabetes would allow for long-term control through behavioral changes. As she explained:

So, when [my friend] shared Hebni with me, when I came in I felt like a burden was relieved from me...so by me taking ownership of my health. And coming here it was like a lightbulb went on. When I went back for my two month...I had lost 15 pounds from in those two months and transitioning to Hebni and they asked me "How?" I said, "I educated myself. I said I sought help. You all did not assist me. You knew I had Cigna insurance. You coulda recommended me to call my insurance company and say, 'I've been tested, my HbA1c is this level. What type of information do you all have for your customers because I want to improve my health?' You all did me a disservice." I felt like I was on a ship without a captain. And I said, "I want you to know that I am very angry because what if you have someone that comes into your office that does not have the resources or the knowledge that I do. I could go online and do research." I'm not happy. And I am in the transition of finding me another doctor. Because yes, it's kind of minor. But I'm not ignorant, you should have been there to help me to be preventative. Don't just give me a pill. You just bandaiding. You just puttin' a little bandaid on top of it. You gave me nothin'. You didn't even give me a flyer, a pamphlet on nutritional value. You didn't give me anything. All you recommend is we gonna give you medication. You didn't help... it is very hurtful to me because I think about someone who is not as knowledgeable as I am that can't seek out resources. I know Florida Hospital has a program. A program for diabetics and prediabetics. But you didn't even... You did nothing. You did nothing to help me. And then you let me walk out your office. I'm not a nurse practitioner. I'm not even in the medical field. I was totally ignorant to the fact of the risk factors. And you didn't even say, "Mary, I'm letting u know what your HbA1c is, and I want you to know the complications that can occur. That's what's hurtful to me. Do you really care about me? Or do you care that I got good insurance that you know that, um, to me, I'm just money to you....On my mother's side, my mother's sisters, her brothers. They had some issues too because of not taking care of themselves properly. They demised from complications that went along with it. I said, "Well I'm not gonna be a statistic. I'm gonna do something about my health". So, I'm taking ownership, but I can't do this on my own I'm not in denial anymore. First, you gotta accept. And I had to accept, "Okay Mary, this is what ya gotta do," and then I have two little people to think about. So ...I have shared this information [from Hebni] with everyone. I feel like this is one of the best kept secrets. One of the promotions should be send a flyer to the churches. Communicate to the churches and let the churches know that this is what is offered here. Get feedback. And I'm not stereotyping no ethnicity over another, but in the African-American community it is a lot of individuals that are suffering from diabetes and a lot of it could be their lifestyle and could change if they know the proper eating.

Allison: So, you've shared this information! Fabiola is very realistic about the changes. Even small...

Mary: She brought it home! She really did. She put a face to it. And I mean, I'm like the guy in Philadelphia in Forrest Gump. It wasn't complex. It goes back to taking ownership. I can give it to you, but it's up to you what you wanna do with it. Empowerment. **[Interview with Mary, September 2016]**

This narrative addresses a variety of themes regarding manifestations of patient empowerment and individual versus collective identity. As stated earlier, Mary did not want to accept the doctor's treatment plan of medication as a first step in disease management. In fact, she took offense to the lack of acknowledgment about her individual desires and felt stripped of her identity. The HbA1c number of 6.7 reflected in the bloodwork indicated a diagnosis of diabetes and reduced her to a pathology, treatable with medication. Mary, on the other hand, wanted to "take ownership" of the disease and wanted to use her own behavioral changes as the initial treatment. This taking of ownership is consistently reinforced to the collective group during the Project Oasis course. From an anthropological perspective, Mary's interaction with her doctor is indicative of the clinical encounter within the context of chronic disease management, specifically diabetes. This framing reflects ideas developed through the ethnographic research of Ferzacca (2000) assessing the clinical encounters of veterans with adult onset diabetes and their doctors. In his research, physicians used lab work—blood work, weight, blood pressure—as a form of history to determine whether patients were "in control" or "out of control" of their health. Physicians created management plans with patients framed around discipline, behavioral changes and self-care. But, many patients created their own strategies to control their diabetes through approaches based on their own personal experiences, which forced them to have a disciplined and rigorous methodology, whether plans were scientifically accurate or not. Physicians viewed these patients' self-care regimens as a challenge to the normative medical discourse of disease management, and therefore, viewed patient self-care as noncompliant behavior. Conversely, Ferzacca (2000) argues that the underlying cultural and social values used to shape both patient and physician approaches to self-care stemmed from the same collective representations of what defines a "healthy individual" within the U.S.. The

clinical encounter for both physician and patient alike, embodies neoliberal values of productivity, discipline, and control to create a healthy self, which is ultimately defined by the clinical encounter. The management of diabetes through behavioral changes is rooted in discipline, self-responsibility, and ownership that will allow for her to continue as a productive member of society.

