

7-11-2016

# The Blurred Lines of HPV and Cervical Cancer Knowledge: Exploring the Social and Cultural Factors of Identity, Gender, and Sexuality in Caribbean Immigrant Women

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The Blurred Lines of HPV and Cervical Cancer Knowledge:  
Exploring the Social and Cultural Factors of Identity, Gender, and Sexuality  
in Caribbean Immigrant Women

by

Maisha N. Standifer

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

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Date of Approval:  
July 6, 2016

Keywords: medical anthropology; Caribbean; Caribbean immigrants; migration and health;  
Genital human papillomavirus (HPV); gender; sexuality; political economy

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## **Dedication**

This dissertation is dedicated to my great-great grandparents, great grandparents, grandparents, parents and other family members who knew and instilled the value of education and the pursuit of academic excellence. I thank my parents for the unwavering emotional, financial and mental support during this process. I am most grateful for my husband's undeniable love and spiritual support throughout this journey. You were my foundation on the days and nights of academic uncertainties and career instability. And lastly, to my recent blessing, Kareem! You are truly my most generous gift and I thank God for you every day!

## **Acknowledgements**

As the African proverb goes, “It takes a village to raise a child.” It truly does. Among the countless amount of people, I’d first like to thank my advisor, Kevin A. Yelvington for being the “Chief” in my academic village over the years! I have matured academically, professionally and personally from your support and motivation. You have been a true asset throughout this PhD process, and I thank you for your unwavering support. I also give thanks to all of my committee members: Rebecca Zarger, Daniel Lende, Ellen Daley and Dawood Sultan. Your fervent commitment, assistance and feedback on this dissertation is insurmountable. My future career goal as a transdisciplinary researcher has been greatly impacted by your advice and wisdom. I would like to thank the Center for Equal Health staff for being a strong support system throughout this doctoral process. I was able to gain practical knowledge in health disparities research and enhance community-based research skills during my tenure at the Center. To those women who bared their souls and surrendered time to tell a stranger the most personal aspects of their lives, I am forever grateful.

I gratefully acknowledge funding support from the Institute for the Study of Latin America and the Caribbean at the University of South Florida (USF), a Graduate Multidisciplinary Scholar Fellowship at USF, a McKnight Dissertation Fellowship, and the Minority Scholar in Cancer Research Award of the American Association for Cancer Research.

Thank you to my mentors, friends and confidants along this journey. It would not have been complete without you. A final thank you goes to all the USF staff, faculty, and departmental colleagues who continuously kept the “village” in civil order over the years.

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## **Abstract**

This dissertation explores how the sociocultural experiences of migration and acquisition of health knowledge influence the beliefs and behaviors related to human papillomavirus (HPV) risks and cervical cancer prevention among women who have emigrated from English-speaking Caribbean nations and now live in the Tampa Bay metropolitan area. Genital human papillomavirus is very common, and cervical cancer is the most common HPV-associated cancer. Additionally, all cervical cancers are caused by the HPV infection. More women of color, including Black and Hispanic women, are diagnosed with cervical cancer and at a later stage of the disease than women of other races or ethnicities. Black women have lower levels of knowledge and awareness of HPV and related preventive measures compared to Whites. The incidence of cervical cancer is higher among African American/Black women and Latina women than among White women. Globally, Caribbean countries have some of the highest incidence and mortality rates of cervical cancer. It is unclear how knowledge, perceptions and behaviors surrounding HPV risks and cervical cancer influence prevention practices among immigrant women from English-speaking Caribbean countries residing in the United States. Existing literature highlights factors which influence cervical cancer prevention behaviors and HPV knowledge among immigrants in the United States, including educational barriers, HPV tests and vaccine costs, duration of time within the United States, in addition to the beliefs, myths and stigma surrounding cervical cancer originating in the birth country. But there is a dearth of information on immigrant women from the Caribbean.

Ethnographic methods were employed in this study, including participant observation, key-informant interviewing, focus groups, and semi-structured in-depth interviewing to assess attitudes, available knowledge, culturally specific perceptions, and behavioral practices of the study participants. This dissertation develops a modified approach in the Critical Medical Anthropology (CMA) genre that links political economy with an interpretive approach. It also utilizes the theoretical approaches of transnationalism and embodiment to analyze the phenomena under consideration. Some key outcomes of this research are as follows: Many women were very aware of HPV, and most women were familiar with cervical cancer. However, the majority of women were not confident regarding how HPV and cervical cancer were connected. They did not know how a virus causes a chronic disease. Even with some of the study participants having the HPV vaccine, they were still not aware of the link between the two. This led the researcher to inquire what HPV or a sexually transmitted disease meant to the women, resulting in a mixture of responses ranging from never thinking about HPV or acquiring an infection to placing blame on being “loose” or “promiscuous” as a woman. Their narratives provided insights into how their childhood and familial experiences as young Caribbean women contributed to how they act upon knowledge about being sick, having an infection, or living a healthy lifestyle since migrating to the United States. This research contributes to works applying anthropological perspectives and ethnographic methodology to narrow the gap in available literature relevant to migration, Black Caribbean immigrant health and cancer health disparities.

## **Chapter One: Rationale for the Research**

This research explores the knowledge about and the meanings associated with Human Papilloma Virus (HPV) and cervical cancer and the influence of perceptions of risks on prevention behaviors among reproductive-aged women who emigrated from English-speaking Caribbean countries and now reside in the Tampa Bay, Florida metropolitan area. While HPV has received some attention from medical anthropologists working in the area of immigrant health, there is at present limited anthropological research focusing on the gynecological health outcomes of immigrants from the English-speaking Caribbean. For immigrant populations in the United States, the existing literature demonstrates that demographic factors and educational barriers influence HPV knowledge, attitudes and behaviors associated with cervical cancer prevention and screening accessibility, in addition to the beliefs, myths and stigmas associated with cervical cancer in the countries and cultures of origin (Chávez et al. 1995, 2001; Martínez et al. 1997; McMullin et al. 2005).

The purpose of this study is to contribute to literature by applying medical anthropological perspectives and methodology to research focusing on narrowing the gap in current works relevant to migration and Black immigrant health, to reveal transnational cross-cultural factors affecting sexual risk perceptions, and to demonstrate the need to integrate applied medical anthropological analysis into the discourse of eliminating cervical cancer health disparities throughout the Tampa, Florida region and beyond.

The research questions guiding this study are:

1. What are common beliefs about HPV and cervical cancer among immigrant Caribbean-born women?
2. What does HPV and cervical cancer mean to immigrant Caribbean women?
3. In what ways have cultural beliefs and individual experiences influenced knowledge about HPV and cervical cancer?
4. How do these beliefs influence behaviors and prevention practices?

Through rich, in-depth explorations of the socio-cultural influences of transnationalism, identity politics, gender relations, and familial roles on health-seeking behaviors in the English-speaking Caribbean population in the United States, this ethnographic research attempts to answer the research questions by providing contextualized meanings of HPV risks and prevention. This research attempts to augment the existing literature in the domain of sexual health risk, disease transmission and prevention to Caribbean immigrant women's gynecological health. Moreover, this research broadens implications toward social, cultural, political, economic and historical concepts in order to bolster anthropological work on Caribbean immigrant healthcare decision-making and sexual health outcomes.

### **Public Health Considerations of HPV and Cervical Cancer**

Cervical cancer is the most common HPV-associated cancer. Additionally, all cervical cancers are often caused by the HPV infection (CDC 2016a). Prevention of cervical cancer involves regular screening (e.g., the Pap test), follow-up treatment, and vaccine protection. The Papanicolaou test (also called the Pap smear, Pap test or cervical smear) detects cell changes, including HPV, on the cervix that might become cancerous if not treated early (CDC 2016b). The human papillomavirus is a group of viruses that includes more than 100 different strains or

types (CDC 2012). The virus infects the skin and mucous membranes. There are more than 30 HPV types of viruses contracted via sexual activity and can infect the genital area of men and women, e.g. skin of the penis, vulva, anus, cervix, or rectum (CDC 2012). HPV is very common. More than 80 million Americans are infected with HPV, while 14 million people become newly infected each year. An estimated 50 percent of sexually active men and women acquire genital HPV infection at some time in their lives (CDC 2016b).

Genital HPV is the most common sexually transmitted infection (STI), and most people who become infected do not even know they have it (CDC 2008b, 2012). According to the Centers for Disease Control and Prevention (CDC), there are over 12,000 new cases of HPV-associated cervical cancer diagnosed in the United States each year (CDC 2008a, 2012). Additionally, an estimated 4,000 women die from cervical cancer in the United States each year (U.S. Cancer Statistics Working Group 2015). Over the past 40 years, cervical cancer rates and deaths to the disease have drastically declined. This decrease is due to the significant efforts of women getting regular Pap screening tests (NIH 1996; CDC 2012). Essentially, when cervical cancer is found early, it is “highly treatable and associated to long survival and good quality of life” (CDC 2009, 2012).

However, more women of color, including Black and Hispanic women, are diagnosed with cervical cancer and at a later stage of the disease than women of other races or ethnicities. This issue could be caused by the decreased accessibility to screening (e.g., Pap test) or lack of follow-up treatment (CDC 2008a, 2012). Regular screenings such as annual Pap smears can prevent cervical cancer and lower-income women are less likely to receive annual screenings, therefore the disease is more deadly in this population (Friedman 2007; CDC 2012). Black women have lower levels of knowledge and awareness of HPV and related preventive measures

compared to whites (Cates et al. 2009; Hughes et al. 2009; Ragin et al. 2009). The incidence of cervical cancer is higher among African American/Black women and Latina women than among White women (Friedman 2007; CDC 2016a). The literature supports the argument that shared cultural knowledge is influential for encouraging preventive health behaviors (Boslaugh et al. 2005; Kreuter et al. 2003, 2004, 2006; Thomas et al. 2004; Yun et al. 2001).

Persistent infections of high-risk types of HPV are a major factor in causing cervical cancer (PAHO 2014). Close to 70 percent of all cervical cancers are attributable to HPV types 16 and 18, while low risk HPV types (e.g., 6 and 11) are responsible for 90 percent of genital warts or condylomas (PAHO 2014). The HPV vaccine protects against the types of HPV that most often cause cervical, vaginal, and vulvar pre-cancers, and most genital warts. The vaccine was developed due to the identification of specific strains of HPV types being the etiologic agents in cervical carcinogenesis. Successful testing and study results in human population trials allowed the vaccine to be introduced in 2006 (PAHO 2005).

HPV vaccines are bivalent (types 16 and 18) and quadrivalent (types 6, 11, 16, and 18) and have been “found to be highly immunologic” (PAHO 2014). All of the vaccines are considered “highly efficacious for preventing persistent type-specific infection, pre-cancerous lesions and associated cervical cytological abnormalities” (PAHO 2005). PAHO officials support “vaccines elicit humoral and robust cell mediate immune responses at higher levels than those observed in natural acquired infections” (PAHO 2005). Yet, the cost of vaccination is a major barrier for even developed nations (WHO 2009).

The annual burden of cervical HPV-related diseases ranges from \$2.25 billion to \$4.6 billion in the United States and the annual burden of cervical cancer ranges from \$181.5 million to \$363 million (Fleurence et al. 2007). The newly developed vaccine, Gardasil, is considered the

most effective method of prevention for HPV (CDC 2008). Currently, the three shot regimen HPV vaccine is recommended for young girls and boys at age 11 or 12, prior to sexual activity (CDC 2015). The cost of the vaccine is \$360 to \$500 for a three-shot regimen (Fleurence et al. 2007; American Cancer Society 2016).

The World Health Organization (WHO) states cervical cancer is the second cause of female cancer mortality worldwide with (WHO 2013), and cervical cancer is the fourth most common cause of death in women globally with an estimated 528,000 new cases globally and 266,000 deaths caused by cervical cancer in 2012 (GLOBOCAN 2012; WHO 2013). With over 500,000 cases of cervical cancer reported each year, nearly 80 percent of those are in developing countries, including Africa with 68,000, an estimated 77,000 in Latin America and the Caribbean, and 245,000 in Asia. The WHO has also issued worldwide program implementation and development guidelines on how countries should formulate national policies on HPV vaccination (2009, 2013). The guidelines include efforts to educate governments, health professionals and the public about vaccines and viruses, along with the importance of collaboration amongst reproductive health, immunization, child and adolescent health and cancer control programs. Ultimately, WHO highlights screening and treatment services will still be necessary due to the 70 percent vaccine coverage rate and the lack of duration in the latency period of the vaccine efficacy (2009, 2013).

In many Westernized countries, cervical cancer is considered highly preventable due to the availability of screening tests and the HPV vaccine. While the incidence of cervical cancer is declining in industrialized countries, 80 percent of the 525,000 annual new cases occur in developing countries (Arrows for Change 1997; WHO 2013). Sub-regional disparities exist at a higher proportion in the Latin American and Caribbean region with cervical cancer incidence

and mortality rates at least four to five times greater than those in North America (PAHO 2014). African and Caribbean countries have the top two highest incidence and mortality rates, exceeding Europe, Asia and the Americas (Ferlay et al. 2014). There is a dire need for initiating prevention efforts for cervical cancer in countries outside the United States and especially to populations of high-risk women.

Current efforts to reduce cervical cancer rates in similar regions have difficulty overcoming resource scarcity in their health care systems in order to improve HPV testing and screening mechanisms for the reduction of cancer diagnoses and deaths. Measuring the incidence of cervical cancer is considered an important step by providing information on the success of screening programs and establishing long-term effectiveness of HPV vaccines. The HPV vaccination initiatives have not gone without adamant controversy regarding efficacy and safety, along with public education concerns on the value of the vaccine (Brody 2007; Hart 2007; Lafferty 2007; Ragin et al. 2009). However, it is still promulgated that cervical cancer rates will decrease over time if both screening and vaccination programs prove to be efficacious.

### **Disparities in HPV, Cervical Cancer, and Caribbean Immigrant Health**

Genital HPV is the most common sexually transmitted infection (STI), and most people who become infected do not even know they have it (CDC 2014). Cervical cancer is the most common HPV-associated cancer (CDC 2016b). In the United States, prevention of cervical cancer involves regular screening (e.g., via the Pap test), follow-up treatment, and vaccine protection. Globally, cervical cancer is a major cause of high morbidity and mortality with 80 percent of cases among women residing in less developed countries (PAHO 2014). More women of color, including Black and Hispanic women, are diagnosed with cervical cancer and at a later stage of the disease than women of other races or ethnicities in the United States. This issue



could be caused by the decreased accessibility to screening (e.g., Pap test) or lack of follow-up treatment (CDC 2014). Regular screenings such as annual Pap smears can prevent the progression of cervical cancer. However, lower-income women are less likely to receive annual screenings. Therefore the disease is more deadly in this population (Friedman 2007). U.S.-born Black women have lower levels of knowledge and awareness of HPV and related preventive measures compared to whites (Cates et al. 2009; Hughes et al. 2009; Ragin et al. 2009). Cervical cancer incidence and mortality rates in Latin America and the Caribbean are four to five times greater than those in North America (PAHO 2005; WHO 2013). Thus, additional investigation is warranted for these high risk populations that have migrated to the United States.

In 2010, Black females in Florida had a higher age-adjusted mortality rate than white females (FL DOH 2010). The percentage of cervical cancer cases diagnosed at an advanced stage was 67.6 percent for Blacks and 49.3 compared to Whites and the prevalence of screening was lower for Black women than for White women (FL DOH 2010). As previously stated, Caribbean countries have some the highest incidence and mortality rates of cervical cancer in the world (Ferlay 2014). Thus, there is evidence demonstrating the need for initiating prevention efforts for cervical cancer within countries outside the United States, specifically in nations with increased migration rates to the United States.

The Caribbean region has been more deeply and continuously affected by the international migration process than any other region in the world (e.g., Foner 2001; Kasinitz and Vickerman 2001; Waters 1999). Caribbean migration patterns have emerged and established a “new face” for major cities in the United States such as New York and Miami, and even entire states, such as Florida, with people migrating from islands such as Jamaica, Barbados, Bahamas,

Dominica, St. Lucia, St. Kitts, Antigua, Bermuda, Guyana and Trinidad. Florida is home to 36 percent of Caribbean-born persons living in the United States (Gelatt et al. 2006).

The number of immigrants from the Caribbean has rapidly increased over the past 40 years. According to a report by the Migration Policy Institute (Gelatt et al. 2006), Caribbean-born persons comprised close to 10 percent of the total foreign-born population living in the United States in 2000. Additionally, more than half of the Caribbean-born population are women (Gelatt et al. 2006). In 2014, Florida was among the top five states where Caribbean-born people resided, and that Caribbean-born people comprised 41.4 percent of the 2.7 million foreign-born people residing in the state. Close to 36 percent of the Caribbean-born U.S. population resides in Florida (U.S. Census Bureau 2014), while the Caribbean-born population comprised 9.5 percent of the total foreign-born population in the nation.

More specifically, fieldwork for my dissertation was conducted in the metropolitan city of Tampa Bay, Florida; specifically throughout Hillsborough and Pinellas counties. Hillsborough County has a population of 1,229,226 with 16 percent Black or African American, and Pinellas County has over 916,542 with 10 percent Black or African American (U.S. Census Bureau 2014). According to the U.S. Census Bureau (2014), there are over 17,000 people from the Bahamas; over 1,800 from Barbados; over 6,232 from the British West Indies; over 163,190 from Jamaica; over 18,115 from Trinidad and Tobago; over 1,610 from the U.S. Virgin Islands; and over 15,454 other West Indians in Florida. Regionally, more than 465,000 Caribbean persons reside in South Florida, primarily from the Caribbean islands of Jamaica, Trinidad and Tobago, Guyana, Bahamas and Haiti (U.S. Census Bureau 2014).



*Figure 1.* English-Speaking Caribbean Nations (in red). Caribbean Christian Publications (2013).

As health disparities among immigrants and medically underserved populations continue to be a major concern for U.S. healthcare, it is imperative to examine the cultural, historical, sociopolitical, economic, and transnational contexts, which situate the health-seeking behaviors of these populations within the intricate complexities contributing to health disparities and Black immigrant Caribbean personhood in the United States.