The empowerment approach to education used by Hebni allowed Mary to question the dominant medical paradigm. Through prescribing medication, a clinically controlled form of disease management, Mary's doctor sought to control her blood sugar and lower her HbA1c. However, the self-care knowledge provided by Hebni allowed her to understand alternative ways to manage the disease within the context of her own world view in a way that made sense to her. Mary reiterated throughout the interview that she felt as though her doctor had done her a "disservice" which was "hurtful," and she worried about treatment of "someone who is not as knowledgeable as I am."

The questioning of the doctor's intentions, whether she truly cared about her patients or just viewed them as avenues to make money, indicates a skepticism toward the dominant biomedical system. On the other hand, Mary referred to Hebni as "the best kept secret," emphatically stating she shared information from Hebni with everyone and believes that through the simple nutrition education they provide, they can help other African-Americans suffering from diabetes.

These statements indicated two issues: (1) There is a suspicion, not necessarily outright distrust, of the dominant biomedical model of health and, in response, (2) alternatives to the dominant model are created to address individual needs and ultimately address the needs and wellbeing of a collective group. This creation of an alternative model is commonly ignited by activists responding to a disparity within a dominant model. For example, reproductive health

activists in post-Soviet Russia have chosen to work outside the formal political realm using strategies responding to cultural knowledge such as “renewed perceptions that politics is corrupt and futile, under socialism and democracy alike, while change directed at the self and interpersonal relations represented a realistic and desirable means of improving the physical and moral health of society” (Rivkin-Fish 2004, 283). Hebni acknowledges that African-Americans, as a collective identity, suffer from health disparities like diabetes, in far greater numbers than their white counterparts. Since little is done from a political standpoint to address the needs of the community, individuals must educate themselves and take responsibility for the greater good. In this way, Hebni’s work seeks to explicitly function outside the formal political realm, which has been ineffective in addressing these disparities.

In the next chapter, I will discuss how community building and social support help address and remove the structural barriers that hinder Hebni participants from sustainable disease management.

CHAPTER 6: REMOVING THE BARRIERS AND CREATING COMMUNITY

Research in both critical medical anthropology and public health has reliably demonstrated that consistent implementation of self-care methods, paired with social support, effectively reduced glycemic levels in patients with type-2 diabetes. The launching of a 2002 project titled “Innovative Care for Chronic Conditions” by WHO addressed increasing rates of chronic disease and implicated unhealthy behaviors and consumption practices as leading culprits. Within the context of a quickly globalizing world, these negative lifestyle changes included the adoption of unhealthy dietary patterns. With the rise in diabetes, WHO acknowledged that self-management through behavioral changes were successful when patients participated in group interventions, had self-management support, and participated in open dialogue with their providers (World Health Organization 2002). In the 2016 Global Report on Diabetes, WHO stated diabetes should no longer be viewed as a disease of the wealthy or a lifestyle disease, as it is most rapidly growing in low-and-middle-income countries. Five core components were identified for health systems to strengthen diabetes management: “diagnosis; health education and counselling to promote healthy choices and self-care; medications in some cases; screening and treatment of complications; and consistent follow-up. Provision of these building blocks of care in a primary health-care setting requires adequate health infrastructure and planning,” with the vital piece to the adoption and application of these components being the requirement of “adequate health infrastructure and planning” (World Health Organization 2016, 79). While 71% of countries have national standards for diabetes management, only half fully implement these guidelines.

While government entities within the U.S. battle over healthcare costs and coverage with health insurance companies, community based health intervention initiatives target health disparities of racial and ethnic minority communities. By training community residents, the Center for Disease Control and Prevention (CDC) funded projects they called REACH, Racial and Ethnic Approaches to Community Health, which developed separate, culturally relevant diabetes intervention curricula for both Detroit's African-American and Latino populations. A study conducted with REACH-Detroit Partnership participants, determining the effectiveness of the culturally tailored intervention materials, revealed that participants demonstrated an increase in post course self-care management, including dietary and physical activity knowledge, as well as a significant improvement in HbA1C levels (Two Feather et al. 2005). Researchers noted that during study development, participants reported limited literacy of diabetes self-management, and reported trouble maintaining suggested dietary habits because of cost and lack of access to specific foods. Addressing such barriers in low-access communities is critical to intervention design (Two Feather et al 2005).

Interventions conducted by REACH-Detroit highlight the success of empowerment theory, a philosophy founded in the belief that patient education and ownership of the disease provides them with knowledge to guide their own successful treatment (Anderson et al. 1991; Spencer et al 2011). In a six-month study employing community-based participatory research (CBPR) principles and empowerment theory in intervention education, Spencer et al. (2011), in partnership with REACH-Detroit, once again demonstrated improvement in HbA1c and self-reported knowledge in intervention participants. The study also attested to the beneficial aspects of using CBPR to address health disparities within disenfranchised communities through building know-how, focusing on health as social justice, and sharing of power and resources

“And it’s just so simple to eat”

Hebni’s Project Oasis, as a health intervention course, creates goals like the intervention programs offered by REACH-Detroit. As dietitians working within their own community, Hebni tailors their nutrition education curriculum material to fit their audience, helps increase diabetes self-care management literacy, and reduces markers of chronic disease, such as HbA1c, blood pressure, cholesterol, weight, etc. They educate community members, but are also aware of the many structural barriers that the African-American community faces. Since many of the participants of Project Oasis are women and mothers, Fabiola knew that they had to address the needs of that demographic. They knew conducting the Project Oasis class on a Monday night had its limitations, but they were willing to overcome them, as Fabiola explains:

People tend to follow us as a nutrition practice, but others were having problems with their programs and people continuing to come. So, I said we have to eliminate the barriers, and the barriers are, if you have a program in the evening...let’s look at a single mom. She gets home from work, she cooks dinner, and then she got to deal with the kids and their homework and by that time it is 8 or 9 o’clock and there is no way she’s going to come to a program. So, if we eliminate the barriers, okay, ya bring your kids, feed everybody dinner, send the kids back to a babysitter who will help them with their homework, and when you get home you throw them in the tub and put ‘em to bed. So, we want to...well then we want to incentivize you to come. So, once you get in the building, here we have a captive audience. **[Interview with Fabiola, June 2015]**

The hypothetical scenario Fabiola illustrates, wanting to engage but having a barrier outside of one’s control, is a common theme within illness narratives told by patients, which explain the origin and experience of a medical condition from their experience (Kleinman 1988; Lowe and Freeman 2000; Mendenhall et al 2010; Williams 1984), but also viewed as a challenge faced in the adoption and implementation of individual “healthy behaviors.” While examining the ways language used during food interactions informed the construction of health and family life for middle-class families in Los Angeles, California, Paugh and Izquierdo noted, “Respondents,

particularly women, oscillate between discursively portraying themselves as active agents in the construction of their health, and alternately as passive subjects who lack the agency to attend to their health because of work, social obligations, financial pressures, and other external forces, like media and peer influence on the family” (2009:189). Parents believed control, personal responsibility, and “moral” food choices crafted “good health.” While they had ideas and goals as to what constituted good consumption practices for their children, negotiations and trade-offs between good and bad foods at mealtime demonstrated a complicated relationship with everyday practices (Paugh and Izquierdo 2009). These are the types of struggles that Hebni addresses in their programs.

Lani, an Orlando native, was diagnosed with diabetes five years ago. Her adult son, who is also diabetic and insulin dependent, moved in with her two years ago when he could no longer care for himself. Even though both she and her son attended Project Oasis, she finds it difficult to make changes to her eating regimen while trying to provide for her son as well.