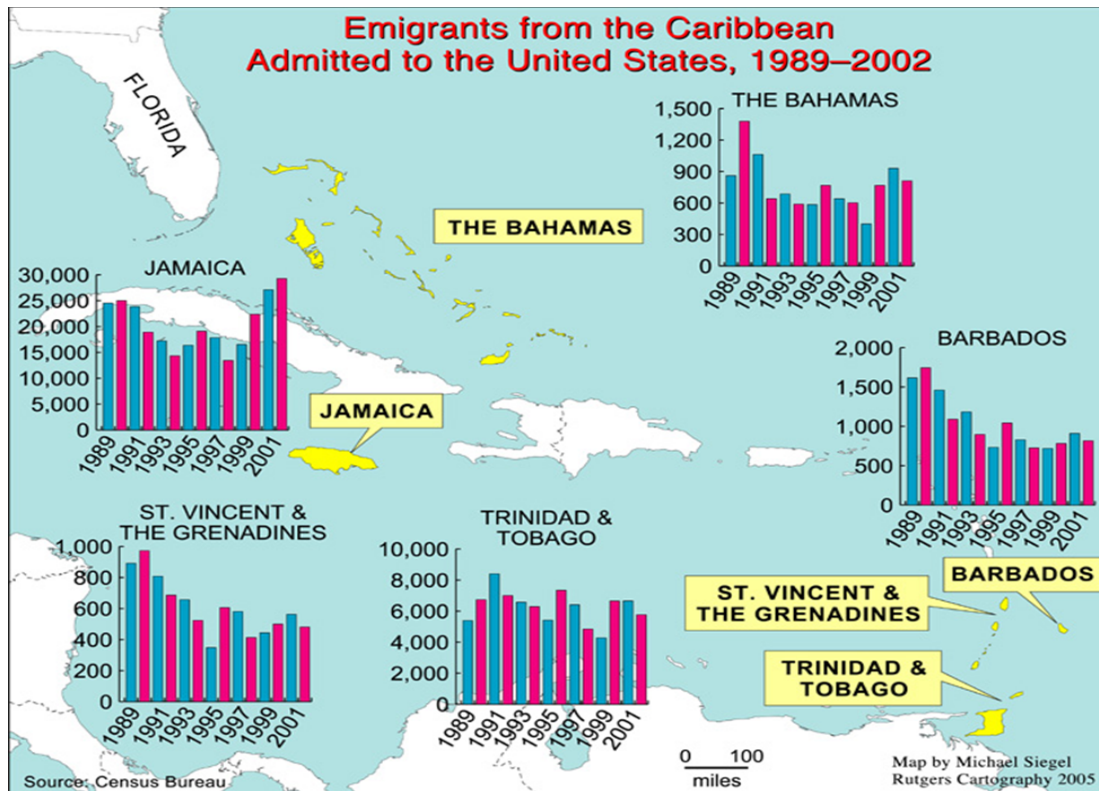


Figure 2. In Motion-Caribbean Migration. Emigrants from the Caribbean Admitted to the United States 1989- 2002. Schomburg Center for Research on Black Culture (2005).

Health care disparities are evident throughout immigrant populations and are associated with higher mortality among minorities (Bach et al. 2002). An individual’s immigration status directly impacts access to health care (Chavez et al. 1992, 2001), and this in turn impacts health-seeking behaviors (Goel et al. 2003; Ward et al. 2004). For example, due to inconsistent documentation status in the United States, along with the loss of autonomy, some women may not have direct access to government-provided medical services and therefore are not able to obtain free and or low-cost screening and preventive procedures as much as women born in the United States. Thus, immigrant consequences of health care disadvantages are embedded in a political economy of health care converging on the influence of structural inequalities (Farmer 1999; Morsey 1996; Whiteford 1996).

Literature reviews yield limited research on Anglophone Caribbean migrants' health consequences. There is limited epidemiological evidence indicating English-speaking Caribbean immigrant populations are suffering from detrimental health inequities (Habenstreit 1988; Orezza 2000; Phillips 2007; Williams 2000; Ragin et al. 2009; McFarlane-Anderson et al. 2008), as much of the social science research on West Indian migrants focuses on constructs of racial identity (Foner 1985, 1987, 2001; Waters 1999) or economic implications of their immigrant status and not on health-related outcomes (Basch et al. 1994). This lack of anthropological work on Caribbean healthcare decisions and health outcomes bolsters the need to conduct exploratory research among this high-risk population.

### **Theoretical Approaches**

Medical anthropology paradigms attempt to explain behaviors and disease outcomes in order to understand the connections between “cultural frameworks, social organizational realities, and human conditions under the rubric of disease” (Joralemon 2006:8). A social science approach showing that cross-cultural perceptions, attitudes, and beliefs can reveal important meanings attached to sexual behaviors and disease acquisition is valuable. It is important to understand – and to modify if necessary – the existing theoretical approaches within the subfield of medical anthropology in order to elucidate the social, cultural, political and economic influences on disease beliefs, knowledge, and practices (Erwin et al. 2010; McMullin et al. 2005). The research reported here utilizes critical perspectives of medical anthropology to explore HPV risk and knowledge in relation to cultural constructs of sexuality and gender, as well as in contexts of transnational migration, by immigrant women from Anglophone Caribbean nations.

A Critical Medical Anthropology (CMA) framework “emphasizes the importance of political and economic forces, including the exercise of power, in shaping health, disease, illness experience, and health care” (Singer and Baer 1995:5). This approach allows anthropologists to expose the social contradictions of the political and economic advantages of the dominant classes. Yet, providing insight into metaphorical conceptions of illness exposing “webs of meaning” in “webs of power” (Wolf 1990) is fundamental to this framework. Economic and political processes must be accounted for in explaining sexual health-related behaviors and decision-making among disenfranchised groups. Medical anthropologist Paul Farmer and others (Kleinman et al. 1997; Das 1995) emphasize the importance of a critical perspective that must be applied in anthropology when studying “illness representations in cultural, political, and historical contexts” (Farmer 1999:182). However, the difficulty that arises from adopting a CMA approach as-is is that with the emphasis on political economy and large-scale processes there has been little emphasis on interpretive approaches and the meanings associated with illness and conceptions of illness among groups and individuals. Researchers seeking an interpretive approach have heretofore been encouraged to abandon one that simultaneously considers questions of politics and power. This situation within the subdiscipline of medical anthropology calls for a new approach that under the CMA umbrella allows us to understand health-seeking behaviors and health outcomes within a single theoretical framework that simultaneously explains health-seeking behaviors and health outcomes with recourse to political-economic forces *as well as* the agency of subjects and their culturally-patterned styles of interpretation and knowledge acquisition and dissemination. An example of this kind of theoretical approach is what this dissertation will provide.

A CMA approach that is at the same time interpretive must confront the fact that humans are embodied – that disease affects bodies and that bodies mediate cultural interpretations of disease and of health-seeking beliefs and practices. The embodiment paradigm engages meaning and understanding of the body as being a source of representations, as Mary Douglas suggests (1970), and as the product of representations as presented by Michel Foucault (Csordas 1999). The paradigm suggests the body must be “accounted for with respect to its cultural and historical mutability...and an opportunity for rethinking various aspects of culture and self” (Csordas 1999:172). This suggests that the body holds an active role in perception and thought (Gibbs 2006) and one that is not mechanical and passive (Lende and Lachiondo 2009).

The embodiment approach offers the opportunity for reflection on the relation between the subject and object (Csordas 1990). As defined by Scheper-Hughes and Lock (1987), this approach emerges from “the assumption of the body as simultaneously a physical and symbolic artifact, as both naturally and culturally produced, as securely anchored in a particular historical moment” (1987:7). This approach views the body as being meaning-laden (Csordas 2002) and emphasizes what people feel and experience. A CMA theoretical framework that is simultaneously based in political economy and that takes an interpretive approach is elaborated in Chapter 3 and used throughout this dissertation.

### **Organization of the Dissertation**

The dissertation is organized in the following manner. In Chapter 2, I provide information on Caribbean migration to the United States and to Florida. I also provide information on the state of health disparities in the Caribbean region. I also report on health-related research conducted on Afro-Caribbean immigrant women. In Chapter 3, I present what I consider to be a new anthropological argument on how medical anthropological contributions,

specifically the critical medical anthropological interpretive perspective and political economy, reveal cultural patterns and structural conditions influencing HPV knowledge, beliefs, perceptions, and health-seeking behaviors. Chapter 4 details the methodological approaches employed in conducting this research, as well as the ethical implications of the study. Chapter 5 presents the findings from the key informants, focus groups and semi-structured interviews, along with analysis of survey data. Finally, in Chapter 6 I conclude with a discussion of the implications of my theoretical contributions for medical anthropology as well as provide an argument for the applied anthropological implications of this research and outline potential further research moving forward.

## **Conclusion**

This dissertation research contributes to theory in medical anthropology by illuminating the meanings and beliefs that interact with behaviors regarding HPV. It also addresses the lack of anthropological literature situating immigrant Black Caribbean women's experiences within the domains of gynecological health and transnational perspectives. The unique application of the critical medical anthropological interpretive framework, to be further elaborated in Chapter 3, guides this research in providing an explanatory model for our understanding of the incidence and the context of HPV transmission in the Caribbean immigrant population. This dissertation research study bolsters available knowledge of transnational social relationships and, further, bridges the gaps in the anthropological literature focusing on English-speaking Caribbean immigrant women. It does so by using narratives of experience to explore cultural domains of women's health-seeking behaviors, HPV risks and associated prevention practices.

This dissertation study calls for further research to be conducted within the Caribbean immigrant population for definitive data indicating belief systems influence over health decision-



making choices. However, this study contributes to literature applying anthropological perspectives and methodology to narrow the gap in available literature relevant to migration and Black immigrant health, reveals transnational cross-cultural factors affecting risk perceptions, and demonstrates the need to integrate applied medical anthropological analysis into the discourse of eliminating cervical cancer health disparities throughout and beyond the Tampa, Florida region.

## **Chapter Two: Caribbean Migration, Health Status, and Health-Seeking Behaviors**

### **Transnationalism and Caribbean Migration**

There is a “new immigration” occurring within the United States. This new transnational migration is formed primarily of non-Whites from Latin America, Africa, the Caribbean, and Asia (Foner 2002). Over the past 50 years, patterns of immigration have changed significantly (Levitt 2001), primarily due to the changes in the U.S. 1965 immigration law, “push” factors in countries of origin (e.g., weak economic and political infrastructure), and “pull” factors (e.g., increased job opportunities and increased wages) in the United States. Never have these forces of immigration been so evident than in immigration patterns of Caribbean peoples. And, of course, these Caribbean immigrants do not come as individuals not related to communities of Caribbean-born and –descended groups already in the United States, as well as with their own notions and practices of the cultural construction of gender, ethnicity, race, class and nationality, as well as traditions of disease concepts and health-related behaviors. The Caribbean diaspora residing in the United States is heterogeneous, and both migrants and settled communities are more diverse and more complicated than they might appear to be from the outside. Further, Caribbean immigrants engage with members of the “host” society in the United States, and the outcomes of these interactions are not entirely predictable. For instance, Afro-Caribbean migrants have engaged with African Americans over the years, and while these groups have found areas of commonality, they have also expressed stark differences, divisions, and disagreements. At the same time, these Black migrants are often placed into the category of “Black” or “African

American” by U.S. Whites and others, meaning that for Afro-Caribbean people, identification along ethnic lines is fraught with contradictions and is highly contextual.

The history of Caribbean migration to the United States goes back over 100 years. This is largely due to the geographical proximity and the historical ties between Caribbean territories and the United States. This history has provoked such evocative scholarly descriptions as being “unbound” (Basch et al. 1994). However, despite the constant increased influx and trafficking of “Caribbeanness” across the waters, little or close to no attention has been focused on Black immigrants and their health-seeking beliefs and behaviors in scholarly writings. Contemporary immigrant accounts often refer to Latino and Asian-origin groups as reference populations while the Black immigrant is generally deemed as an “invisible” element in American immigrant illustrations (Kasinitz 2001). Although the migration numbers fluctuate due to economic conditions (DuBois 2004), there is no reason to propose that the flow of the new immigrants will decline in decades to come.

West Indian immigration is a “multiracial, multiethnic movement” (Holder 2007) and denotes classifications such as Afro-Caribbean, Afro West Indian, Caribbean, islanders, and West-Indian American. Many Caribbean individuals originate from the English-speaking islands in the Caribbean Sea and those territories in South America (Guyana, Surinam) and in Central America (Belize and Panama). English-speaking or Anglophone countries were former British colonies in the Caribbean Basin, and these nations have common traditions linguistically, historically and culturally. The countries with the largest population were Jamaica at 658,062 individuals, Guyana at 218,329, Trinidad at 181,682, and Barbados at 59,975 (United States Census Bureau 2014).

Recent social science scholarship on West Indian diaspora has been able to see the population in their own right and not as the “other” Black in America. As the diaspora expands beyond the borders of traditional settlements of New York City and Miami, so does the breadth of knowledge contributing to the personal experiences of the English-speaking Caribbean population. More specifically, as health outcomes among immigrants continue to be a major concern for U.S. healthcare debates, it is imperative to examine the historical, sociopolitical, economic, and global perspectives that contribute to the complexities of Caribbean life in America to offer a solution.

Ethnographic research on English-speaking Caribbean immigrants has been centered around the themes of transnationalism, immigration, identity, and citizenship (Basch et al. 1994), race and identity (Sutton 1973; Foner 1985, 1987, 2001; Waters 1999), personhood and collective identity (Rouse 1995), media representation and public consciousness (DuBois 2004), class consciousness and politics (Kasinitz 1992; Vickerman 1999), and public recognition (Scher 2003). Unfortunately, literature on health and ethnomedicine are not as prevalent for the English-speaking Caribbean Americans as it is for other non-English-speaking immigrant groups from the Caribbean Diaspora (e.g. Haitians, Puerto Ricans) or Latin America (e.g., Mexicans) as noted in Chapter 3. Therefore, a contextualization of the history of West Indian migration is important to understand the factors that contribute to the demographic characteristics and settlement patterns that contribute to West Indian identity in America.

### **Transnationalism and the Caribbean Migration Experience**

The transnational context brings another set of meanings about disease for immigrant women: A new space, a new social role, and a different perception of preventive behaviors. A significant shift in agency occurs. Assumptions and interpretations of sickness are needed to understand the social structures of individualized experiences and groups suffering experience

from or at potential risk from an illness. The process of exploring disease manifestations across realms of gender, race, ethnicity, class, language, and religion are revealed within the immigrant women residing in this transnational context.

Although not a new perspective, “transnationalism” is being redefined by anthropologists to evaluate the lived and fluid experiences of those “new immigrants” who migrated to America. Transnationalism is “the process by which immigrants, through their daily life activities and social, economic, and political relations, create social fields that cross national boundaries” (Basch et al. 1994). By forging and sustaining the multi-stranded relationships, the country of origin is still an active part of an immigrants’ life abroad. Transmigrants are those who maintain multiple relationships, either among families, economic, social, organizational, religious and political affiliations in their home country.

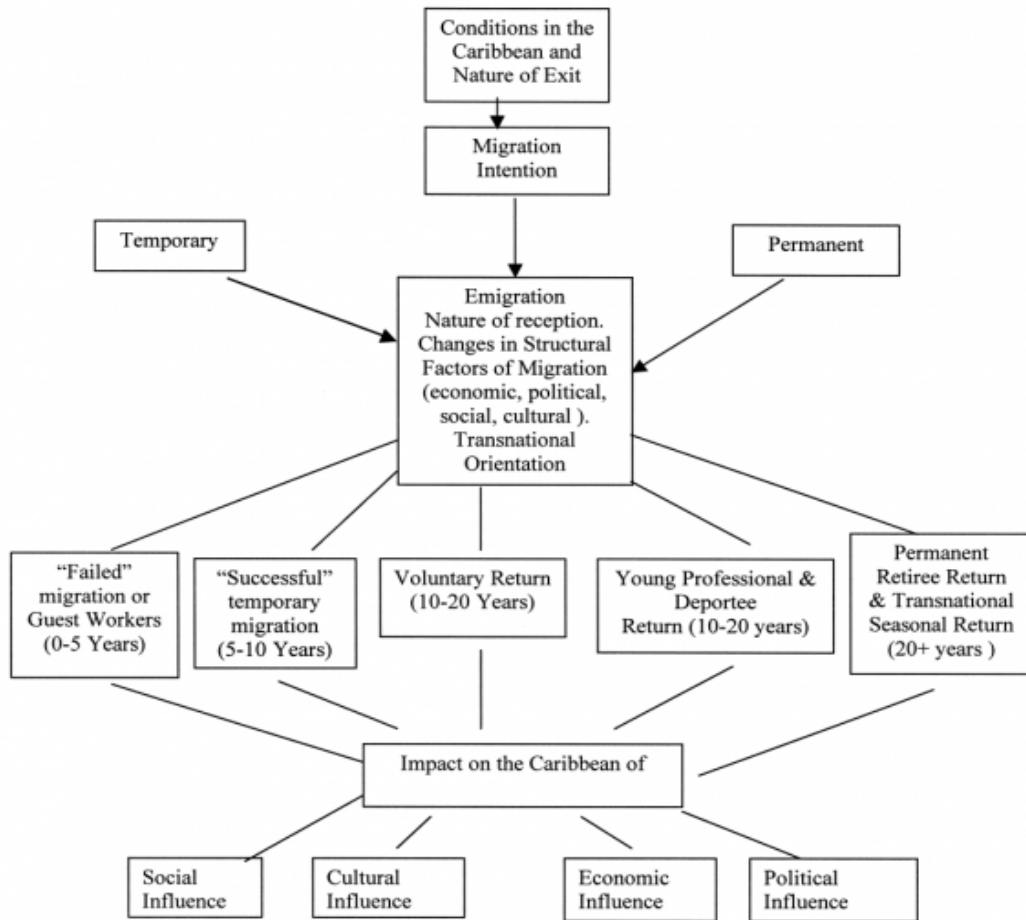


Figure 3. Transnational Factors and the Caribbean. Plaza (2008).

In *Nations Unbound: Transnational Projects, Postcolonial Predicaments and Deterritorialized Nation-States* (1994), Basch, Glick Schiller, and Szanton Blanc provide an analytical framework to contextualize the life of the new immigrant. Moving away from historic patterns of studying immigrant and migrant life, the authors argue for a unique domain to detail the developed networks, activities, patterns of living, and ideologies that span their home and host countries. General notions of transnational spaces (e.g., Georges 1990; Kearney 1991) were not specific in articulating transformations in technology of communication and transportation, accessible air travel and telecommunications (Wakeman 1988), and language as driving forces

for political and economic transformations (Asad 1986). Basch et al. also found themselves among other scholars (e.g., Appadurai and Breckenridge 1988; Gupta and Ferguson 1992; Kearney 1991) rediscovering the concept of transnationalism.

Basch et al. advance their framework by building upon the global perspective of world-systems theory (Wallerstein 1974) and more insightful explications on the role of migration in the international division of labor (e.g. Portes 1978; Portes and Walton 1981). Although debates on inherent issues of hegemony (Williams 1977; Rouse 1995) are encapsulated within the theory of transnationalism, Basch et al. further their analytical framework by addressing the link between “culture and the relations of power and domination” (Roseberry 1989:25) and build on the work of those who examine hegemonic contentions between the colonizer and the colonized, and regions of the Third World in the colonial and post-colonial periods (Fox 1990).

Examining the way Caribbean migrants are transformed by their practices and demonstrating how their practices affect nation-states of the transmigrants’ origin, as well as the societies of settlement, is essential in order to understand the social, political, cultural, and economic complexities of living in an interconnected world. This dialectical approach establishes an appropriate framework to explicate some of the forces that transform cultural practices and subjectivities of Caribbean transmigrants.

The literature on Caribbean transnational linkages stresses that these migrants are concerned with the positive evaluation of what they see as their home or pre-migration cultures, the importance they place on of keeping a “foot in both countries,” and establishing and maintaining important ties with their home societies even though they spend more of their lives abroad (Basch et. al 1994). Anthropological scholars attest that West Indian immigrants have an affinity for wanting to be in their home country and be in the receiving country at the same time.

As Foner highlights, “Wherever they go, West Indian immigrants carry with them a ‘memory of things past’ that operates as a filter through which they view and experience life in their new home” (1998:49).

Anthropologists have made significant contributions to the understanding of transnational migration. However, practicing anthropologists are still faced with challenges of understanding exactly how transnational practices affect migrants’ lives and their involvement in U.S. communities and organizations. Also, they face the challenge of understanding how migrants transform both home and host countries while maintaining engagement in both places. Yet, transnationalism theory incorporates the processes anthropologists use to emphasize connectedness of the social borders immigrants cross geographically, culturally, and politically.

Immigration patterns are bidirectional and circulatory, as immigrants from Caribbean islands continually engage in social and economic transactions that transcend national boundaries (e.g., Sutton 1987; Basch et al. 1994; Portes, Guarnizo, and Landolt 1999). The largest wave of immigrants emerged on the American landscape after some of the West Indian countries gained independence and the enactment of the 1965 Immigration Act. This legislation was most profound in ushering in the large migratory resurgence of Anglophone immigrants into the United States. This influx was caused by the legislation shifting away from the consideration for entry into the United States based on country of origin and toward the principles of family reunification (Vickerman 1999). Since a large Caribbean community already existed in certain cities, naturalized and permanent residents were able to file documents for relatives to enter the country. Additionally, the legislation enabled sponsorship for those to perform services such as domestic work, encouraging Caribbean women to migrate.



In *Caribbean Migration: Globalized Identities* (1998), the anthropologist Nancy Foner provides a comparative framework for understanding the Caribbean migration experience in the United States and Great Britain. This framework highlights the distinct processes and dynamics that might go unnoticed or minimized if only one place is investigated. For example, by examining the occupational attainments of the immigrants in the United States and Great Britain, it was apparent that cultural heritage and immigration status did not thoroughly account for West Indian occupational achievements.

Occupational background in the home society and the presence of a large native Black population in America assisted in explaining immigrants' accomplishments in the United States (Foner 1979). For example, the author argues that West Indian life abroad is neither inevitable nor "natural" for the Jamaican population she studied, and that the migration experience depends heavily on the receiving location. Structures of incorporation in the receiving society, including the structure of race and ethnic relations, gender, family structure, class, age compositions, political and educational systems, and occupational opportunities, are all critical components that shape adaptation and assimilation into the cultural fabric of America.

Consequently, there are pitfalls to limiting exploration of immigrants' adjustment processes to one receiving society (Campbell 1995; Truzzi 1997). Overgeneralization about cultural influence can misalign the explanation for similarities *or* differences, which can ignore a number of factors determining immigrants' context of incorporation. Additionally, anthropologists and other Caribbeanists succumb to their own weakness. By focusing solely on the historical uniqueness of the immigrant group, they have put aside linking to the larger issue of how West Indian immigrants are reshaping the receiving society (Kasinitz 2001).

## **Identity and the Anglophone Caribbean**

Contemporary Caribbean diasporic communities have increased in the United States, establishing new transnational spaces and agency among those who migrate (Basch et al. 1994). Movement to other locations is constantly reforming the new Caribbean identity, depending upon one's place of relocation. This reshaping is most expressed with the Puerto Rican migrant communities (Conway 2003). The reformulation of identity for Caribbean immigrants is continuously evolving along with cultural patterns and social constructs being altered to accommodate this newly developed space (Baranov and Yelvington 2009). Transnational communities are multifocal, meaning that they maintain linkages with their home countries yet forge new identities and locales in their host countries. For example, in Foner's work on Jamaicans in New York City, she shows how the changing dynamics in demographics and immigrant incorporation promote an increased sense of freedom for Jamaicans and other Black Caribbean groups to express their distinct West Indian identity. The process of transnationalism orients Caribbean immigrants back to their homelands, and therefore strengthens ethnicity and slows the process of assimilation.

Caribbean migrants in New York is a kind of "dual-place orientation and identities resulting from the active ties Caribbean individuals maintain to their homelands while becoming New Yorkers, has resulted in a transnational sociocultural system coming into being" (Sutton 1987:21). Cultural transformations of the West Indian immigrant population have been examined (Sutton 1987; Kasinitz 1992), but very few studies have explored factors affecting the countries of origin. This has led some scholars to debate whether or not there are any significant influences that returnees have on their home societies (Chaney 1987; Olwig 1993).

For example, Scher notes the positioning of the transnational community with respect to Trinidadians in New York and the West Indian Carnival celebrations. The Carnival in Brooklyn is essential to Trinidadian ties back to the country of origin, as it is part of “national culture playing a role in the dissemination of nationalist mythologies of multicultural harmony...and an important component in the development of national cultural narrative to be mobilized internationally” (Scher 2003:65). Trinidadian immigrants call upon their own cultural narratives and developments in Trinidad “and mobilize these factors in response to local political issues” (Scher 2003:66). They actively construct public identities while simultaneously becoming part of the identity of their transnation. Further, it is salient to note that immigrants are moving throughout the United States to cities where their numbers have been few. As Greenbaum notes, “immigrant communities from Asia, Latin America, the Caribbean...have become increasingly prominent features of southern urban life” (1998:144).

Historically, Caribbean persons are defined by ethnic and racial identity based upon the gradations of skin color, notions of heritage and kinship, and many other factors such as social class, colonial legacies, and nationalist constructs (Baranov and Yelvington 2009). These markers of Caribbean identity intersect in many ways and are derived from the region’s history of colonialism and plantation slavery. Social classification in the region is a fluid process of contestation rather than fixed, static, and unchanging categories. In broad terms, these patterns are similar for the societies in the English-speaking Caribbean. Therefore, when West Indians migrate to the United States, they bring with them similar cultural constructions of ethnicity and race. Further, these migrants are often better educated than their peers and come from higher socio-economic statuses. Combined with conservative social values, this leads them to strive beyond measure to attain their primary goal of economic success in America (Vickerman 1999).

This has led some observers to profess that West Indians are becoming their own distinct ethnic group.

Early on in Caribbean scholarship, Bryce-Laporte, a Black Panamanian sociologist of Caribbean descent, wrote (1972) that Black immigrants for the Caribbean were “doubly invisible,” signifying their invisibility as non-White in America because they were not North American Black, but foreign Black. This has played out crucially in the search for identity and establishing a secure future for Black Caribbeans (DuBois 2004). As Sidney Mintz articulates, the identity saga “happens in variable degree and at different speeds, migrants arrive as culturally different and then change, often with considerable pain and unease” (Mintz 2004:xi).

There are pertinent cross-pressures that shape how West Indians react to race, ethnicity and related issues in the United States (Vickerman 2001; Waters 1999). The most poignant difference is how Black Caribbean immigrants are forced to enter a contrasting racial hierarchical system than they are not accustomed to in their home country. They are thrust into the low realm of a stratified level of being “Black,” something they are not accustomed to being in their home countries where they are demographic majorities. Some West Indians themselves may argue that despite a history of colonialism and continued sentiments of color consciousness, race is not a major part of West Indian livelihood, so the emphasis of merit as the basis of upward mobility is highly valued. Nevertheless, despite being a distinct ethnic immigrant in the United States, West Indians are often not seen any different than African Americans in mainstream America.

### **Gender, Family and Sexuality in the Anglophone Caribbean**

Immigrant women’s experiences are not isolated to gender alone. Their daily lived experiences are simultaneously impacted by other statuses such as race, class, generation, and

legal position. It is important to understand that, beginning early in life, Caribbean women begin to construct gender-based identities in relation to the division of labor within the household and outside the home. Gender-based ideology favors men and inhibits women's advancement throughout Caribbean society (Senior 1991). At the same time, Caribbean women are expected to be strong and independent and often are. They are often heads of households – the rates of women as heads of households in the Caribbean reach as high as 70 percent in some societies – and they are almost always participating in the formal and informal (and often both at the same time) economic sectors. Ultimately, with the initiation of women's movements and gender-based rights, the traditional culturally-mediated roles are changing, especially regarding educational attainment and career aspirations. Caribbean women are achieving at all levels, prompting some researchers to now worry about “male marginality” (e.g., Miller 1991, 1994).

The histories of Black women are often the “politics of silence” which traditionally have displaced scholarly works about Black female sexuality. This obscuring knowledge reaches far beyond just the lack of education but into the domains of health-seeking behaviors, specifically with sexually transmitted infections and diseases that are detrimental to the Black community (Hammonds 1997; Kempadoo et al. 2001). Presenting existing models and works to examine Caribbean-born women's health-seeking behaviors in the United States will not only expand available literature in the transnational context on women's health, but also bridge the knowledge gap between anthropological inquiry and public health contribution toward immigrant and diasporic health research.

Pertinent here are constructs of the family, gender, and sexuality. Trouillot (1992) asserts that historically, kinship studies have been gender studies in the Caribbean. In the history of social science scholarship on the Caribbean going back to the post-World War II era, there is a

legacy of viewing through the lens of “social pathology” the Black Caribbean family and of developing theories of female-headed households where men are depicted as absconding of their duties as fathers, husbands, and providers (for this literature, please see the review by the anthropologist Christine Barrow (1996). This dominant focus in anthropology, where the so-called “pathological” female-headed Black family was blamed for the economic underdevelopment of Caribbean societies, has given way to a focus on gender and sexuality and their interrelations.

The model provided by Peter J. Wilson (1973) of “reputation and “respectability” as the value orientations, around which Caribbean gender relations and representations revolve, was provocative. Wilson’s view of women striving for “respectability,” which is hierarchical and concerned with Christian morality, local in colonial cultural and moral codes, and involves men trying to earn a “reputation” (requiring egalitarianism and sharing of material resources and experiences with other men, part of their “crew,” and displaying their oratorical and musical talent as well as sexual conquests over women), was evocative and influential in the anthropology of the Caribbean. However, disagreement with Wilson’s work is illustrated by numerous scholars (e.g. DuBois 2004; Yelvington 1995). Some, like Yelvington (1995), feel that Wilson’s descriptions resonate with Caribbean reality and are borne out in the ethnography. However, Yelvington argues that Wilson’s approach that claims that value orientations are causal is flawed. Instead, Yelvington argues that respectability and reputation are the ways in which gender subordination are marked, with men enforcing respectability and traditional, heteronormative, male-dominant gender norms both in the pre- and post-colonial eras. Further, he joins others to argue that women, too, compete with each other in the engagement with “reputation”-like behaviors.

In the United States, the constructs of reputation and respectability are distinguished among social class levels for West Indian immigrants. DuBois's research on West Indians in mass media (2004) highlighted females expressing concern about "reputation" in media representation, with immigrants from the higher social classes fronting efforts of "respectability." DuBois and other scholars disagree with Wilson's assertion about social patterns of West Indians and question Wilson's views on West Indian livelihood as a result of his work with the immigrant population. I caution against using Wilson's overarching ascription to gender-based ideals of reputation and respectability in the public sphere due to the context of newly established gender roles in the United States. At the same time, as we will see, Caribbean women, like other women, gain status to the extent that they adhere in their behavior and consciousness to the norms of respectability. They often police themselves and adhere to what can be described as traditional, male-dominant views of women's sexuality and gendered practice. It is evident how Caribbean gender systems have been ill-constructed on an "insecure and ambivalent foundation" due to slavery and colonial systems imposing dominant ideology of masculinity and femininity (Barrow 1988:xvii). Current modernizations and development processes throughout the region are threatened by economic hardships that are noted to "inevitably impact Caribbean gender identities and relationships" (Barrow 1988:xvii).

If gender relations are still represented through the idioms of respectability and reputation, then sexuality certainly plays a key role. Kempadoo (2004) navigates through terrains of Caribbean gender and sexuality, arguing that gender is discursive and materially produced, indigenized and socially constructed, and politically and theoretically etched in the threads of Caribbean identity. Caribbean masculinity and femininity, as these cultural constructs and practices relate to sexuality, are commonly attributed to sex and located in reproductive functions

and biological facts (Yelvington 1995). Trinidadian historical sociologist Patricia Mohammed acknowledges Foucault's contribution in understanding the difference between sexuality and gender: If gender is deemed as a historical construction rather than biological in origin, then sex, sexuality or sexual relations should also be examined from an historical perspective (Mohammed 1995). Sexuality is noted for not just being operationalized in social practices, as M. Jacqui Alexander (1997) points out, but deeply rooted in state laws and legal discourse in her study of the Anglophone countries of Trinidad and Tobago and the Bahamas. In terms of practice and values, in their study of Jamaica, MacCormack and Draper (1987) identified expressions of sexuality as conceptually linked with the need to have children. Social status and influence is bound closely to identity domains, especially for women. Seeking social power through conception was quite evident in many Caribbean researchers' ethnographic findings. Having a child is a social affirmation, which signifies adulthood and selfhood. This affirmation of adulthood is observed throughout Caribbean societal structures. Symbolically, biological processes of menstruation were found to contextualize the idea of "strength," "having vitality," and being "natural" (MacCormack and Draper 1987).

To what extent do these norms, values, and practices extend to the Caribbean Diaspora? Does this "culture" travel? Before answering this question, we should identify what is meant by culture. The doyen of Caribbeanist anthropology Sidney W. Mintz (1982) stipulated culture should be "viewed historically if it is to be understood at all" (1982:508) and that culture and society are neither "perfectly coherent in themselves nor necessarily congruent with each other" (1982:509). What this means for our purposes is that symbolic systems and conventions of meaning – that is, what might be taken to be "culture" – are intimately related to and dependent upon (and indeed cannot be separated in the realm of theory) social structural properties and



forces. Culturally-mediated frameworks of Caribbean cultural constructions of gender and sexuality must be viewed within the trajectory of the evolving landscape of Caribbean migration and incorporation into U.S. society.

An immigrant's mode of entry into the United States contributes significantly to the differences in family structure (Glick-Schiller et al. 1997). For example, from 1970 to 1990, changing patterns of extended family household structure for immigrants in the United States indicated those who migrated earlier and who chose to remain in the United States are less likely than new arrivals to live in a horizontally extended household (Glick et al. 1997:187). Their family structures affect and are affected by their positioning in the labor market, their socioeconomic status, and their access to supportive social networks directly influencing living arrangements.

Of course, by confronting the new way of life in the United States, many of the "good old traditional" beliefs, values, and behavioral patterns must undergo change. As expected, this change and the new patterns of life are shaped by a complex combination of factors related to the nature of the receiving society, characteristics of the migrant streams, and the period of migration. Watkins-Owens (2001) notes that in the early twentieth-century Caribbean, women were central in the family-based social networks to linking relatives in New York and the home community. She notes that examining the early Caribbean immigrant experience is vital to understanding the entire transnational migration system of Caribbean immigrants, especially regarding women's roles in initiating labor and political activism. Migrants had to negotiate the color categories, as complexion served to be a source of conflict between African American and Caribbean immigrant women. As bi-racial immigrants, often members of the privileged class in the Caribbean, they were able to "pass" as White and find better employment opportunities than

dark-skinned women who faced greater challenges related to color, race, gender, and foreign-born status. Early Caribbean migrants were influential in the economic set-up of resources throughout the city by choosing alternatives to household work and developing their own income-earning enterprises. The early immigrants played an even larger role in the real estate and credit services offered before the Second World War.

In her book *In a New Land* (2005), Foner details how Caribbean gender roles changed post-migration. The absence of close kin dictated more of the male partners' involvement in household tasks such as watching the children while the women went to work or taking the child to school, which were also once considered "women's work." These are just two examples of the changes as part of transnational processes. When working, women's wages were part of the family income even as most Black immigrants worked for lower wages.

As Glick Schiller et al. argue, transnationalism is best seen as a practice for families; "By stretching, reconfiguring, and activating... networks across national boundaries, families are able to maximize the utilizations of labor and resources and survive within situations of economic uncertainty and subordination" (Glick-Schiller et al. 1995:54). Work and family complicate in different ways transnational modalities and communities (Gabaccia and Ruíz 2006). What is a strength in the home context might become a liability in diaspora. Relatives left behind, for example, may be a drain on resources needed for services in host locations. Those in favor of strong family support argue that transnational mothers work for children they left behind and suffer personal strain. Mothers worry about the type of care their child is receiving, whether their child will get into trouble in adolescent years, and whether their child who was left behind will show allegiance and affection toward the "other mother" (Hondagneu-Sotelo and Avila 1997).

At the same time, some social science researchers argue that West Indian immigrants and their children have an easier immigration experience compared to other contemporary immigrants due to the ease of adaptation (Kasinitz 2001). For them, “becoming American” is a shorter journey than for others. This immigrant journey is deemed easier because the Anglophone Caribbean immigrant arrives as an English-speaker and is considered more Westernized than other immigrant groups due to the permeations of American mass media and the tourist industry creating greater exposure to Americans (Kasinitz 2001).

Movement from a smaller population where a large portion of their population has emigrated to the United States and the experience of emigration have been normal and expected parts of the adult life experience for West Indians (Olwig 2001). This expectation also operates as a mechanism that facilitates adaptation, thus allowing West Indians a considerable amount of exposure to the lifestyle and knowledge of the United States from family and friends and from their social networks that they are able to easily access upon arrival. All of these factors have significantly contributed to their economic integration and advancement.

### **The American Life of the Anglophone Caribbean**

Ira De A. Reid’s seminal study, *The Negro Immigrant* (1939), details accounts of West Indian migration to the United States at the turn of the twentieth century to cities like New York, Boston, and Miami, often to seek contract labor on returning tourist steamships. Resettlement to Harlem in New York City occurred in the first part of the 1900s until the restrictive Immigration Act of 1924. After 1930, most of the immigrant influxes were males seeking professional degrees, migrating to join family members, or to become agricultural workers.

The location of settlement for Caribbean immigrants is vital in the way Caribbean immigrants perceive their new home and how they develop social and cultural patterns in the

new area. As Foner says, “the social and cultural context of incorporation is undoubtedly the most important factor accounting for the difference in the Caribbean migrant experience across nations and cities. It is important to consider who moves – in terms of characteristics of the immigrants – as well as the period in which the immigration takes place” (1998:58).

Occupationally, the upward mobility of West Indians are attributed to their work ethic and the obscuring of racial or ethnic discrimination. But in reality, they are often better-poised because of their education and class position compared to many sectors of the native population. In some cases, they have competed with African Americans for employment in the same industries, and their successes have proved detrimental to African American interests (Kasinitz and Vickerman 1999). Politically, Black Caribbean immigrants continue to have a presence within local political schema by providing a voice on community issues including race and ethnicity and immigration issues (Kasinitz and Vickerman 1999) and at times constituting more of a swing vote between the Democrats and Republicans compared to African Americans who tend to vote for Democrats.

Transnational connections are also operationalized in political arenas. For example, the Jamaica Progressive League was founded in New York in 1930 and played a major role for initiating the country’s independence and helped to establish the People’s National Party, a major political party in Jamaica. Social and cultural spheres of West Indian influence in American society are evident with reggae, soca and calypso music (Kasinitz and Vickerman 1999), public celebrations such as carnivals and parades (DuBois 2004), and even popular cuisines such as jerk chicken, rice and peas, patties, and roti.

West Indians have built upon existing religious and social institutions or have created new ones (Holder 2007). They have been known to create new Episcopal or Methodist churches,

or even recruit West Indian ministers directly from the West Indies. They have even created Caribbean high schools or college alumni organizations in host cities, demonstrating their vast network and strength of transnational linkages throughout the United States.