Lani: My son will order food and have them bring deliver it to the house. Yeah so, you got neighborhood...restaurant home base? It's crazy! I don't have so much control what my son eats. I only have so much control. I stopped taking him to the store for a week, so I know he didn't put a lot in his system, but it's like that same week, “Well can you take me to McDonalds?” No, we have food. That same week this guy comes up and he had a hamburger and a two-liter Sprite. And that was delivered to the house! See what I'm saying. I can't always monitor what he is putting in his system. He's not five, he's thirty-four. But I can watch what I put in the house.

Allison: How often would you say you cooked at home?

Lani: I just started back cooking. Maybe three times a week? Ya know, because it's just like I'm on a fixed income and my son doesn't always like what I cook, so I can't waste money buying groceries and cookin' and you aint eating. So, that's the kind of thing we got goin' on. And my friends say, “Lani, just cook. Cook. Cook for you and if he wants some hell eat. And my brother said, “You get hungry enough you'll eat.” So, there's food there, it might not be what he wants, but it's something you can put together. And the best thing I heard Fab say was that you don't need breakfast food to eat. Since the class, I ain't bought no breakfast sausages or breakfast meats...the sausages, the bacon, none of

that. We got oatmeal, we got grits, we got eggs. Ya know, so. **[Interview with Lani, September 2016]**

Lani's situation touches on various barriers that impede her ability to make changes and demonstrates how social factors impact decisions even if they contrast with the "rational" response. Supporting both she and her son on a fixed income places an economic strain on her life. If her son will not eat the food she cooks, there is a chance it will go to waste. She and her son will receive an immediate return on their investment if they order from a restaurant, and she can guarantee he will like the food ordered. The advice her brother gives her is logical, but as a mother and a caretaker, she wants to make sure her son eats and she wants to provide. In this sense, "rational" advice may not reflect or be usable in the reality of lived experiences. In addition, she knows that if she does not bring him to the store or make food that he enjoys, he will order food and have it delivered to their house. As a negotiation, she takes advice given at Project Oasis and does not buy the processed breakfast meats. She provides her son with breakfast foods he enjoys, but since she has control of items purchased for the house, she decides to stray from the meats for the sake of his health. Hebni gives small recommendations like these to show that making diet changes do not need to be overwhelming and restrictive. Removing one thing from a diet or household gives an individual the initial feeling of empowerment and control.

The nutrition education provided by Hebni breaks down health issues and self-care methods outside of the biomedical paradigm and allows for participant incorporation of lay discourse in disease explanation. Besides physical barriers, success in self-management of chronic illness is strongly associated with psychosocial barriers—stress, social support, and self-

efficacy (Schoenberg et al 2005; Walker et al. 2014). Having access to such comprehensive information for free was a blessing for Janie, another Hebni course participant.

The information, it's free! That's the hit right there! Because, ya know, where you gonna get this information like this for free? Because I'm sure there are dieticians out there that are getting paid. You understand what I'm sayin? Because my son goes to a diabetic doctor, a specialist, and they was gonna have somebody go to the house, but it was something about he didn't have Medicaid. Or something. Or wasn't gonna cover it. So this right here just fell right in place and so much information to look back on..the different recipes. I was just in awe of the different recipes on Mondays that was just so simple. And it's just so simple to eat.... I just really commend them for doing what they do and ya know? Being here. No question is a stupid question. And they willing to give the information. And I know I asked a lot of questions! They just open it up! Whether you got a husband, girlfriend, boyfriend whatever they just open it up! So there is no reason for people to not to be here, unless there is an emergency or their late, that's a plus too, ya know? Come on now, ya can't beat that! **[Interview with Anne, August 2016]**

As community based health workers, the staff of Hebni can bypass the traditional biomedical model of health care and, by offering the class for free, relieve some of the economic stressors patients face when addressing chronic disease. Opening the class to friends and family provide that extra social support, and the ability to ask any question without fear of shame removes the authority that many doctor-patient interactions have within a clinical setting.