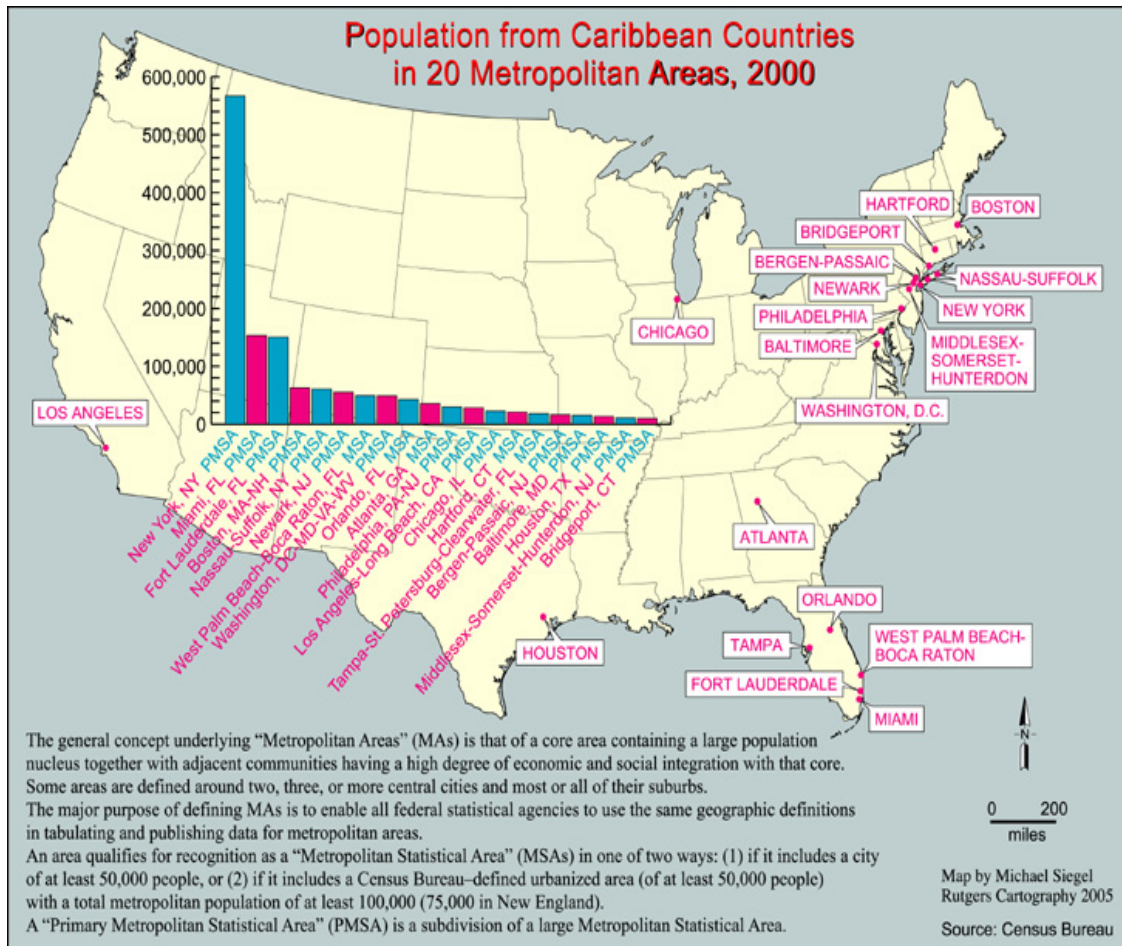


Figure 4. In Motion-Caribbean Migration. Population from Caribbean Countries in 20 Metropolitan Areas, 2000. Schomburg Center for Research on Black Culture (2005).

### Caribbean Women and Health Implications

There are recent scholarly works that explore HPV and cervical cancer domains in Black and Caribbean populations within the United States. I will concentrate the remaining space in this chapter on the breadth of scholarly knowledge examining culturally-mediated influences on

health-seeking behaviors. These studies have informed the preliminary framework for the dissertation project and ethnographic research design concepts. Unfortunately, there are to date few research studies illustrating disparate health outcomes of Caribbean-born immigrants (Habenstreit 1988; Orezzaoli 2000). Therefore, in what follows I review studies from the Caribbean itself as well as studies about African Americans in the United States because it is possible that Anglophone Caribbean migrants have been included in these studies without regard to their unique status and origins. As well, I review studies about African Americans because it is possible that Afro-Caribbean migrant communities will conform to the relatively disadvantaged (see Figure 5) health outcomes of African Americans given the structural forces of U.S. racism. In any event, given the dearth of specific studies (a fact in itself which provides further justification for the present study), these studies might be seen as providing a kind of proxy for the health situation and statuses of West Indian migrant women.

## Racial and Ethnic Disparities in Cervical Cancer

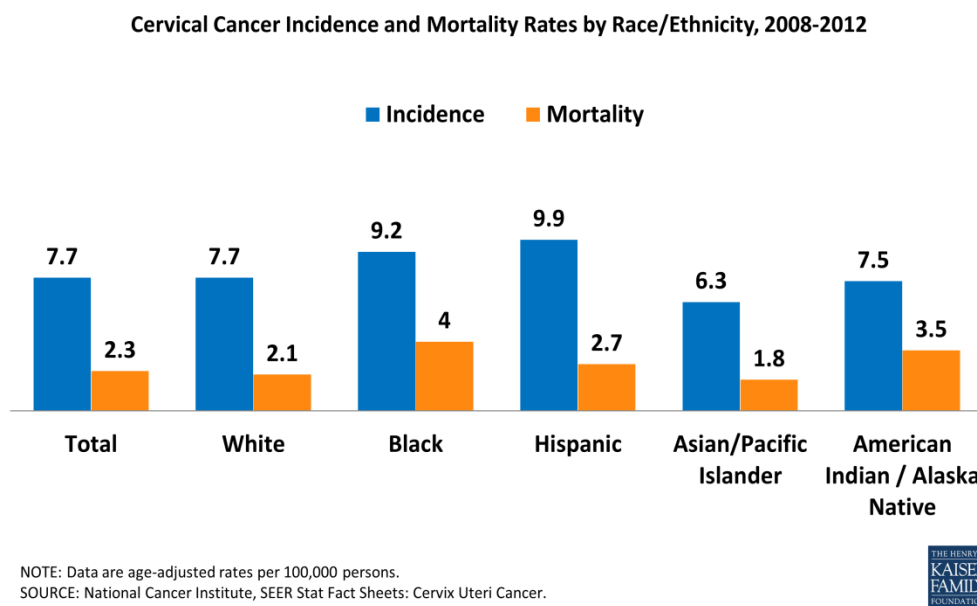


Figure 5. Racial and Ethnic Disparities in Cervical Cancer. Kaiser Family Foundation (2015).

The leading causes of mortality and morbidity in Jamaica are chronic non-communicable diseases (Ministry of Health and Environment of Jamaica 2008). In general, the ranking is as follows: cardiovascular disease, neuro-psychiatric conditions, cancers, diabetes, and nutritional disorders. The leading causes of death are due to chronic non-communicable diseases, a change from the 1950s when the leading causes were primarily infectious diseases. In Jamaica, cancers accounted for 15 percent of non-communicable diseases and nine percent of total disease burden in 1990. An estimated 400,000 women are diagnosed with breast or cervical cancer each year in Latin America and the Caribbean, with close to 120,000 dying from these diseases (PAHO 2013).

A total of 2,862 gynecologic cancers were registered for the years 1973-1997, which represents 26.8 percent of all female cancers from Kingston and St. Andrew, Jamaica. Cervical cancer accounted for 62 percent of these gynecologic cancers. In 1999, 268 cancer-related deaths (168 due to cervical cancer) were registered in Jamaican women representing approximately 15 percent of all female cancer-related deaths. In Jamaica, the incidence (27.9 per 100,000) and mortality rate (15.8 per 100,000) of cervical cancer are much higher than those that are documented for American women comprising both African Americans and Whites. This indicates the limited efforts to decrease the incidence and mortality of cervical cancer in the country by not implementing effective cervical cancer screening programs (Blake et al. 2003).

Some studies indicate invasive cervical cancer is a leading cause of death among Caribbean women (Fletcher 1999; IARC 2004; Bessler et al. 2007; PAHO 2001, 2013). Despite the availability of Pap smear screening in Jamaica, 90 percent of women who die from cervical cancer have never been screened (Fletcher 1999). The effectiveness of Pap smear screening depends on women's knowledge of and attitudes toward screening, the availability of this

service, the adequacy of laboratory facilities to process the smears, staffing within clinics and laboratories, quality controls, a system of recall among women with positive smears, and economic factors (Fletcher 1999). Use of the Pap test has resulted in a decline in cervical cancer mortality in developed countries. Despite established cervical cancer screening programs, a significant portion of Jamaican women are not undergoing screening for cervical cancer (Bessler et al. 2007).

A national study in Jamaica indicated women are aware that the Pap smear exists, but factors preventing them from accessing this service include a fear of the test and the result of the test, cost of the test, and a lack of urgency and understanding of the meaning and value of the test (Ministry of Health and Environment of Jamaica 2008). The study reported concerns about confidentiality and a lack of timeliness to receive results. Some myths surrounding the causes of cervical cancer include: belief that large penises and “hard-core sex” can damage the cervix and lead to cancer; and scraping of the cervix during the Pap smear procedure can also damage the cervix and lead to cancer (Ministry of Health and Environment of Jamaica 2008).

In the United States, African Americans have disproportionate rates of morbidity and mortality for most cancers than any other racial or ethnic group (Thurman et al. 2009). Additional studies suggest that low educational attainment and additional markers of low economic status, which are prevalent throughout African American communities in the country, play a role. Thurman et al. examined knowledge and perceptions related to general cancer prevention and awareness in African American adults to determine their knowledge and perception of cancer. Results of the study indicated that African Americans are less knowledgeable about risk factors related to cancer occurrence, knew less about cancer treatment



options, and were less knowledgeable and had more negative perceptions about clinical trials compared to Whites.

Studies have highlighted that the majority of cancer educational and prevention materials are culturally insensitive and exclude African Americans, who are at higher risk of cancer health disparities (Thurman et al. 2009; Wolff et al. 2003; Erwin et al. 1992). Moreover, cancer prevention strategies are often tailored to populations who are White, educated, and middle-class (Wolff et al. 2003). This indicates the necessity for culturally appropriate and population-specific cancer education and prevention strategies to reduce the disproportionate burden of disease on the African American community.

Regarding cancer risks, racial and ethnic minorities are less likely to understand associated risk factors for cancer (e.g., factors relating to age, education, sex, income, alcohol use, body mass index, family, and physical activity) and perceived cancer risks compared with non-Hispanic White populations (Neuhauser et al. 2008). Thurman et al. (2009) attest to how less knowledge and poor perception of cancer facts contribute to increased rates of morbidity and mortality in minority populations, particularly within African American communities. The authors suggest that this lack of knowledge and decreased perceptions of cancer influences behaviors that can increase cancer risk in minority groups. Changes in the reduction of behavioral risk factors (e.g., smoking, diet, adherence to cancer screening tests) are linked to the decrease in cancer mortality (Thurman et al. 2009).

Health information tailored to high risk populations are needed to reduce cancer rates. Research studies suggest that African Americans, along with other individuals, benefit and respond to health information that reflects their cultural background, values and belief systems (Hoffman-Goetz et al. 2006; Williams et al. 1997; Paskett et al. 1996). However, educational and

prevention strategies extend beyond materials and health messages. Psychosocial influences can determine the likelihood of engaging in behavioral lifestyle patterns that contribute to decreased knowledge and acquisition of cancer prevention services.

Behavioral risk factors can vary across racial and ethnic groups. For example, adherence to cancer screening tests have linked various fears to cancer preventive and detection behaviors (Consedine et. al 2004), especially among medically underserved minority populations. Cancer-related emotions including fear and worry are characteristics that contribute to screening outcomes and can also influence the rate of cancer rates among minority populations. Limited studies have been conducted to explore emotional responses to cancer with medically underserved groups. Gaps in anthropological literature are evident, which are even more so for Black Caribbean groups.

However, Consedine et al. (2009) explored cancer-related fears in sub-populations of African descent, including immigrants from island nations in the Caribbean. Anxiety, screening-related fears and cancer worry were investigated across Caribbean subpopulations and indicated differentiated emotional responses independently predicting screening behaviors in multivariate models (Consedine 2004, 2007, 2008). Consedine and colleagues conducted behavioral research exploring the role of emotions and cancer prevention utilizing the emotions theory perspective. These authors illuminate the important of exploring how the role of fear in health behavior in diverse groups is predicated on understanding the object or source of fear (Consedine 2007, 2008); alternatively, they contributed to an understanding of how the role of anxiety motivates avoidance of particular behaviors (Consedine 2007).

Findings from the study elude that cancer worry is generally lower among women from Caribbean immigrant groups than U.S.-born African Americans; fear of screening is higher

among U.S.-born African American and immigrant men from English-speaking Caribbean nations. In summary, there was greater cancer worry predicting screening that is more frequent while fear of screening predicted less frequent screening. Emotional characteristics predicted screening outcomes, suggesting that emotional responses of certain Caribbean-born groups place them at risk for poorer screening frequencies. Therefore, providing evidence that interventions addressing emotional responses in certain populations can offer insightful opportunities to improve cancer-screening frequencies, essentially improving cancer health outcomes.

Comparative research conducted by Ragin et al. (2009) notes that disparities in cervical cancer incidence and mortality rates exist among all women of African ancestry (African American, African-Caribbean and African). The age-adjusted incidence and mortality rates per 100,000 African American women are 8.6 and 3.4, respectively, compared to Caucasians in the United States at 6.7 and 1.7, respectively (Ries et al. 2007). Additionally, African and Caribbean nations have the top two highest incidence and mortality rates in the world (Ferlay 2004). Jamaica's rate of cervical cancer is 27.5 per 100,000 (Fletcher 1999). High-risk genotypes, access to screening, and having multiple sex partners are associated factors related to cervical cancer, especially in the Caribbean, yet accurate prevalence of HPV infection and distribution throughout the region has yet to be thoroughly investigated.

Ragin and her colleagues (2009) conducted the only study examining the prevalence of HPV and the association with cervical dysplasia throughout the Caribbean population. The researchers also sought to examine the prevalence of certain types of HPV (HPV16 and HPV18) throughout the population due to the promotion of the HPV vaccine that prevents most cervical cancers. Ragin and fellow researchers thought it was important to evaluate the potential impact of the vaccine on an "at-risk" population. Specifically, HPV infection and the type-specific

distribution of HPV were compared among women study participants from Tobago, Jamaica and United States. The study revealed a higher prevalence of cervical HPV infection and multiple high-risk infections in Caribbean and U.S.-Black women. Age-adjusted prevalence of infection among women from the United States, Tobago, and Jamaica participants was 34 percent, 35 percent, and 84 percent, respectively. While the age-adjusted prevalence rate for any type of HPV infection was the highest in the Caribbean (47 percent), there was no statistically significant difference compared to the U.S. population. Findings indicated that while a higher proportion of HPV16 and HPV18 infections were evident among Caribbean women compared to U.S. women, they were not the predominant high-risk genotypes detected in cancer-free Caribbean women. In general, HPV specific-types were preventable, ranging from 2-6 high-risk types. Caribbean women had HPV45 infections, less prevalent strains, at a higher proportion than any other types. However, the current HPV vaccines do not target HPV45 infection type. In summary, Ragin and her research team's results support limited research on how Caribbean and U.S.-born Blacks have a higher prevalence of HPV infections that could be related to social class, sexual activity and behaviors, high parity, and contraceptive use (Watt et al. 2009; Bazuaye et al. 2004).

More recently, researchers in Jamaica, the English-speaking country in the Caribbean with the largest population, have begun to examine the phenomena of cervical cancer morbidity and mortality. An investigation of HPV high-risk types in Jamaica was conducted by Watt et al. (2009) to determine genotypes commonly found in high-risk and multiple-HPV infections in women. After taking cervical cell samples of over 250 women, 87 percent of the women were HPV positive and 80 percent of the population was positive for high-risk types. HPV 45, 58, 16 and 35 were the most frequent types at 21 percent, 18 percent, 18 percent and 15 percent,

respectively. Bacterial vaginosis predicted the presence of multiple infections, while alcohol use and age of first sexual encounter were significantly associated with high-risk infections.

The study highlighted the HPV genotype distribution in this population, which differed from patterns observed in North America, Europe and some areas of Asia (Clifford et al. 2005; Pavani et al. 2005). Populations in Cuba, Trinidad and Tobago, and some parts of Africa have reported different genotype distributions other than HPV types 16 and 18 (Ragin et al. 2007; Rodríguez 2005; Si-Mohamed 2005; Mayaud et al. 2001; Wall 2005; and Sahasrabudde et al. 2007) similar to Jamaica. Therefore, Watt and colleagues implicate how the most common prophylactic vaccines are in question regarding the efficacy in relevant populations. This evidence suggests that additional investigations need to be conducted regarding HPV genotyping along with Pap smear screenings.

McFarlane-Anderson et al. (2008) examined the association of hormonal contraception use and cervical dysplasia. Women visiting gynecological clinics were interviewed about reproductive and lifestyle factors along with contraceptive use in Jamaica. Results indicated participants reported 35 percent oral contraceptive use, 20 percent injection use, two percent intrauterine devices, and 23 percent reported use of other methods (e.g., barrier contraceptives, no form of contraception).

The study conferred hormonal contraceptive use influences the risk of dysplasia that may be modified or confounded by barrier contraceptives, amount of sexual partners, increased number of biological fathers, parity and alcohol consumption. The data suggest that less than 50 percent of women received regular Pap smear screenings. Overall, hormonal contraception usage indicated there was a risk of cervical dysplasia among women using hormonal contraceptives. McFarlane and colleagues suggested that education be provided to women receiving hormonal

contraception and regular Pap smear screening should be encouraged to prevent increased risk to HPV.

Since gendered processes and sexuality constructs mark the behaviors of Caribbean persons, it is imperative to include research examining knowledge and awareness toward HPV types, HPV and cervical risk, and contraception. Phillips (2007) mentions in her assessment of cancer mortality and incidence in the Caribbean that as immigrants from the Caribbean settle in the United States, they not only bring disease risks to the United States, but they also bring their attitudes and beliefs from their country of origin. As the expected number of cases of cancer is expected to rapidly increase in developing countries, this exploration will have a broader reference for potential immigrants in the near future. Thus, immigrants should be granted access to adequate healthcare services when in the United States to not only reduce national healthcare costs but improve economic stability for families and individuals.

### **Health-Seeking Behaviors of U.S. Caribbeans**

Much of the scholarly research on West Indian migrants focus on their constructs of ethnic and racial identity or on the economic implications of their immigrant status (please see the citations provide in the discussion above). Studies of the health status or health outcomes of West Indian immigrants are virtually nonexistent. Therefore, initiating this exploratory dissertation study is relevant and necessary.

For those who migrate to the United States, immigration status, length of time in the country, and the ability to engage in movement within the country (Kearney 1995) are factors that influence knowledge and access to health services. Migratory transformations related to acculturation, adaptation, and family structure directly impact utilization of health care services. As Leclere et al. emphasize, “socioeconomic characteristics, access to health insurance, and

differences in morbidity [directly impact] recent immigrants [and therefore they] are much less likely than both the native-born and those immigrants of longer duration, to receive timely health care as well as fewer total contact with physicians” (1994: 381).

It is vital to differentiate political and economic factors that influence the allocation of health care for immigrants (Leclere et al. 1994). Many immigrant groups encounter numerous obstacles related to health care services to their “legal status, economic resources, their degree of cultural understanding of United States medical and the political climate in Washington” (Rumbaut et al. 1988:196).

Immigration and migration have long played a role in the structure of the American economy (Chávez and Torres 1994). There is a “strong relationship between duration of resident and health care utilization” (Leclere et al 1994:370). An individual’s immigration status directly impacts access to health care (Chávez et al. 1992), access to healthcare, and health-seeking behaviors. Chávez et al. say that for undocumented immigrants they studied, “education and literacy were related to knowledge and use of available health care services” (1992:11).