Even though Hebni is not associated with a particular doctor, physicians within the community have familiarized themselves with Hebni's services and often refer patients to them. Many general practitioners do not have formal nutrition training, so an organization that understands the issues and provides a comprehensive affordable treatment plan is great for the community. The fact that the dieticians are African-American can also be a common ground on which class participants can identify. Chrissle, who moved from Jamaica to Orlando 17 years ago, was referred to Hebni by her doctor for self-management of high blood pressure and acid reflux:

I guess that is why my doctor recommended I talk with someone because I needed that kind of .That kind of one on one. That kind of info to put things together to better help myself. Before the class, I eat vegetables. But, I eat a lot of white rice. I know what I'm supposed to do. I know I'm supposed to do. I know I'm supposed to eat brown rice and I do sometimes but, as a person of color, we are more prone to diabetes and things like that too and my doctor told me I was prediabetic. I knew I needed to cut down on a lot of the starchy food and sugary things and stuff like that. But I would say I was pretty, kinda health conscious prior to the class, but they kind of reinforced it because they had me realized more and that I needed to stick to more what I knew I needed to do...The setting was awesome. The people were great. Very friendly. Courteous. Available to give information. Provide advice. Comradery. I would do it again. It was so fulfilling and refreshing. The presentation was awesome. I think that is really necessary. There are many more people who need more help than I do but they may not know about it.
[Interview with Chrissle, June 2015]

The social support in the class reinforced conceptions she had around food, and she also acknowledges that there are more people in the community who could benefit from the information provided. Chrissle's acknowledgment that she "knows what to do" and hesitancy to do it demonstrates that the discussion of self-management of chronic disease, especially with medical professionals, needs to take into consideration psychosocial and cultural factors as well.

A common phrase used by participants was "good health." This abstract idea is promoted via a form of "generic healthy eating," perpetuated by media and literature, which views eating from a physiological perspective that focuses on the nutritional value and bodily needs, ignoring sociocultural aspects of consumption which may hinder the ability to change specific behaviors (Wiggins 2004). Eating is not merely a static and individual activity, rather, it is interactive, social, and cultural. The moral dichotomy placed on food and health creates an abstraction, an unreachable ideal, rooted in concepts of the neoliberal individual. It assumes persons will make rational decisions without consideration of variables such as "irrational" desires for foods that may be unhealthy, as exemplified by Lani's struggles with her son choosing hamburgers and Sprite. In studying dialogues of "mealtime talks" of families,

Wiggins (2001) argues that the construction of food is a fluid, ongoing process and can be negotiated, defined, and constructed through conversation. Thus, the decision to consume specific food items is not solely based on individual assessment. Within a social setting, eating is recursive through a constant reassessment of choices based on the actions and words of others.

Simone, a 36-year old, single mother, had her three children participate in the Project Oasis class with her. She said she did not find making changes to the food at home difficult because, “they came here with me...So whatever we had here, they were willing to try.” She did struggle with making changes initially:

It’s kinda hard sometimes to let go of what you’ve always known, especially when you don’t have the spirit of change. And it is difficult to do so. But, uh, it’s always a struggle in the beginning, but when you realize you can have the same foods and alter it, uh, then it becomes...you become less resistant to it, ya know, which I’ve noticed was something that did happen to me in the beginning. Because I’m like, “Oh, I dunno if I can eat that,” but then you come in here and they have the food all prepared for you and this is how they did it and I’m like, “Shut up, you lyin’.” Ya know, cause this is good! So, that’s a hard thing to do. Ya know, within my family at least because it’s tied down to the culture and emotions. **[Interview with Simone, September 2016]**

The meals served at the beginning of each class expose participants to foods and recipes they would typically not seek out on their own. Eaten as a communal meal, the staff describes meal preparation and ingredient selection, and discussion continues around dinner. Participants frequently reconsider their decision not to eat a food item after hearing others rave about it. One evening, a gentleman in his mid-60s scoffed when I offered him a pistachio whipped topping dessert. He proceeded to motion his hand to stop me and emphatically stated, “I do not eat that stuff.” Thirty minutes later he called me over and nonchalantly asked, “Can I have some of that green stuff? I want to see what everybody is fussin’ about.”

The education for the self-management of chronic disease provided by Hebni does not define the success of the organization. The methods and tips offered do not vary much from

information passed on by doctors or other healthcare professionals, the way they broadcast the information does. Having people from the community teach other community members in such a dynamic way provides a relatability aspect to their teaching methods. Although they do provide clinical explanations for various chronic diseases, they are peppered into personal narratives from staff and fellow class participants. For two hours a week, people come together with shared concerns to eat, learn, and laugh about ways to take charge of their health. The approach takes very serious, sometimes deadly, topics and makes them easily digestible. Everyone is on an even playing field. .