Health care disparities are evident throughout immigrant populations. Health care inequalities are substantial when accounting for factors associated with disparities including health insurance, income, and life longevity. Access to health care, preventive medicine, and early intervention have been shown to combine to decrease the onset of chronic disease and the onset of chronic illness (Hayward and Heron 1999).

Immigrant health seeking behaviors can be affected by medical insurance coverage for preventative measures such as mammography screenings (Ward et al. 2004), along with cervical, breast, and colorectal screenings (Goel et al. 2003). The results of low screening rates among immigrants tend to present advanced stages of disease and have poor health outcomes and

survival rates due to these barriers. Besides health beliefs, there are numerous structural factors constituting barriers to health seeking behaviors, including access to and the availability of preventive and treatment services, employment, environmental and occupational risks, residential location, transportation issues and geographical access differences in health coverage, clinical provider options, political climate and legislative efforts.

Cultural factors influencing health seeking behaviors include belief systems attributed to life experiences, individual and group identity, religious values, and social network and community cohesion. A myriad of factors acts as a powerful filter that shapes English-speaking Caribbean individuals' health-seeking behaviors. Undocumented immigrants' experiences should also be considered when examining health-seeking behaviors, as "the economic and political constraints shape the use of health care by low-income undocumented immigrants" (Chávez et al. 1992:20).

Factors impacting the underutilization of available health services for immigrants, including Medicaid emergency medical care options, are fear of being deported, distrust of the health care system, unfamiliarity with the U.S. medical system, and the official restriction of health-seeking options for immigrants. These factors combine to minimize the opportunity to seek early prevention health, thus contributing to late diagnoses of disease and the narrowing of possible disease treatment options. These issues are applicable when addressing contributors influencing health care inequalities, inclusive of ethnicity, social class, and immigration status.

There are identified subgroups of West Indian communities, primarily in New York City, grappling with health crises. Cancers of reproductive organs, infant mortality, and AIDS are pressing issues of concern in those communities. Health disparities are associated with higher mortality among minority populations (Bach et al. 2002). There has been much attention paid to



clinician and/or physician bias as one of the major barriers related to health care inequities and health disparities within minority or medically underserved populations. Discrimination or stereotypical views held by these care providers can affect the way they administer their care services. In the health care provision arena, “race/ethnicity, gender, age, sexual orientation, and socioeconomic status influence providers beliefs and expectations of patients...and White providers are less comfortable interacting with members of racial and ethnic groups” (Burgess et al. 2004:1155-1156). Due to the evident health disparities in health care access and inadequate provider communications, the Institute of Medicine has called for further research to be conducted to better explore the relationship between social and cultural backgrounds and health-related beliefs and behaviors (National Academy of Science 2003).

Immigrants bring beliefs, behaviors, fears, prejudices, values, and established assumptions about physical and spiritual attributes that often contradict dominant Westernized biomedical realities (Chávez 2003). Medical anthropologist Leo Chávez, speaks of the “multidimensional and multidirectional” changes endured by immigrants, receiving societies, and sending countries when identifying the assimilation or acculturation of health care practices which are often presented as unidirectional. Chávez and others recognize that at times immigrant behaviors and cultural beliefs can be protective and paradoxical to the biomedical literature, appropriately confirming how assimilation can be bad for your health (Rumbaut 1997).

For example, some immigrants enter into the United States with healthy behaviors, including healthy dietary habits, drinking and smoking less than U.S.-born American women (Chávez 2003). It is not until years of residency in America that their health behaviors tend to become “American,” or unhealthy. Engaging in risky sexual behavior, increasing alcohol intake,

smoking cigarettes, and eating high-fat foods are consequences migrants are challenged with in relation to maintaining a healthy lifestyle in the new American home.

The “Healthy Immigrant Effect” of immigrants coming to the United States who are healthier than most Americans is upheld in the case of West Indians. Some epidemiological studies identify these Black immigrants as having a health advantage (Read 2005; Nazroo 2007). This health advantage can be historically linked to the administration of the 1924 immigration law that mandates officials in home countries conduct medical exams before the immigrants’ departure to the United States (Kraut 1994). Knowing that those who are deemed healthy are accepted into the United States would skew the indices to support the Healthy Immigrant Effect.

Disease and illness stigma influence the beliefs and health practices of Black immigrants. The stigma of AIDS ascribed to Black immigrants, such as the unfair and erroneous association of Haitians with AIDS, has led to questions of Caribbean suitability to donate blood (Farmer 1992). Chávez writes about how stigma characterizations mask the structural factors associated with the health of Caribbean immigrants, including illness manifestations, focusing on poverty, dangerous occupations, lack of medical insurance, and crowded living conditions.

The research by Martínez, et al. (1997) on knowledge and beliefs regarding breast cancer held by Latina immigrants shows that knowledge about risk factors are transmitted from family and friends, including via transnational links, popular media, and conversations with health practitioners. The immigrant women’s risks are centered within the moral, gender, and material contexts of their lives.

The use of alternative health agents or health-care providers is evident in ethnographic literature. Chávez (2003) emphasizes that not all immigrants are equally disadvantaged, specifically focusing on undocumented immigrants. Undocumented immigrants are even less

likely to seek health services due to financial limitations, fear of being deported, and a lack of access to medical insurance coverage. Chávez's ethnographic accounts of research on immigrant health-seeking behaviors include investigations into how these immigrants turn to non-traditional providers such as spiritual leaders when facing illness associated with what they see as originating in the spirit worlds (Chávez 1984; Fadiman 1997; Holliday 2001). For example, these immigrants turn to traditional herbal medicines (Holliday 2001) and traditional or folk healers (Chávez and Torres 1994). Chávez's (1984) work specifically identifies immigrant use of health remedies such as teas or salves to eliminate a variety of health problems. While Chávez's work illustrates these convergences for Latin American immigrants in America, he asserts that his argument is applicable to the West Indian context, as Caribbean literature denotes practices of spiritual and folk illness remedies in the United State and the reshaping of an evolving layered identity through "luggaged" health beliefs and behaviors among immigrants (which is dynamic within the social context of the host country).

The blending or merging of folk prevention practices with Western biomedicine is referred to as medical pluralism. Folk models of disease and healing practices are often marginalized, providing evidence of the hegemonic positioning of the U.S.-style biomedical system (Reeser 2014). Medical pluralism has become the norm in individuals' lives (Goldstein 2004), especially among those who are marginalized in a hierarchy class-based system in the Caribbean and elsewhere. This pluralistic concept is explored by fellow colleague Doug Ressler throughout his dissertation, which examines the utilization of the national health care system by residents of a town in the Caribbean nation of Belize. His ethnographic study situates alternative health care options or folk medicine as a vital necessity that is practiced by marginalized groups "to fill the gaps in health care that biomedicine is unable to reach" (Reeser 2014:17).

While medical pluralism is connected to those who endure “suffering and inequality” (Broom et.al. 2009:704), the concept does challenge the traditional biomedical system of the Western world that does not allow local biomedicine professionals to have a choice in the use of local healing practices - a stationary, immobile notion within certain communities. As Resser (2014) argues, these populations use all options of health care practices to sustain overall health, which in turn affects their health care decision-making.

Consequently, immigrants must become resourceful in the confrontation of social, economic or cultural barriers to health care in a new land. Medical knowledge of family and friends and alternative practitioners meet their immediate needs. These social networks serve as a safety net and reinforce ties and solidarity among local neighbors and family members (Chávez 1984). In this dissertation study, some study participants relied on transnational networks for more than just information. There was evidence of folk remedies being sent from host countries to the United States. This strategy can reinforce the strong bond between the home and host country, thus bolstering the value of the transnational exchange of these resources.

Chávez (2003) stresses that medical anthropology and immigration studies work in tandem, supporting collaborative research when seeking answers to the behaviors of immigrants. A medical anthropology approach must be “holistic in approach and perspective,” and he reminds us that “health and use of medical services are not separate from working conditions, living conditions, the politics of belonging to society, and the allocation of resources and benefits. We cannot fully understand the range of meanings and limitations of concepts such as citizenship, community, and social interaction without attending to the health and well-being of immigrants” (Chávez 2003).

Jennifer Hirsch (2003) articulates the advantages of using medical anthropology research with migrant populations. Through her studies of *machismo* and Mexican men, she employs a critical research paradigm to understand how migrants strategically negotiate through the systems of migration. She emphasizes this perspective indicating “learning what people are trying to achieve through their use of specific services helps us see health-seeking behavior as an act of consumption, a way of constructing [identity] [and where]...issues of identity and belonging may be played out through the use of health services” (2003:251). With English-speaking Caribbean immigrants, this can be played out with decisions on choosing folk remedies or rituals as opposed to using a biomedical practitioner to maintain health. The questions she asks are instructive for my own study. She asks to what extent do culture and identity shape the decision-making processes on whether to heal themselves or use a products and services of modernity? We will see below that my own research respondents grapple with these very issues. When exploring immigrants’ health-seeking behaviors, it is best to investigate the strategies of the group to include the way healthcare choices are made, as their choices may express who they are or who they are becoming, all while navigating though the barriers of the U.S. health care system (Hirsch 2003).

## **Conclusion**

It is vital to differentiate political and economic factors that influence the allocation of health care for immigrants (Leclere et al. 1994). Vulnerability is demonstrated by individuals and groups when conditions including the loss of autonomy, power and authority are present. Minorities, low-income individuals, immigrants and women constitute vulnerable populations and often experience increased “poor physical, psychological, or social health” (Aday 2001:53) Gender is considered a significant determinant of health, including health status, social roles,

patterned behavior and access to health care along with other determinants of health (Marshall et al. 2005). Additionally, gender also has a strong influence in the allocation of health care resources, cultural assumptions, and decision-making processes related to health (Albrecht et al. 2000).

Social science research on Latino immigrants in the United States present the population as vulnerable to social and health issues due to their socio-demographic characteristics (Marshall 2005). Migration status is another factor that places immigrants in a vulnerable state, especially among those who are undocumented (Passel et al. 2004). There is limited research on the vulnerability of Caribbean immigrants, however. Yet, given that Caribbean women have been migrating to the United States and became integrated into the complex role of being a “double minority” (Waters 1999) – as a Black woman and as an immigrant – the barriers to health care and health-related needs constitute this population as one that is also vulnerable. This indicates that research is needed on factors beyond economic and immigration status that affect health outcomes of migrant populations. Immigrant transformations related to acculturation, adaptation, and family structure can directly impact health-seeking behaviors.

### **Chapter Three: Theoretical Approaches in Medical Anthropology**

This dissertation research describes how social identity, gender and sexuality constructs interact with health-seeking behaviors and knowledge surrounding HPV risk and cervical cancer. Exploring how HPV risk and knowledge is transferred within the contexts of sexuality, gender, and transnational migration is instrumental for developing targeted prevention messages to reduce cervical cancer to a high-risk population of immigrant women from the Anglophone Caribbean. This chapter reviews the literature that is relevant in contributing to the exploration of cultural and structural constructs influencing the health behaviors, beliefs and knowledge about HPV and cervical cancer among immigrant women from Anglophone Caribbean countries. There is a paucity of literature dealing specifically with this population. The lack of research concentrating on Caribbean immigrant women and health outcomes in the United States was evident when I began to search for existing literature, therefore securing the need for this dissertation research to be conducted.

I will present the anthropological theoretical frameworks guiding this research. I argue how medical anthropological contributions, specifically a modified Critical Medical Anthropology interpretive perspective, reveals cultural and structural constructs embedded in social, gender and sexuality identities which interact with behavioral practices surrounding HPV knowledge, beliefs and perceptions. Understanding the meaning and representations of an illness is vital to understanding how an individual interprets their risk for a disease. These anthropological “ways of seeing” provide insight on how the study population evaluates their

risk for HPV and cervical cancer. Additionally, public health considerations will be examined to identify the interdisciplinary constructs incorporated into this dissertation research study.

### **Theoretical Frameworks in Medical Anthropology**

Medical anthropology attempts to explain behaviors and disease outcomes in order to understand the connections between “cultural frameworks, social organizational realities, and human conditions under the rubric of disease” (Joralemon 2006:8). The applications within the subfield of medical anthropology are essential when elucidating sociocultural and economic influences of disease knowledge, beliefs and practices among this population. It is important to understand – and to modify if necessary – the existing theoretical approaches within the subfield of medical anthropology to elucidate the social, cultural, political and economic influences on disease beliefs, knowledge and practices (Erwin et. al. 2010; McMullin et al. 2005).

Moreover, it is important to understand the cultural and structural factors influencing Caribbean-born women’s social roles, health and illness experiences, along with gender and sexuality parameters within Western society. Cross-cultural perceptions, attitudes and beliefs reveal important meanings about sexual behaviors, patterns of behavior and disease acquisition (Martel et al. 2004) Additionally, cross-cultural perceptions, attitudes and beliefs can reveal important meanings about sexual practices and disease acquisition in a postmodern context.

Yet, a cross-cultural perspective on its own is necessary but not sufficient. It must be combined with a critical approach. According to LeCompte and Schenshel (1999), critical theorists unveil inequities to discover avenues to take in order to change the imbalance of power, cultural assets, and other resources. Critical theory focuses on assessing “general, class, cultural, race, ethnicity and power intersect to shape inequities” (1999:46). For example, in *Sickness and Wealth: The Corporate Assault on Global Health*, Fort et al. (2004) argue that the “diseases of



poverty” are attributable to the trade barriers and corporate interests of the world’s wealthiest nations. Economic inequalities throughout the world have historical implications strictly due to globalization and colonialism. The collaborations, motivations, and exploitations initiated by the international financial institutions are detailed to illuminate how structural adjustment programs have detrimental effects on health outcomes in Latin America, the Caribbean, Asia and Africa.

A Critical Medical Anthropology (CMA) framework “emphasizes the importance of political and economic forces, including the exercise of power, in shaping health, disease, illness experience, and health care” (Singer and Baer 1995:5). This approach allows anthropologists to expose the social contradictions of the political and economic advantages of the dominant classes. These contradictions, in turn, explain the health outcomes for the relatively disadvantaged. Importantly, it provides insight into metaphorical conceptions of illness by exposing “webs of meaning” in “webs of power” (Wolf 1990); this feature is fundamental to this framework. Medical anthropologist Paul Farmer and others (please see Kleinman et al. 1997; Das 1997) emphasize the importance of a critical perspective that must be applied in anthropology when studying “illness representations in cultural, political, and historical contexts” (Farmer 1999:182). Economic and political processes provide an appropriate framework for determining sexual health-related behaviors and decision-making processes among disenfranchised groups.

Singer et al. (1995) state that the CMA framework “emphasizes the importance of political and economic forces, including the exercise of power, in shaping health, disease, illness experience, and health care” (Singer and Baer 1995:5). A CMA perspective emerged from the structuralism and cultural materialism paradigms initiated by scholars recognizing the global impact of Western economic structures (Wallerstein 1974; Wolf 1982) globally. Driven by the

theories of Marx and Engels, anthropologists wanted to explore health consequences and class-based differences under the rubric model of capitalist development (Joralemon 2006).

HPV-associated cervical cancer is considered a disease of poverty (Freeman and Wingrove 2005; PAHO 2008). A CMA framework has the ability to bring together a consideration of the health consequences of immigrants with the postcolonial history of the country of origin for migrants, the various statuses of the (women in this case) migrants themselves, and the socio-political dynamics of Caribbean nations. The framework unveils various levels of analysis for this study, from the “macrocultural” level (e.g., local, national, political, economic, and global systems) to the “microcultural” and individual levels (e.g., personal beliefs, behaviors, social networks, morals and values). The illness experiences of the oppressed (e.g. immigrants) emits the structures of by-definition unequal and exploitative capitalist development and has the potential to unveil the neoliberal initiatives that continue to stigmatize those confined by structural factors such as immigrant status, class, race, ethnicity and gender classifications at the cost of differential access to health resources and thus producing differential health outcomes. Further, cultural constructions and experiences of sexuality are especially amenable to an interpretive approach, as many anthropologists have noted. For example, Parker (1994) suggests that subjective and intersubjective meanings focusing on the social construction of human reality should lead the new direction in research on sexuality. An interpretive perspective’s usefulness is shown in understanding the role of micro-level and macro-level relationships relative to health care and disease distribution. As Good and Good (1980:176) propose with respect to the development of a “meaning-centered approach” to illness:

An illness or symptom condenses a network of meanings for the sufferer; personal trauma, life stresses, fears and expectation about the illness, social relations of friends and authorities, and therapeutic experiences. The meaning of illness for an individual is grounded in – though not reducible to – the network of meanings an illness has in

particular culture: the metaphors associated with a disease, ethnomedicinal theories, the basic values and conceptual forms, and the care patterns that shape the experiences of the illness and the social reactions to the sufferer in a given society.

Now, there have been medical anthropologists who have sought to integrate an interpretive perspective with CMA. Scholars supporting a cultural constructivist model want to bring the study of meaning to studies of sickness, and in doing so offer a holistic understanding of the multiple dynamics of the origins and experiences of disease (Joralemon 2006). Some anthropologists have suggested that there are weaknesses in the CMA framework, because it deemphasizes micro-level forces and is insensitive to local differences. These critics suggest the necessity for a more localized approach to health experiences (Scheper-Hughes and Lock 1986). Further, this points to a need to incorporate a critical interpretive approach that takes as its point of departure the political economic perspectives on health and is able to consider ethnomedical, phenomenological, and ecological perspectives that are fundamental to a meaning-centered approach. Scholars supporting a cultural constructivist/interpretive model want to bring meaning to sickness, offering a holistic understanding of all dynamics of a disease (e.g., Lock and Scheper-Hughes 1990).

A CMA approach that is also interpretive must confront the fact that humans are embodied – that disease affects bodies and that bodies mediate cultural interpretations of disease and of health-seeking beliefs and practices. The embodiment paradigm engages meaning and understanding of the body as a source of representations, as Mary Douglas suggests, and as the product of representations as presented by Foucault (Csordas 1999). The paradigm suggests the body must be “accounted for with respect to its cultural and historical mutability...and an opportunity for rethinking various aspects of culture and self” (Csordas 1999: 172). This

suggests that the body holds an active role in perception and thought (Gibbs 2006), which is not mechanical and passive (Lende and Lachiondo 2009).

The critique of these scholars mirrors my own. They suggest that CMA, as presently constituted, “focuses on the analysis of the social systems and things...neglecting the particular, the existential, the subjective content of illness, suffering, and healing as lived events and experiences” (Scheper-Hughes and Lock 1986:137). Two of the most recognized proponents of the interpretive perspective are Nancy Scheper-Hughes and Margaret Lock. These medical anthropologists expound upon the CMA framework by applying the interpretive perspective on the exploration of health risks and references using the “Three Bodies” framework: individual body, body social, and body politic. The individual body refers to the “lived experience of the body-self” (Lock et al 1990:50) and the cultural shaping of one’s sense of self as an embodied entity (e.g., experience of pain). Immigrant women’s self-identity is thus embedded in the historical and social daily lived experiences of maturing in a nation that is impacted by the Western capitalistic system and compounded by power, unequal gender relations, economic differentials, and ideology that affect their health-seeking behaviors.

The social body concept refers to the “representational uses of the body as a natural symbol with which to think about nature, society and culture” (1990:50). This concept asserts how beliefs exemplify the link between the health or illness of the individual body and social body. The body that is “good to think with” refers to ethnographic representations of bodies used as a symbol (utilizing Mary Douglas’s symbolic interpretations). Mary Douglas (1970) explores how the body is made to represent a symbol that supplies resources for metaphors, including cultural constructions of and about the body, which are useful in sustaining particular views of society and social relations.

Finally, the body politic concept indicates the “regulation, surveillance, and control of bodies (individually and collective) in reproduction and sexuality, work, leisure, and sickness” (1990:51). The authors state that power and control are evident in relationships between social and individual bodies that represent more than metaphors and collective representations of natural and cultural occurrences. The concept of the body politic is often used by social scientists “to describe metaphorical association frequently made, across a range of societies, between society and the state...and the human body...” (Erickson and Murphy 2006). The French philosopher Foucault used this concept to examine life and the living form and process. The concept incorporated observing how life and living affect trade and capital within the social and cultural constructs of society.

As Lende and Lachiondo (2009) highlight, embodiment theory stresses how the body is not just biological, but is considered equally a religious, ritualistic, aesthetic, historical, and cultural entity (please see Csordas 2002; Thomas et al. 2004). In their research on examining breast cancer screening decisions with African American women, Lende and Lachiondo propose that a focus on embodiment as a perspective is instrumental for overcoming the mind-body dichotomy that permeates biomedicine while examining how embodiment as a practice shapes women’s willingness to obtain breast cancer screenings. Lende and Lachiondo found that women bring an embodied understanding of breast cancer to light when asked about breast cancer examination. Their experiences and meanings held about their bodies guide thoughts about what to do with their individual bodies. Throughout screening exams, women not only rendered “cultural beliefs” but embodied meanings into doctors’ offices about their bodies that contrasted with the traditional biomedical mechanical aspects of the body (e.g., clinical screening examination by a doctor as an invasive procedure that brings memories and experience).

Ultimately, Lende and Lachiondo conclude that meanings from women's childhood and from their community about sexuality, their social relationships, and their breasts were more enlightening than the often abstract and misguided biomedical model of breast cancer decision-making processes.

The most productive approaches to embodiment also incorporate power relations into a theoretical model. For example, Seth Holmes's (2013) ethnographic examination of the migrant labor system in the United States details the structural inequalities and processes in migrant farm workers. He explores the intersections of power, immigration, and health outcomes among the marginalized population of migrant farmworkers through their involvement with the hyper-exploitative U.S. transnational labor system. Here, Holmes unveils the exploitative hierarchal structure embedding brutal suffering and detrimental illness outcomes.

An approach to embodiment is suggested by Caribbean ethnography. In *One Blood: The Jamaican Body* (1993), Sobo investigates the links between the embodied experiences, sociocultural forms, and ethnophysiological issues related to family planning in rural Jamaica. Sobo reveals how cultural influences impact bodily experiences with Jamaicans. In the book, she situates the relationship between the body and the social world, arguing how the body is ideally suited for symbolic interpretation, which is essentially an embodiment explanation. She examines the physical (e.g., reproduction) and social determinants of cultural experiences (e.g., social interaction) that influence health-related models of illness and health and illustrates women's experiences of and through their bodies formulates the foundation of traditional health knowledge. More specifically, Sobo argues that health experiences guide somatic display and social interaction and that these create local models of general health, reproductive health, and social reproduction.

Exploring another ethnographic work within the body imagery context in Jamaica, Sobo (1996) examines emotional experiences through perceptions of sensations by emphasizing the complexities embedded in what she argues is a bridge between mental and body connection via daily lived experiences. She displays how emotions are expressed in the culture and are a path to establish an “equilibrium model of health” for Jamaicans. Through certain social situations, “nerves” are relegated as an indication of social order. Jumpiness, joint trouble, and visual dimness are sensations Jamaicans describe when explaining how cultural interactions affect the body.

Medical anthropology traditions align themselves along the themes of power, education, health access and bodily experience in the work of Jessica Gregg (2003). Gregg’s ethnography on cervical cancer interpretations among low-income Brazilian women identified how the generalized construction of gender and sexuality shapes, and even enforces, women’s concepts of themselves and their behaviors. The concept of multiple cultures connected instantly via contemporary technology is addressed by Gregg illuminating not just how people, but ideas travel swiftly throughout all different parts of the world. Culture is therefore not static, stable, or discrete, but difficult to define as discreet “multiplicities of thought and opinion pushing at national boundaries” (Gregg 2003:5). The concept of one homogeneous culture characteristic of one group cannot be sustained. Gregg (2003) argues that for a diverse population such as in Brazil, one cannot make sweeping generalizations about a population that includes rich, poor, Blacks, mulatos, Whites, indigenous peoples, southerners, northerners, and so on. This problem of glossing over by using an antiquated concept of culture is problematic and does not allow us to identify the inherent structural inequalities within a system or a nation. At the same time, Gregg points out how notions of gender and sexuality, which vary across class and subgroups,

are embedded within everyday interactions of all Brazilians. Women in various communities in Brazil act within a range of cultural traditions and structural conditions. These, in turn, dictate and entail their behaviors, knowledge about screening and prevention behaviors, and experiences with cervical cancer.

Critiques of the embodiment approach are evident in the followers of the philosopher Maurice Merleau-Ponty (Diprose 2008) who utilize a phenomenological perspective, and in Gadow's (2000) "lived body" perspective. Nevertheless, an embodiment approach emphasizes the importance of the subjective experience and the importance of using the body as meaningful and relational. The body is not just an object to be manipulated (Lende and Lachiondo 2009). Therefore, an embodiment approach might be fitting for examining how women reflect upon the duality of their lived experiences navigating their own sexuality, gender assumptions, and risk perceptions for HPV. Additionally, this approach is well-suited for ethnographic research methods on embodiment (Csordas 2002). It also proves useful when engaging minority populations (Bailey 2000).

While the approach of Scheper-Hughes and Lock is suggestive, it is not, however, adequate to simply add an interpretive dimension in an "external" way, simply tacking this on to a CMA approach. This, I believe, is what Scheper-Hughes and Lock do. It is essential that an integrated and interpretive CMA approach provides an interpretation not of some notion of "culture" disconnected from material processes, but remains rooted in an approach from political economy that interprets symbols, ideologies, attitudes, and the production and products of knowledge as material social processes. Scheper-Hughes and Lock sidestep this procedure when they posit levels of embodiment. However, fortunately, there is redress for the position I am



advocating here in the critiques of interpretive anthropology à la Clifford Geertz (1973) provided by anthropologists working in the political economy tradition.

Examples include Roseberry (1988) who reviewed anthropological studies and political economy theorists through the historical development of a political economic anthropology since the 1940s. Having an early historical cultural approach supported by Wolf and Mintz, he also discussed the related works from British Marxists such as the literary critic Raymond Williams, as well as the theories of the Italian labor organizer Antonio Gramsci. Roseberry argues that Wallerstein's (1974) world-systems theory was too limited to be of use in understanding local situations, while an unmodified Marxist mode of production concept was too abstract and not attentive to human actors in society. Ultimately, Roseberry advocated for approaches that theorize the intersections of local and global histories, incorporating culture, history, and practice while considering the role of capitalism, class and power.

More recently, Robotham (2012) stated that a political economy perspective views the economy from a production angle as opposed to one that prioritizes distribution, exchange, or consumption. Robotham examined the central themes of anthropology and political economy through a structural Marxist perspective, which influenced early economic anthropology by insisting upon analysis of economic, political, and familial relationships within society. Influenced by Lévi-Strauss and Althusser, structural Marxism centered upon synchronic and not diachronic structures, meaning history had no structure and that each mode of production could exist in its own right. Simultaneously critiquing structural Marxism and calling for an interpretive approach, Robotham advocated for a humanist anthropological political economy. The debate between political economy and the cultural perspective continues to be a source of contention amongst scholars (Peck 2006).

Roseberry (1982) severely critiques Clifford Geertz's application of phenomenological and hermeneutical approaches to understanding culture, but is also appreciative. Roseberry approvingly acknowledges how Geertz sought to establish anthropology as an interpretive endeavor searching for meaning and significance. This is unlike the cultural materialist Marvin Harris, who establishes the rigid scientific application of anthropology as limited and a "learned repertory of thoughts and actions." According to Harris, culture is a mere product situated in a specific time and space and with social groups interacting within a range of behaviors. This rather limited etic perspective is based on an analysis of how behavioral modes in production and reproduction are distinctly embedded in the infrastructure, structure, and superstructure of a culture conceived as bounded by these collective qualities. Harris does not include the meaning of culture or the socially constructed mechanisms of how people act within society. Harris dismisses Geertz's distinction of meaning in culture as "obscurantist," lending heavily to the debates between explanation and interpretation that characterize disagreements between materialists and idealists.

In his famous essay "Thick Description: Toward an Interpretive Theory of Culture," Geertz (1973) boldly defies anthropologists who identify with Harris's materialist distinctions and assertions. By criticizing those agreeing with such a rigid explanation of culture, Geertz focuses on symbols implicating meaning by and for the social actors who actually develop them. Geertz emphasizes the construction of meaning, and of subjectivities, through symbolic processes embedded in the social world. His perspective was developed from Max Weber's interpretive sociology. Geertz's perspective contributes to his theory by focusing on the transformation of symbols operationalizing culture and society. He supports analyzing how

public symbols are critical to identifying the “ethos” of a culture and how symbols can be viewed as agents and become a source of solidarity and mechanism in a society.

Yet, as Roseberry argues in his analysis of Geertz seminal work “Deep Play: Notes on the Balinese Cockfight,” the gaming or deep play of cockfights are related to the hierarchical segmentation of Balinese society, interpreting status organization and involving the metaphorical concepts of cultures viewed as text. But for Roseberry, Geertz cannot account for the forces and processes of domination in cultural formation that produce what according to Geertz is a coherent body of symbols, meanings, and worldviews. Roseberry criticizes Geertz for being a creature of his own critique, defining his concept of culture as an actual product itself. Geertz’s cultural concepts can only imply the missing elements of social and cultural differentiation, thus referring to the connections between culture and the aspects of power and domination in his work on Balinese cockfights. Geertz cannot conceive of culture as being *a material social process, made and remade in a political crucible of domination and resistance*. Roseberry critiques both Geertz and Harris and says that both are at fault for treating culture as a product, thereby removing culture from the process of being created by social actors. Roseberry calls for Raymond Williams’s version of “cultural materialism” as a concept that simultaneously allows for an ideational definition of culture while conceiving of culture creation as a form of material production. Therefore, both material and ideational processes are conceived of as ever changing and constantly being created. Williams explores how meanings that are socially constructed inform action by examining the idea of tradition in a group’s history and defining it as a reflection of that group’s history while at the same time conceiving of a determining social structure setting limits and parameters on agency. Roseberry advocates that anthropologists must not only account for the meanings that become expressed and make their way into our field data,

but that they must be attuned to “alternative meanings, alternative values, alternative versions of people’s history are available as a potential challenge to the dominant. Whether such alternative versions are constructs depends upon the nature of the cultural and historical material available” (Roseberry 1982:1025).

Roseberry declares that “the unity of structure and agency, the activity of human subjects in structured contexts that are themselves the products of past activity but, as structured products, exert determinative pressure and set limits upon future activity” (1988:172). The women who participated in this dissertation study have a past and are navigating the landscape of new knowledge and social relationships in diaspora. Therefore, such an approach as outlined here reifies itself. An interpretive CMA approach in the political economy tradition will be proven useful for trying to understand meanings produced by Caribbean immigrant women while they navigate a new economic, social, political, and cultural landscape.

### **Medical Anthropology, HPV, and Cervical Cancer**

In this section, I provide a lengthy discussion that illustrates the utility of some of my arguments presented previously. I do so by considering work in medical anthropology that may not advertise itself as taking an interpretive CMA approach, but nevertheless can be considered to be emblematic of such an approach. Anthropological paradigms provide powerful lenses to navigate the domain of sexual health-related behaviors and decision-making processes. The discipline of anthropology also provides the means to access the “cultural meanings of cancer as a disease and as a lived experience in order to increase our understanding of the challenges of health care access and to reduce cancer disparities in screening, morbidity, and mortality among subpopulations in the United States” (Erwin 2009:144). Although few anthropologists have focused their research on sexually transmitted infections, other than those writings specifically

addressing HIV/AIDS (and even fewer on HPV), some existing anthropological literature demonstrates how demographic, socioeconomic, and educational variables influence HPV transmission, as well as the beliefs, knowledge, attitudes and behaviors associated with cervical cancer screening and prevention (e.g., Chávez et al. 1995; Fernández-Esquer et al. 2003, 2004; McMullin et al. 2005; Cates et al. 2009; Luque et al. 2009; Menard 2010).

Anthropological literature also shows how demographic, socioeconomic and education variables affect accessibility to HPV infection and cervical cancer treatment and care services (Chávez 2001; Martínez et al. 1997; Fernández-Esquer et al. 2004; Katz et al. 2009).

Consequently, this literature also elucidates the nature of the associations between the length of time an immigrant woman spends in the United States and beliefs, myths and stigma about cervical cancer typically found in the country of her birth (Martínez et. al 1997; Fernández-Esquer et al. 2003, 2004; Menard 2008).

Much of my literature review conducted with AnthroSource, PubMed, Google Scholar and ProQuest resulted in limited research studies that explore HPV knowledge and cervical cancer screening among women at high risk for cervical cancer, more specifically African American, Black or Caribbean-born women. However, within anthropological literature, there are works exploring cervical cancer in high-risk, immigrant populations from Latin America and a few for Haiti. The available works presented demonstrate the importance of ethnographic research in illustrating the positioning and impact of health-seeking behaviors upon the demonstration of agency among immigrant women in the United States.

Leo Chávez is one of the most recognized anthropological scholars conducting HPV-related ethnographic research with marginalized and medically underserved immigrant women in the United States. His numerous works with the Latina community are pivotal and have forced us

to understand that cervical cancer's distribution can be traced to cultural and structural explanations. Chávez et al. (2001) explored the ways that culture and belief systems impact the use of cervical cancer screening and prevention efforts among Hispanic women in Southern California. In this study, ethnographic interviews and survey methods were used to elicit qualitative data from Latina and Anglo women, along with physicians' beliefs about cervical cancer risk factors. Additionally, the systematic data collection technique called freelisting was used to attain interviewees' understandings of the reasons for contracting cervical cancer. Chávez and colleagues asked study participants to rank 24 risk factors for the disease. Their findings revealed various cultural models among Latina immigrants and physicians. Mexicans and Salvadorans indicated low levels of agreement with physicians compared to Latinas born in the United States and Anglo women. In general, listed risk factors provided by Latina immigrants showed the least agreement with the risk factors understood by the physicians in the study. Birth control pills, abortions, rough sex, and sex during menstruation were some of the listed factors by Latinas. Physicians believed that sexual relations, having multiple children, smoking cigarettes, and poverty were a few factors that increase the likelihood of cervical cancer. Latina immigrants ranked the same factors lower than the physicians. Mexican immigrants and U.S.-born Latinas ranked the same combination of factors including lack of medical attention, vaginal infections, and an infected sex partner. While Anglo women and physicians ranked several risk factors similarly, there were some factors that differed. For example, physicians ranked heredity, birth control pills, and ignoring the body's needs lower.

Overall, the freelisting technique allowed researchers to not just review the respondents' rankings, but examine and understand the reasons why women from various ethnicities ranked the factors they did in a certain matter, further supporting the claim that clarifying and explaining

cultural beliefs indeed matter regarding risks for cervical cancer and HPV. Structural and cultural influences determined the experiences of women and expressed how the daily-lived experiences of being married, language acculturation, education, insurance status, and age were significant predictors of their utilization of Pap smears. With the Caribbean-born women, many of the same predictors are expected to contribute to their belief system surrounding HPV and cervical cancer.

Chávez et al. (2001) note that existing literature emphasizes the role of family and gender relations upon general cultural beliefs, including beliefs about sexuality, patriarchy, and morality. Perceptions of risk and beliefs about immoral behaviors and virtue might impair Pap smear use by women who are considered to be involved in such behaviors. Domains of sexuality and gendered processes impact lived experience throughout Caribbean ideology (MacCormack and Draper 1987; Kempadoo 2004), and it is expected that these factors will impact the mediated context of illness and health construction in this study.

Due to the unscrupulous and politically contentious positioning of immigrants in the United States as “legal” or “illegal,” women may not have direct access to medical services depending upon their legal status and ultimately may not be able to obtain screening procedures. However, the authors did conclude that the explanation of why Latinas do not use prevention health services was not clearly supported. Most importantly, the ethnographic interviews allow us to begin to understand the embedded specific cancer-related belief system surrounding concepts of social relationships and normative behavior within the studied immigrant population.

One of the first explorations by Chávez, et al. (1995) examined Latinas’ variation of beliefs about risk factors for cervical and breast cancer. In the study, beliefs from women born in Mexico and El Salvador were compared with Chicanas (U.S.-born women of Mexican descent) and Anglo women, in addition to physicians’ beliefs about the cancers. Qualitative and

quantitative methods were employed in order to analyze the reasons women get breast and cervical cancer, as well as recognize the importance of the risk factors elicited from the study participants.

While structural barriers, including low income, lack of medical insurance, and lack of knowledge about available health services in the area were investigated, as in similar studies (Chávez 1995; McMullin et al. 2005), the cultural beliefs regarding Latinas' use of existing health services is not quite defined. Chávez et al. highlighted that anthropologists believe culturally shared knowledge is systematically patterned within a culture. Comparing the knowledge of a shared cultural group can explain cross-cultural or intra-cultural variations of knowledge that are systematically patterned (Chávez 1995).

Chávez et al. recognized how other social scientists value the examination of inter- and intra-cultural variation by utilizing research methodologies that allow for informative and comparable analysis (Weller 1993). The "cultural model," or level of agreement on specific elements on breast and cervical cancer beliefs within the Hispanic populations, was explored with Mexican, Salvadoran, and Chicana women. Consensus analysis concluded that general themes were consistently applied across all groups regarding a model of cancer risks for cervical and breast cancer. The two primary themes that emerged were related to physical trauma or stress to the body and behavior or lifestyle-related actions. Blows or hits to the breast were held as beliefs for breast cancer, and for cervical cancer risks it was miscarriages, sex with large penis, abortions and operations. Drinking or taking illegal drugs were seen as behavior-related risks for breast cancer, while a lack of feminine hygiene practices and immoral sexual behavior were blamed for cervical cancer.



More importantly, Latina immigrants tended to have different views compared to Anglo women and physicians. At times, Chicanas' views coincided with Mexican immigrants, while at other times these views coincided with Anglo women. This situation displays the bicultural position or a mixture of familial and historical perspectives with the current biomedical belief system that women experience in the United States. For English-speaking women from the Caribbean, this phenomenon might occur due the heavy Western influence in home countries and established acculturated health-seeking practices immigrants might adapt once movement occurs to the United States.

Essentially, a single cultural model of breast cancer risk factors did not exist when all of the rankings were analyzed. However, the Chicana group of women did have a single mode of risks for breast cancer regardless of their bi-cultural beliefs. This study suggests that there is no homogenous model for risk perception of breast and cervical cancer by Latinas. As women shared their beliefs about the etiology of each cancer, the influence of immigration on the cultural model of disease risks perceptions was evident. One of the most important findings from this study is the demonstration of the contrasting views of breast and cervical cancer risks among immigrants compared to those of physicians. Moreover, these findings could be advantageous for health practitioners providing services in immigrant and minority populations. In order for effective health communication strategies to be acknowledged, there must be initiatives to account for the patient's cultural consensus and knowledge level to improve disparate health outcomes.