In the next section, I will discuss how my findings and research can impact both anthropological and public health research.

CONCLUSIONS

As a community-based, grassroots, non-profit organization working outside the formal political and biomedical worlds, Hebni Nutrition Consultants, Inc., empowers clientele to challenge dominant ideologies and create their own pathways to health and chronic disease management. I have argued that while remaining apolitical in their approaches, Hebni staff must concede to the narratives produced by funding institutions that reinforce racial stereotypes and structural violence as they work to improve lives in underserved communities. Within the current political-economy, doubt is cast by neoliberal discourses upon the public sector and its capacity to promote the general social welfare of its citizens. This view argues that individuals, not the presumably incompetent government, know what is best for their wellbeing and therefore access to the free market (for example, the “freedom” to buy one’s own health insurance) will allow them to make the best decisions in their own self-interest. This “rational actor” and neoliberal subject theory often fails in addressing real and pressing social issues, including health disparities. When it does, the free market has created a space for a “third sector,” the nonprofit sector, to deliver specific services to individuals in need (Gilmore2009).

Over time, the normalization of the idea that government is hindering the social and economic development of its citizens becomes naturalized and government intervention becomes limited. Ironically those who work within political positions to denounce state power, gain state power— this is evident, for example, in major tax advantages for corporations, also known as the “corporate welfare” phenomenon (Gilmore 2009: 43). This leads to the creation of the “non-profit industrial complex,” wherein non-profits that provide direct social services to citizens and receive funding and contracts from state entities, must work within the parameters of government

regulations, and provide transparency and accountability for all services rendered. They are at the mercy of the state and free market alike, as geographer Ruth Gilmore argues, “funders who want to return their inherited wealth to communities who produced it should reflect on whether they are building glorious edifices that in the end perpetuate inequality” (2009: 51) . Relevant to this argument are my own research findings showing that even though Hebni accepts funding from public institutions for programming, the positioning of Hebni as a grassroots non-profit providing no direct social services, like immediate healthcare and treatment, places them in a unique position. Through programming, social cohesion, and empowerment theory, Hebni is creating a *social movement*. Courses like Project Oasis aim to make small changes in the way participants understand the complex relationship between chronic disease, dietary changes, and structural institutions, but in the long run these transformations have a powerful effect not only on participants’ lives but also their sense of working toward shared interests.

Another significant research finding is Hebni’s approach to nutrition and chronic disease-self management through empowerment and structural competency approaches. The neoliberal self-care model for disease management is one that is fully integrated into the rhetoric of medical professionals, so even though Hebni staff must maintain this ideology, they utilize the empowerment approach to remove the anxiety surrounding medical authority that leaves participants questioning structural and psychosocial barriers to health. As an organization serving a predominately African-American community, Hebni is not ignorant of the inequalities and victim-blaming perpetuated by biomedical literature. This mixture of clinical explanation of disease and an understanding of structural focus creates a form of medical education termed “structural competency”. While designed to educate medical professionals in clinical settings, the main belief of structural competency is that “just as stigma in clinical encounters must be

addressed structurally, so too must inequalities in health be conceptualized in relation to the institutions and social conditions that determine health-related resources” (Metzel and Hansen 2013:127). Staff at Hebni also teach structural competency to the participants so that they can understand social determinants of health and engage in meaningful dialogue with their doctors. This approach aims to remove the idea that the patient is merely a pathology and forces a reassessment of victim blaming ideology and discourses, which solely focus on individual behaviors for causes and solutions of disease (Crawford 1977).

Lastly, Hebni has created its own vision of success, and it does not measure the success of its Project Oasis program solely on quantitative data. Funding sources require quantitative data and participant enrollment as measurements of success. From an economic standpoint participant weight loss, lowering of cholesterol, blood pressure, and HbA1c equate to the adoption of healthy habits and being on the road to a healthy life. The lower the numbers, the less people will visit emergency rooms for complications. While this is a goal, when I asked Roniece how she measures success, she answered differently.

We measure it...Um, I don't know if I would use the word success. Success is defined in multiple ways. Did you get the client to change their behavior? That's a success. Did you get them to understand nutrition in a different light? That's a success. Did you get them to lose weight, change their BMI? That's a success. Drop their cholesterol, drop their hemoglobin A1c. All those are successes. Did you get the lady who doesn't have any issues to get her husband to change who wouldn't change? So, there are a variety of successes. Did you get the woman, the nutritionist of the family, to get all the sodas out of the house and add water and more fruits and vegetables? That's a success. All those behavioral outcomes, I claim them as successes. **[Interview with Roniece, June 2015]**

Hebni's staff encourages the sharing of information and actively encourages participants to bring friends and family to the course. As Roniece argued, it is a traditional belief that women are nutritionists of their families, therefore in this view, by educating the woman in a home, the entire family's dietary practices can be influenced. Small changes, like removing sodas from a

household, are much bigger successes when viewed from the perspective of household dynamics. Hebni does not want people to view health and eating habits in one limited way. Behaviors constantly change and there is no one way in which to define “healthy eating.” By not restricting food items, yet promoting portion control and label reading, Hebni makes nutrition education simple. During classes Fabiola stresses, “You have five days a year when you can binge: Christmas, Easter, Thanksgiving, your birthday, and Fourth of July...or your divorce. Whichever you choose, but the other 359 days watch your portions. You’re gonna fall off the bandwagon at some point, but don’t throw it all away. Get back on it!”

From an anthropological perspective, this research provides insights into how grassroots organizations work on the margins of both the public and private spheres in the U.S.. Since non-profits were crafted from neoliberal climate, their ambitions will always cater to such ideologies to some extent, given that their existence, both financial and political, is embedded in and constrained within this larger politico-economic system. However, in what ways, and to what degree, an organization will espouse such beliefs varies. Small grassroots, community based organizations, such as Hebni that do not have the level of bureaucracy that major non-profit foundations do, may have more control over what they want to adopt in their philosophies and strategies. Moreover, this research highlights the critical role of the grassroots nature of this group, which positions them in a place of knowledge and shared understanding of the local community in ways that allow them to create innovative, mosaic programs while successfully navigating the world of funding

APPENDIX A: IRB APPROVAL LETTER



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

Approval of Exempt Human Research

From: **UCF Institutional Review Board #1**
FWA00000351, IRB00001138

To: **Allison Matos and Co-PI: Joanna Zofia Mishtal, Ty S. Matejowsky**

Date: **January 06, 2015**

Dear Researcher:

On 01/06/2015, the IRB approved the following activity as human participant research that is exempt from regulation:

Type of Review:	Exempt Determination
Project Title:	Understanding Dietary Changes and Self-Care Methods among African American Adults in the Prevention of Dietary Related Chronic Illnesses in Orlando, FL.
Investigator:	Allison Matos
IRB Number:	SBE-14-10758
Funding Agency:	
Grant Title:	
Research ID:	N/A

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request in iRIS so that IRB records will be accurate.

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

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

A handwritten signature in black ink that reads "Kanille Chay" followed by a horizontal line.

IRB Coordinator

**APPENDIX B: SEMISTRUCTURED INTERVIEW QUESTIONS FOR
HEBNI NUTRITION CONSULTANTS INC., STAFF**

Interview Field Guide for Research Project (Hebni Employees/Personnel):

“Understanding Dietary Changes and Self-Care Methods among African American Adults in the Prevention of Dietary Related Chronic Illnesses in Orlando, Florida”

In-Depth Interviews with African American adults attending an eight week nutritional class with the goal of changing dietary habits.

General Instructions to the Investigator:

Let the interview be guided by the answers you get to the questions listed in this instrument. Explore leads that the provider raises by using specific probes and additional exploratory questions. Ask the questions in a conversational manner, keeping in mind that the questioning will not always follow the order suggested below. If you do not cover all of the following topics completely in the time allowed, attempt to schedule a follow-up appointment with the provider for a time that is mutually convenient.