Chávez et al. (2001) also examined the influence of cultural beliefs on behavior and risk factors and the use of Pap smear exams among Latinas. Their studies revealed structural factors such as medical insurance, age, marital status, education, and language acculturation that

explained the use of the Pap smear. Ethnographic interviews and surveys were used to illuminate the beliefs influencing the behavior of the target population. Comparing perspectives about cervical cancer can reveal thematic categories about perceived risk factors, level of knowledge, and attitudes toward screening practices and motivations toward HPV prevention in the research setting.

A local pilot project conducted in Dover, Florida led by anthropologists Luque and Casteñeda et al. (2009) sought to understand the associated barriers that limit cervical cancer prevention efforts at local community clinics in the small Florida town. The authors explored these barriers via multiple ethnographic methods by examining levels of knowledge, cultural beliefs and attitudes towards HPV, the vaccine, and Pap screenings among low-income immigrant women. Specific ethnic groups included in the study were Honduran, Puerto Rican, and Mexican women. Anglo-American women were interviewed for comparative purposes. The study involved developing a tailored structure survey that was implemented at community clinics.

The results showed that among all of the ethnic groups, Anglo-Americans and Puerto Ricans are more aware about HPV and the HPV vaccine. In contrast, study participants from Mexico and Honduras had decreased knowledge about HPV and prevention. Cultural barriers affiliated with beliefs about cervical cancer and understanding cancer and its health implications were identified, including negative thinking about the outcome of cancer diagnosis and issues related to screening behaviors and prevention practices. Structural barriers included a lack of insurance coverage, financial cost, and inability to get time off from work for preventive screenings. Similar barriers and attitudes toward the HPV vaccine were identified in the study population.

The most revealing aspect of the study is how Latina women are less likely than the control group to associate HPV with abnormal results of Pap smears or connect HPV infection to cervical cancer. More specifically, the project provides additional emphasis on the need for immigrant women to understand and implement educational programs regarding HPV, cervical cancer risk factors, and prevention practices. The lack of knowledge regarding HPV awareness and its link to cervical cancer is cross-cultural. Increased efforts are needed in the Caribbean population to examine how foreign-born status, ethnicity, duration in the United States, educational level, insurance status, and economic factors can inform prevention efforts to reduce the transmission of HPV.

Regarding prevention and screening practices, McMullin et al. (2005) suggest culturally-related beliefs play a significant role in the decision to obtain Pap smears for Latina immigrants. McMullin and colleagues performed semi-structured interviews with Mexican immigrant women to discuss their beliefs about risk factors for cervical cancer and Pap smear screening. Topics discussed by investigators during the interviews included sexual behavior practices, links between sexually transmitted diseases possibly causing cervical cancer, and knowledge about the Pap smear.

Qualitative content analysis was used to identify four major themes, including knowledge of cervical cancer knowledge, knowledge of the link between sexual behaviors causing infections that lead to cervical cancer, the belief in the need for a Pap smear if there are no symptoms, and the misperception that only women participating in risky sexual practices need Pap smears. None of the women in the study had heard about HPV and often referred to limited general knowledge of cancer when discussing cervical cancer. Physical trauma to the cervix,

having rough sex, and lacking good feminine hygiene were mentioned as potential causes of cancer.

This study showed how cultural constructions and belief systems surrounding the etiology of cervical cancer are important factors to consider when exploring why women do or do not seek Pap smears. Implications of this study indicate the importance of educating Latina immigrant women on the primary prevention of HPV infection and emphasizing the relevance of screening to deter cervical cancer rates in this high-risk population. By locating the health priorities and soliciting beliefs and behaviors related to cervical cancer, as researchers did in the study, culturally-appropriate materials could be developed in the applied dimensions with the findings from the project.

Scarinci, et al. (2007) conducted a research study to attain additional insight from high-risk populations of women regarding the acceptability and dissemination of the HPV vaccine in Alabama. The study purported to show that by assessing the barriers to HPV and vaccine acceptability among African American and Latina immigrant women, future tailored interventions can be developed to improve acceptance of the preventive vaccine. The study was also conducted to address the lack of a thorough examination of studies exclusively focusing on minority women and barriers to HPV vaccine acceptability. Ethnographic methods included performing eight focus groups with African American and Latina women who were ages 17 to 39, had no history of cervical cancer, and were sexually active in the previous 6 months. A presentation about cervical cancer and HPV was conducted prior to asking group participants questions about prevention and acceptability of the HPV vaccine.

Questions were asked pertaining to the topics of sexually transmitted infections where the researchers sought to solicit respondents' knowledge of causes and prevention of HPV, their

concerns and knowledge of their risk of HPV infection, and the extent of their motivations for getting the HPV vaccine. Both groups of respondents voiced their concerns about their lack of information about how HPV infection is connected to cervical cancer, the cost of the vaccine, and the vaccine's potential side effects. These concerns were similar to results from studies of young women (Waller et al. 2005; Holcomb et al. 2004; Mays et al. 2000). African American women were more leery of the vaccine and voiced more concerns about the effectiveness and related side effects than Latina immigrants. Numerous studies have illuminated this issue with the historical aspect of the mistrust the health care system in America with African American and Black populations (e.g Sengupta et al. 2000; Shavers et al. 2002). These studies collectively illustrate that it is advantageous to explore how Caribbean women's constructions of illness are influenced by the traditional biomedical infrastructure and history within the United States.

Motivating factors for using the vaccine among African American participants included knowledge of others being vaccinated, affordability of the vaccine, good clinical trial results, and receiving more educational information about the vaccine. Latina women emphasized how multiple sources of information are important toward obtaining the vaccine, including information obtained via educational talks, television, churches, doctors' offices, and other women. Overall, both groups of women were receptive about the HPV vaccine as an acceptable method of prevention.

Most of the women in the Scarinci et al. (2007) study had never heard of HPV, which is consistent with previous findings in other populations as mentioned earlier. As indicated by the authors, this was the first study to be published that examined vaccine acceptability among these targeted population in the United States. Again, with the use of ethnographic methods to explore the sociocultural aspects of HPV knowledge and vaccine acceptability among Caribbean

immigrant women, preliminary information can assist in developing future targeted programmatic interventions and culturally-tailored health education materials for this group.

Qualitative analysis produced similar findings with Latina women in New Mexico by Vanslyke et al. (2008), who suggested that the relatively high incidence of Hispanic women with cervical cancer stems from a variety of complex sociocultural issues including, economic, social and cultural factors. Researchers conducted community-based focus groups to assess their respondents' knowledge related to cervical cancer, HPV screening, and vaccination. Again, the authors state that there are limited studies that examine the public's knowledge about HPV and more specifically, the link to cervical cancer. Seven focus groups were administered to Hispanic women between the ages of 18 to 60.

Themes emerging from the focus groups included stigma about cervical cancer, overcoming embarrassment to receive the screening exam, the fear of screening test results, and the need for education on HPV screening, prevention and vaccines. Most women reported the need to discuss the importance of preventing sexually transmitted disease, especially HPV. The need to know how HPV is transmitted, the associated symptoms, prevention and testing procedures, was also expressed. The results of this study could potentially guide future research within minority populations in the United States who experience health disparities in cervical cancer outcomes. The authors suggest that future research should examine social, economic, and cultural factors along with public policies that influence knowledge about HPV testing and the acceptance of the vaccine. Identifying the range of barriers to cervical cancer prevention and HPV testing should lead, the authors argue, to increased efforts to reach women in the target population to access, accept and adhere to the primary and secondary prevention strategies for reducing disparities of cervical cancer.

In Appalachia, exploratory research conducted by Katz et al. (2009) recognized how values, beliefs, and attitudes about cervical cancer play a major part in the increase of cervical cancer incidence and mortality rates in the geographic area. Researchers assessed these factors along with psychosocial factors (e.g., fear and stress related to cancer diagnosis) and behavioral factors (e.g., risky sexual activity and tobacco use). Focus groups were conducted, and discussions yielded themes surrounding lack of knowledge about prevention and risk related to cervical cancer, affiliated cultural attitudes and beliefs. Additionally, focus groups consisted of parents, community leaders, and health care providers to gauge their respective viewpoints.

Feedback from the groups indicated the lack of knowledge about cervical cancer, HPV and the vaccine. Most importantly, participants mentioned that attitudes and beliefs about the vaccine are due to the Appalachian population being proud, religious, and conservative people. Abstinence is often taught in many churches, and they felt that if the HPV vaccine was made widely available then this would possibly lead to an increase in sexual promiscuity. Health care providers mentioned this as a belief often raised by parents of young girls. The lack of trust in the medical system, questions as to whether cervical cancer is simply inherited, and pharmaceutical companies using young women as “guinea pigs” were other themes that emerged during the focus groups. Overall, results of this study highlight the myriad attributes contributing toward the disparity of cervical cancer and HPV prevalence in the geographic region. This study supported the need for comprehensive tailored development of educational material and interventions about cervical cancer prevention and HPV risks throughout underserved populations.

Cates et al. (2009) examined the differences in knowledge and attitudes about HPV, cervical cancer and the HPV vaccine with rural Black and White women in North Carolina. The

primary purpose of the study was to inform future studies related to HPV vaccine programs in similar populations for those at high risk for cervical cancer. Structured interviews and questionnaires were administered while questions were asked pertaining to knowledge of HPV and HPV vaccines, the likelihood of getting HPV and cervical cancer, and perceptions regarding the likelihood of cervical cancer for the participants and their daughters. Results indicated that Black respondents were less knowledgeable and aware about HPV infection than White women. They also were less likely to perceive the severity of and the susceptibility to cervical cancer among themselves and their daughters.

The authors suggested misperceptions about the HPV vaccine are influenced by the mistrust of the biomedical health systems, providers, and providers' health messages. Both groups of women had limited exposure to information about the HPV vaccine. In general, this study strengthened findings of the limited research supporting the dire need to provide and promote HPV education in high-risk populations. Developing targeted messages to address the belief and cultural systems are a necessity for further prevention efforts.

Psychosocial factors associated with primary and secondary prevention of cervical cancer were reviewed by Fernández-Esquer et al. (2000). The authors assist in formulating new approaches to coordinating prevention strategies, including preventing HPV (e.g., contraceptive use) and increasing knowledge and cervical cancer screening rates. The article focuses on the following areas of psychosocial research: sexual behaviors associated with HPV infection; knowledge, attitudes and beliefs associated with Pap smear and HPV screening; and the role of the medical provider in facilitating prevention activities.

Furthermore, Fernández-Esquer (2004) explored factors that influence repeated Pap smear screening among recently immigrated Latinas working in *cantinas* (bars). Screening



practices were examined among women who may have high-risk behaviors due to their limited social and economic resources. The study also noted how trading sex is also an option this population might adopt to supplement limited income. Researchers attempted to associate screening practices of the *cantineras* based upon demographic characteristics, cancer screening barriers and facilitators, and psychosocial factors.

Cognitive influences including knowledge, perceived risk, beliefs, and attitudes were assessed along with social aspects including social networks and encouragement. Observations were conducted to choose *cantina* selection sites, and bar owners were contacted to request their participation in the study. Women who worked in local bars were approached by interviewers and asked to participate in face-to-face anonymous interviews at scheduled times. Gift cards to local supermarkets were provided as incentives for participants of the study. The rigorous ethnographic methods used through this study rendered the following findings: the most important determinants preventing Latina women from obtaining Pap smears include being an immigrant, being unemployed or inconsistent employment, having low levels of education or low health literacy, and being undocumented.

Although researchers proposed that demographic characteristics, cancer screening barriers and facilitators, and psychosocial factors influence repeated Pap smear screening, this proposal was tested with a hierarchical linear regression. Study results indicated that risk behaviors did not act as barrier and that there is a need to propose greater efforts to promote screening practices to newly immigrated women during health care clinic visits so that clinicians can encourage annual examinations.

As Luque and Castañeda et al. (2009) note, “Cervical cancer disparities may be identified by gaining an understanding of the barriers to Pap screening and in the future, access to the HPV

vaccine will further elucidate how health inequalities affect cervical cancer outcomes for Latinas” (2009:19). More importantly, this dissertation project recognizes the value of cultural perceptions, attitudes and knowledge level about HPV, and cervical cancer associated risks factors. Thus, I am advocating for the importance of understanding the intricacies of STIs and cervical cancer along with the best intervention strategies to reduce disparities. This dissertation enhances medical anthropological discourse by using narratives of experiences by Black immigrant women to explain the cultural domains of women’s health-seeking behaviors, cervical cancer and HPV prevention practices.

In “Beliefs Matter: Cultural Beliefs and the Use of Cervical Cancer-Screening Tests,” Chávez, et al. (2001) examine the role of socio-cultural beliefs regarding behavioral and risk factors and about the efficacy of Pap smear exams upon Latinas, Anglo women, and among physicians. The study reveals that structural factors such as medical insurance, age, marital status, education, and language acculturation all help explain belief systems about cervical cancer risks and Pap smears. Results of the study reveal that the Latina immigrants have embedded beliefs about cervical cancer that are situated within a larger context of social relationships and normative behavior. The authors highlight that the literature guiding their research emphasizes the impact of family and gender relations on general cultural beliefs, including beliefs about sexuality, patriarchy, and morality (please see Peña 1991; Hondagneu-Sotelo 1997; Martínez et al. 1997). They conclude that these factors have an impact on how Latinas think about the causes of HPV-associated cervical cancer and their risks of transmission and infection. For Caribbean women, domains of sexuality and gendered processes impact lived experiences across Caribbean cultures (MacCormack and Draper 1987; Kempadoo 2004) and

should be expected to influence the health-related beliefs and practices among Caribbean immigrant women in the United States.

As the literature illuminates, a multitude of factors influence disease transmission and prevention efforts. Anthropology brings a unique lens to enhance the understanding of HPV transmission and prevention in a holistic and cross-cultural and comparative context. In efforts to eliminate the global disparities related to HPV-associated cervical cancer, it is imperative to hear the “voices” of those unheard in order to promulgate the platform of advocacy and praxis among anthropologists’ in the cervical cancer disparity domain. Adding the position of this underrepresented population into anthropological and HPV literature can play an integral role in diffusing culturally and linguistically situating initiatives for women in the immigrant spatial domain of the Caribbean Diaspora in the United States.

## **Conclusion**

With current efforts to eliminate global disparities related to HPV-associated cervical cancer, it is imperative to hear the “voices” of those who are affected yet silenced in order to enhance the platform of advocacy and praxis in the HPV and cervical cancer domain. This research project provides additional knowledge and bridges the gap in anthropological literature on English-speaking Caribbean immigrant women by using narratives of experience to explain the cultural domains of women’s health-seeking behaviors, HPV transmission, and prevention practices.

This consideration of theoretical approaches in medical anthropology argued for a CMA approach that is at the same time interpretive. I showed the utility of this approach by providing a lengthy discussion of research that might be considered to arise from this paradigm. The implications of this procedure are that the application of medical anthropological knowledge to

research on HPV transmission and prevention has broader implications toward social, cultural, political, economic and historical context that can be identified and integrated into efforts toward reducing HPV-associated outcomes and prevention mechanisms among the Caribbean immigrant women high-risk population. In summary, this study bolsters medical anthropological discourse by using narrative of experiences by Black immigrant women to explain the cultural domains of women's health-seeking behaviors, cervical cancer and HPV prevention practices.

The dissertation research attempts to examine the following: What is the meaning of HPV and the influence of the meaning on the perceptions and beliefs within the population? What shapes the meanings (i.e., gender, sexuality, power, embodied experiences)? How is particular knowledge about the disease manifested? How is the knowledge valued in the community? The answers to these questions will assist in revealing an embodied set of meanings that is culturally and socially constructed, based upon the experiences of Black transnational women from the Caribbean about HPV and cervical cancer.

## **Chapter Four: Methodological Approaches**

### **What Kind of Methodology is Appropriate for this Study?**

The lack of social science research in the exploration of the lived experiences of Caribbean-born women regarding health-seeking behaviors and knowledge warrants further exploration. This chapter details the ethnographic methods used to examine the social and cultural domains of women's health-seeking behaviors regarding HPV risks and cervical cancer prevention. Data collection methods were conducted including observation, participant observation, key informant interviewing, and in-depth semi-structured interviewing. Ethnographic methods employed throughout this study elicit a deeper understanding of the sociocultural context that Black Caribbean immigrant women bring with them to the United States about HPV and cervical cancer.

The conceptual framework informing this exploratory study bridges across the domains of sexual health risk, knowledge, and disease prevention influencing Caribbean immigrant women's HPV and cervical cancer health outcomes throughout the Tampa Bay area. The research design was derived from similar studies with immigrant populations in the United States indicating links between HPV knowledge and risks, cervical cancer screening and perceptions, and sexual behaviors (Chávez et al. 1995; Hubbell et al. 1996; McMullin et al. 2005; Luque et al. 2009; Menard et al. 2010). One study by Menard (2008) examined sociocultural meanings of gynecological health, including assessment of health behaviors and culturally mediated feminine practice hygiene practices among Haitian women in Central Florida. Questions of *how* women assign meaning to disease, perceive risks, and engage in reproductive health behaviors

throughout a transnational context were investigated. Findings concluded that STIs were associated with women practicing particular culture-bound feminine hygiene practices, yet HPV infection and cervical cancer was not associated with these practices. Cultural beliefs were also connected with constructions of gynecological health that emphasized certain feminine hygiene practices and product usage. Additional anthropological works on the social and cultural constructs of HPV and cervical cancer highlight usage of ethnographic method application for elicitation of beliefs and meanings (Dyer 2008; Luque 2012).

The present study focuses on the cultural construction of *how* knowledge is attained about HPV, the perceptions of risks associated with HPV and cervical cancer, and the *meanings* of HPV and cervical cancer through the lens of the transnational context of English-speaking Caribbean-born women residing in the United States. The inquiry focus is guided by ethnographic interviews from study participants who were able to detail knowledge about HPV and cervical cancer experienced in their birth country compared to their lived experiences in the United States, and examine how this knowledge has influenced their health decision-making choices. As LeCompte and Schenshel (1999) highlight, ethnographic results produce snapshots of culture and the constituent social groups from specific views of group-affiliated members. One of ethnography's goals is to describe one or more cultural domains in terms that are understandable both to other social scientists and to the people who are being studied. Ethnographic portrayals of individuals' lives can correct misperceptions and misinterpretations of actions, motives or needs. By exploring the social cultural construction of knowledge, risk perceptions and health-seeking behaviors surrounding HPV and cervical cancer through the lens of a transnational context, this research can begin to reveal important social and cultural factors influencing the attitudes of English-speaking women from the Caribbean about HPV risks. As

such, this study contributes to developing culturally-tailored prevention messages to reduce the HPV disparity in specific immigrant populations in the United States.

A note on “Caribbean women” is needed here. It must be pointed out that there are problems when grouping all individuals from Caribbean nations as “one” or assuming people from all Caribbean territories nations easily identify with each other’s social, political, and economic agenda. The nations should not be deemed as “one community,” but as one Caribbean writer indicates, “if you were to describe Caribbean states as a family, you would have to call it a complex unit – and one in which there is much sibling rivalry” (McIntosh 2007:1). The postcolonial Caribbean has a “unique collection of people strung together by a common history and increasingly and perhaps irreversibly influenced by Americana” (2007:1). While indeed the Caribbean is marked by insularity and differing colonial legacies that bequeathed differing languages, religions, and social structures, at the same time there is “a common fun-loving thread which binds Caribbean cultural and social life;” and while there are unique “subtle differences that define each particular island such as lingo, food and self-image,” at the very core Caribbean people “are a singular people bound by a common and undeniable history” (2007:1).