Interview

Thank you for taking the time to speak with me today. I'm Allison Matos from The University of Central Florida, and I'm the Primary Investigator for research site in Orlando, Florida, for project titled: "Understanding Dietary Changes and Self-Care Methods among African American Adults in the Prevention of Dietary Related Chronic Illnesses in Orlando, Florida." I will be conducting an interview with you about your experiences establishing and running a nonprofit aimed at changing dietary habits of the community. All of the information you give me will be confidential – I will not ask you for your name or any information that could identify you. The interview is voluntary and it will take 30-60 minutes. At the conclusion of the interview, I will ask if you would be willing to participate in a follow-up interview at the end of the course. I would like to start now; is that OK?

Date: _____

Time: _____

Q1: Why was Hebni formed?

Q2: What were the initial goals of the organization?

Q3: How did you gain support from the community?

Q4: How did you design the Project Oasis course?

Q5: How do you measure the success of the programs?

Probes:

How do funders measure success of the programs?

Q6: How do you measure participant success?

Q7: In your experience, what do participants like the most? Least?

Do you have anything else you'd like to add that I didn't ask you about? Would you be willing to be contacted for a follow-up interview at the end of the course?

Thank you very much for your time. Please don't hesitate to contact me if there's anything else that you would like to add that you have not had a chance to say during this interview.

APPENDIX C: SEMI-STRUCTURED INTERVIEW QUESTIONS FOR PROJECT OASIS PARTICIPANTS

Interview Field Guide for Research Project (Participants):

“Understanding Dietary Changes and Self-Care Methods among African American Adults in the Prevention of Dietary Related Chronic Illnesses in Orlando, Florida”

In-Depth Interviews with African American adults attending an eight week nutritional class with the goal of changing dietary habits.

General Instructions to the Investigator:

Let the interview be guided by the answers you get to the questions listed in this instrument. Explore leads that the provider raises by using specific probes and additional exploratory questions. Ask the questions in a conversational manner, keeping in mind that the questioning will not always follow the order suggested below. If you do not cover all of the following topics completely in the time allowed, attempt to schedule a follow-up appointment with the provider for a time that is mutually convenient.

Interview

Thank you for taking the time to speak with me today. I'm Allison Matos from The University of Central Florida, and I'm the Primary Investigator for research site in Orlando, Florida, for project titled: "Understanding Dietary Changes and Self-Care Methods among African American Adults in the Prevention of Dietary Related Chronic Illnesses in Orlando, Florida." I will be conducting an interview with you about your experiences with food, cooking, and diet. All of the information you give me will be confidential – I will not ask you for your name or any information that could identify you. The interview is voluntary and it will take 30-60 minutes. At the conclusion of the interview, I will ask if you would be willing to participate in a follow-up interview at the end of the course. I would like to start now; is that OK?

Date: _____
Time: _____

Q1: Why did you decide to attend the Hebni Nutritional classes?

Probes:

(If bring up learning what to purchase) What are some staple food items in your regular diet?

Q2: Do you remember being taught by anybody, either at home or in school for example, about nutrition.

Probes:

(If says none) Why do you think nutrition was never addressed?

Besides this class, where else do you obtain nutritional information?

Q3: What kinds of foods did you eat growing up?

Probes:

Where did you the food items come from?

Which of those foods do you think were healthy or good for you?

Q4: What would you consider healthy foods?

Probes:

Where do you purchase most of your grocery items?

What is most available for you to eat?

Q5: Do you think community you live in influences your eating habits?

Probes:

What are certain foods that that you view as “traditional”?

Do these foods evoke particular emotions?

Q6: Does anyone close to you suffer from chronic illness?

Q7: Does your doctor currently, or in the past, discuss how eating affects your health?

Probes:

(If yes) What kinds of information do they provide?

(If no) What are some changes you would like to see made?

Do you feel comfortable talking to your doctor about your diet?

Q8: How are you using the suggestions given at the Hebni classes?

Probes:

Are you the one in your household who plans meals and shops?

How did you explain the class to people in your household?

Q9: What do you like/dislike most about your Hebni experience?

Probes:

Do you have any suggestions for improvement?

Do you have anything else you’d like to add that I didn’t ask you about? Would you be willing to be contacted for a follow-up interview at the end of the course?

Thank you very much for your time. Please don’t hesitate to contact me if there’s anything else that you would like to add that you have not had a chance to say during this interview.

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