The question of perspective is therefore raised. While, overall, the Caribbean is united by colonial legacies of slavery and indenture and monocrop cultivation, and, in more contemporary times, through tourist-based economies and significant out-migration, there are at a more local level felt differences between Caribbean peoples residing on different islands. Even among those from the “West Indies,” referring to the former British colonies, comprising common linguistic, social, and cultural traditions, there are significant distinctions that mitigate any image of a homogeneous “Caribbean woman.” Some of these differences emerge in the data. The overall point is that it is recognized that there are some general cultural commonalities and backgrounds

in Caribbean immigrant women living in the United States while, at the same time, it is also recognized that there is much diversity in terms of class, education, cultural background, local traditions, and so forth – especially, given the theme of this dissertation, the multiple modes of communicating health messages on risk, health behaviors and prevention of a sexually transmitted infection. That is, I want to problematize “Caribbean women” as a kind of caveat to the arguments made and the data provided in this dissertation.

This being said, it is vital to examine the complexities of immigrant life and the influences upon health-seeking behaviors that were learned in their birth country, which lead to decision-making processes toward healthcare services used in the United States. Immigrants can experience barriers in the U.S. healthcare system and the daily lived experiences of the women can explain the disparity of HPV in this population (Hirsch 2003). The literature highlights the need to assess knowledge, education and belief systems impacting HPV and cervical cancer disparities. The data presented from this study inform research in the development of tailored messaging and targeted interventions to reduce disease in this immigrant population.

### **Study Setting and Field Site**

Tampa Bay has a uniquely diverse Caribbean population. The metropolitan area occupies a large number of restaurants, cafes, night clubs, lounges and social venues that cater to islanders. Once you walk into a local eatery or gathering place, newspapers, fliers for local concerts, parties and events are posted on walls or distributed to individuals. The Caribbean population across metropolitan Tampa Bay is distinct and identified as a hub for all nations to be identified separately yet united as a unified Caribbean diaspora. The research field provided a natural landscape to explore those multidimensional spaces of Caribbean livelihood.



## **Study Participants and Data Collection Methods**

Data collection occurred from June, 2013 to October, 2013. There were three phases. Phase I entailed informal conversations with Caribbean-born community members for their reactions to my intended research project. Phase II entailed a focus group meeting. A total of five participants participated in the focus group. Phase III consisted of interviewing 28 Caribbean immigrant women in open-ended semi-structured interviews. Study participants were recruited based on inclusion criteria, including subject self-identification as born in the English-speaking Caribbean (e.g., Jamaica, Trinidad and Tobago, Bahamas, Barbados, Belize, Guyana, and Dominica, etc.), between ages 18 to 60, self-identification as a Black immigrant, and residence in Hillsborough and Pinellas counties.

The focus group occurred for just over an hour. Individual interviews lasted over an hour on average. Each person was interviewed once; no focus group participants were administered the semi-structured interviews. Quantitative demographic data from self-administered survey questionnaires were collected at the end of the focus group and at the end of each interview. The self-administered survey instrument asked demographic characteristics including age, place of birth, marriage status, employment status, and household income. Responses about health insurance and sexual partner encounters were collected. Survey questions were derived from relevant social science studies (e.g., Chávez et al. 1995; McMullin et al. 1996; Daley et al. 2008; Chávez et al. 2001; Luque et al. 2010, 2011).

The questionnaire instruments and inclusion criteria were developed using existing validated instruments from relevant literature exploring immigrants' HPV and cervical cancer risks (e.g., Chávez et al. 1995, 2001; McMullin et al. 2005; Scarinci et al. 2007; Luque et al. 2009) and HPV knowledge and health-care decision making in African American and other

minority populations (e.g., Fazekas 2008; Cates 2009; Consedine et al. 2007). Semi-structured interview questions were developed from the results of the focus group. Focus groups are an excellent resource for establishing contexts and obtaining meanings and perceptions of health-related concepts that are not able to be captured through quantitative instruments (Kitzinger 1994). Focus groups are often used to understand why people feel the way they do about a topic or the steps they go through in making decisions (Bernard 2002). One of the primary advantages of focus groups is that they provide an opportunity to observe a large amount of interactions on a specific topic in a limited amount of time based upon the researchers' objectives (Morgan 1996). Focus group data illuminated general attitudes, knowledge and risk perceptions of HPV, and sexual practices.

By conducting a focus group as a preliminary data collection method to solidify interview questions, as Principal Investigator (PI) I captured a variety of interactions about the meanings and perceptions of HPV and cervical cancer, garnered insight on behavior patterns, and engaged in open discussion about sexuality and gender-related issues from immigrant women. However, a disadvantage of focus groups for obtaining insight on a topic is that they are organized in unnatural social settings that are limited to only verbal behavior, limited to interaction of a small group, and are controlled and managed by the researcher(s) only (Morgan 1996).

Questions for the focus groups ranged from knowledge, beliefs and risks about HPV and cervical cancer, to questions on behavior and lifestyle including health care visits, Pap smear screenings and clinician experiences (please see Appendix E). At the start of the focus group, participants were provided a verbal explanation of what the research study was about, an overview of question topics, and information about the survey instruments I used to collect further information. All participants were told that they could refuse to participate or leave the

focus group or end the interview at any time. At the beginning of the group or interview, participants received an information sheet about the purpose of the study and whom to contact for more information. A CDC HPV prevention fact sheet was provided at the end of the focus group and each qualitative interview session. The focus group was conducted at the University of South Florida (USF) library in one of the study rooms. Interviews were administered in private and public locations, including restaurants, libraries, offices, and in homes.

Exploratory or in-depth interviews along with unstructured observations are some of the first steps in initiating the data selection and reduction process for research (Schensul and LeCompte 1999). In-depth, semi-structured individual interview questions ranged from general cancer concepts and meanings, beliefs and attitudes about cancer, and HPV and cervical cancer. Risk perceptions and screening tests experiences, healthcare provision and transnational perspectives, along with migration aspects in healthcare-decision making, were also addressed. Questions were derived from validated instruments in social science research studies (e.g., Chávez et al. 1997; McMullin et al. 1996; Daley et al. 2008; Chávez et al. 2001; Luque et al. 2010, 2011; Menard 2008). All focus group discussions and interviews were digitally recorded. Group discussions and interviews were conducted in English, and the qualitative demographic survey was self-administered and written in English. Gift cards worth \$25 each from Walmart were provided to each study participant once the data collection was complete in appreciation for the women's time.

I collected sensitive narratives from women specific to the knowledge, beliefs, and experiences of participants by administering an in-depth, semi-structure interviewing technique, elucidating the cultural context for a range of perceptions and attitudes relating to HPV, in addition to cervical cancer risks and disease concepts. Both qualitative and quantitative data

collection strategies were implemented. This triangulated research approach reinforces the use of qualitative and quantitative methods. The combination of data collection techniques bolsters traditional strengths of contextual and cultural knowledge with enumeration and measurement. I incorporated the triangulation of my data collection methods with the conduct of focus groups, in-depth interviews, and survey instruments to ensure that key informant and population-based results were reliable and accurate.

Purposive or “snowball” sampling is used in exploratory or field research and utilizes a wide range of methods to locate specialized populations. This is a nonrandom sampling method often used to locate hard-to-reach populations for in-depth investigation (Neuman 2006). Snowball sampling is a multistage technique for selecting cases or individuals. The process begins with a few cases and then expands via interrelationships from those cases and direct or indirect links (Neuman 2006). Snowball sampling occurred for this study due to the scattered Caribbean populations in the Tampa Bay metropolitan area.

I incorporated participant-observation into the study by recording situations and meanings of events at cultural and heritage activities. I conducted in-depth interviews and a focus group to assess attitudes, available knowledge, culturally specific perceptions, and behavioral practices of women in the specified community. Key informants were contacted to obtain anecdotal insight into the community that would otherwise not be incorporated into the formalized research process. The informants advised me on group venues to recruit interviewees and focus group members, which included places, events and locations to observe individuals and target and recruit additional study participants. Key-informant interviewing allows the researcher to obtain an authentic insider or “expert” view from formal or informal leaders of a particular community (University of Wisconsin 2015). These community experts can offer

valuable knowledge about the issues, beliefs and motivation of cultural members and attain candid sensitive information that may not be revealed in focus group or individual interviews (Katz 2007; UCLA Center for Health Policy Research 2012).

Observation methods are useful in research by allowing researchers to look at nonverbal communication and expression of feelings, to examine individual interactions, explore who communicates with whom, and to see the amount of time spent on various activities by individuals (Schmuck 1997). As a Caribbean food aficionado, I found the most valuable and rewarding observations and recruitment opportunities at local food eateries. Beauty hair salons were excellent sources of participating in beauty salon gossip with some of the Caribbean women who frequented the salon where I normally obtain hair services. The restaurants and hair salons served as recruitment locations for study participants. The USF Caribbean Cultural Exchange, USF Medical School Student Caribbean Society were additional resources for recruitment.

Participant-observation is central to identifying and building relationships with the research community. It endorses the presence of the researcher in the community and provides the researcher with the cultural experiences that can be discussed with the key informants or research participants in the study (Schensul et al. 1999). To gain further social insight into the study population, I attended Caribbean heritage festivals in Tampa and St. Petersburg. I also attended local health educational workshops and community-sponsored events that would allow me to see if educational materials related to HPV and cervical cancer were distributed and to detail how the materials were disseminated and received by women.

As Schensul et al. (1999) note, participant-observation assists in identifying and forming relationships with informants along with unveiling what members deem to be important

regarding leadership, politics, social interaction, and taboos. By assisting with the student organizations by volunteering with them (e.g., Caribbean health fairs), I was able to become known to the Caribbean community, thus easing facilitation of my goals as a researcher. Bernard (1994) states that this method facilitates the researcher in collecting different types of data and establishes the researcher in the community over a period of time. Therefore, it enabled me to become an involved member of the study community and to discuss key sensitive topics that I would not normally be able to access and accomplish. Participant-observation offered insight on the types of questions to be addressed with study participants during the focus group and individual interviews. This research design strengthened my study and provided validity by incorporating observation methods, interviewing, and survey administration (Dewalt et al. 2002).

### **Data Analysis**

The data generated were recorded in participant-observation notes, focus group and interview transcripts, and post-interview notes. What was attempted was a grounded theory approach (Strauss and Corbin 1998; Guest and McLellan 2003). Grounded theory is considered an interpretive approach that attempts to explore meaning and understanding and provides guidance on “how social structures and processes influence how things are accomplished through a given set of social interactions” (Starks et al. 2007:1374). This allows for examining an issue’s causes or elements within context, and any related conditions in order to understand the patterns and associated relationships among the elements (Strauss and Corbin 1998). Assuming that meaning is negotiated and understood through interaction and along with others in social processes and that social processes have structures, implied or explicit codes of conduct, and procedures that circumscribe how interactions unfold and shape the meaning that comes from

them (Blumer 1986; Dey 1999; Jeon 2004; Starks et al. 2007), this approach can guide interpretation of social realities through behavioral observation and speech practices.

All notes and transcripts were coded and arranged in major themes of analysis (Bernard 2002). Answers to the research questions emerging from the critical interpretive and associated perspectives were analyzed using thematic analysis. According to Boyatzis (1998), thematic analysis is a process of encoding qualitative information creating a complex model of themes, indicators and codes that are related (1998:vii). Often used to gain a deeper understanding or insight into a topic, this approach can extract words or similar phrases from texts or narrative data that can provide labels for specific sections of data. This qualitative analysis method assists with “identifying, analyzing and reporting patterns or themes within data...describes your data set in (rich) detail...and interprets various aspects of the research topic” (Braun and Clarke 2006:79). Thematic analysis allows the researcher to develop codes from linked data. It is specifically used for the discovery and ordering of ideas or themes for sorting or clarification of textual data.

The resulting abstract knowledge assisted in developing enhanced culturally-appropriate messages on disease transmissions and risk prevention in populations of Caribbean-born women residing in Florida. Eventually, from an applied approach, I obtained narrative-based perspectives to inform effective ways to make knowledge relevant and address conflicting meanings about disease, in this case with HPV and cervical cancer.

The data were analyzed after the focus group and each individual interview to ensure that the interviews were 1) reaching a diverse population of healthy women study participants (in terms of geography and nationality), 2) received well by participants, and 3) addressing any

critiques by participants in order to prepare for the next session. Finally, I continuously monitored the data.

### **Ethical Considerations and Positionality**

As an aspiring medical anthropologist with research interests in the Caribbean Diaspora, it is imperative to have insight and experience with the target population. My prior research experience with the Caribbean population offered insight into the study community. This came from my work with the Ministry of Health and Environment of Jamaica in 2000 where I conducted a qualitative assessment of occupational health hazards in a free trade zone garment processing factory in Montego Bay. I conducted focus groups with factory workers and in-depth interviews with factory managers. This research experience allowed me to participate as an observer and researcher. I was able to garner information about respiratory health issues related to fabric processing and related co-morbidities. I was also able to see gender inequalities in the labor work force (e.g., women stitchers compared to men warehousing), and how women in factory work are more susceptible to a myriad of hazards comparable to men. Most importantly, I was able to see how she was viewed as an outsider no matter my complexion, language, or similar features and a seemingly pleasant personality. I was viewed as an American, a student, coming to collect *their* information and then *leave*. I was not one of *them*, a worker or a friend, or even Jamaican!

Locally, in Tampa, the established close connections with leaders, prior research experience and key informants of various Caribbean Diaspora communities facilitated an ease in validating myself among the Caribbean community. From 2007 to 2009, I conducted research on a Medical Migration-Brain Drain project where I was responsible to facilitating Tampa-based outreach to West Indian immigrant medical professionals. I continued to nurture those



established relationships with contacts beyond the end of the project. I am a young, Black female who has previously worked within the community organizations; so reflexivity was present throughout the project. I established close connections with leaders and informants of the groups that “placed” me into the target audience fairly easy without emphasizing my age, ethnicity, graduate or socioeconomic status. I have been trained in implementing qualitative and quantitative techniques and equipped with experience in administering qualitative data collection methods and comfortable in establishing a good rapport with the target community.

I am aware that the study population is a vulnerable group due to their immigrant identity and related conditions contributing to the loss of autonomy, power, and authority. Vulnerability is defined in some cultures based on socioeconomic status, race, and ethnic backgrounds (el-Sadr and Capps 1992) and even being a woman in some cases (Woodsong et al. 2006). Persons who are legally identified as incompetent, poor, have limited education, and the elderly are considered vulnerable populations. Communities can also be considered vulnerable to issues of coercion, injustice, or social harm from lack of confidentiality (Whiteford et al. 2008).

As mentioned previously, immigrant women often are limited in their access to health-related needs due to lack of health care coverage, low education, labor opportunities, income level and employment options (Grieco 2003). Although studies have found immigrants to self-report a healthier status and lower rates of disease among those who are not foreign born (Frisbie et al. 2001; Lucus et al. 2003), there are evident barriers to health care access and utilization of services by those who are foreign-born (Carrasquillo et al. 2000; Hatzenbuehler et al. 2014). Ethical dilemmas such as deception and a breach of confidentiality, especially when working with immigrant populations, can occur. Study participants involved with this research project are Black immigrant women who are considered vulnerable. Recognizing that this special population

might be leery of the PI, an “outsider,” coming to ask questions ranging from sexual activity to demographic indicators, I was forthcoming when disclosing the nature of my research. A trusting environment was cultivated and a sincere delivery of the research purpose was carefully crafted when explaining the details for the study to participants. No women in my study seemed hesitant about answering questions pertaining to their sexuality and sexually-related behaviors, and none indicated that they would not like to continue participating in the study. Participants were able to withdraw from the study at any time. I asked questions related to life experiences in participants’ country of origin, their marriage and relationships status, questions pertaining to their sexuality and sexual activity, and their income and educational levels. I remained conscious of the sensitive subject matter being reported. The USF Institutional Review Board (IRB) provided oversight to my ability to secure confidential data and maintain the anonymity of the study participants.

Consent is one of the most important elements of implementing ethical research. It is a complex set of actions that is powerful for the researcher and the research participant. It is embedded in the guidelines for respect for people’s ethical considerations. The consent information sheet (please see Appendix B) identified the researcher and research institution, and included contact information in the event of future questions or concerns related to the project. The form summarized all detailed aspects of the research and allowed for potential participants to agree to or refuse the conditions of the study project (Whiteford et al. 2008).

Numerous ethical guidelines were considered while conducting the research study. The following guidelines from the National Committee for Ethics in Social Science Research in Health (Whiteford et al. 2008) were adhered throughout the research study: The anonymity of individuals involved in the study was assured; confidentiality of all research participants’

identities and responses to focus groups questions and surveys was kept; and the privacy of all data collected by the researcher has not been breached.

Individuals and populations deemed vulnerable must be given special attention and additional protections beyond the typical standards of informed consent, voluntary participation, and equal treatment. Whiteford and colleagues (2008) state “power and authority differentials and the lack of loss of autonomy are all conditions that produce vulnerability in individuals and groups” (2008:89). I had to abandon preconceptions on what type of people I might encounter, what stories I thought I might hear, and how I should interpret detailed accounts from all project collaborators. As an applied researcher, it was essential to build strong rapport, reciprocity, and empathy for ethnographic inquiry. Anthropologists have the responsibility of making vulnerable groups appear and not be erased, thus being “ethnographically visible” (Whiteford et al. 2008).

Researchers have suggested that same-ethnicity data collectors are important to a study and the similarities in background enhances participants’ trust of the research and provides accurate information (Bloom and Padilla 1979). Having the same ethnicity or background of research participants enhanced rapport, willingness to disclose, and the validity and reliability of the data (Marin and Marin 1991). This was particularly important to the methodological process the research. However, there are some studies that indicate there is an interviewer effect on these type of data provided by participants who are influenced by same-ethnicity researchers (Schaffer 1980; Cotter 1982; Anderson et al. 1988).

As a young, Black female who previously worked with one of the communities, I established close connections with leaders and informants of the cultural group that allowed me to maneuver into the captured audience fairly easily without emphasizing my age, ethnicity, graduate or socioeconomic status. I have received qualitative and quantitative training and am

equipped with much experience in administering qualitative data collection methods that felt very comfortable in establishing an adequate rapport with the community of women interviewed.

I obtained a waiver of documented consent from the IRB. This meant that the IRB determined that subjects through their participation in the study were at minimal risk of harm. The waiver included the demographic questionnaire survey that asked for anonymous information. Believing that this process would have been an additional burden to the study participants and unnecessary to collect each individual name, I decided to collect information in this manner. Neither did I collect identifying information or participants' names on the informational consent forms. Copies of the informational consent form were distributed to each participant and read in their entirety with each participant at every interview and during the focus group introduction. Verbal consent was received from each study participant. Data were encrypted and entered into an electronic database.

I ensured the privacy and integrity of the collected data by keeping the completed questionnaires kept in a locked cabinet drawer in her office. Pseudonyms were used in the transcripts for privacy of the study participants. I monitored the security of the data daily throughout the research project. Data were continuously monitored and kept confidential during data collection, analysis, and storage. The digital recordings were kept on the digital recorder and downloaded into a private Dropbox account on my personal computer. The personal computer was locked securely with a password.

## **Conclusion**

This chapter details the ethnographic methods used in the research design, setting, methodological approaches and ethical implications in the study. By employing grounded theory and thematic analyses I was able to begin the research with limited expectations and let the

participants tell their experiences with no biased expectations or guided questioning toward a particular answer. As social actors, the ladies detailed their childhood memories and contemporary journeys from home country to America with openness and nonjudgment. Patterns of behaviors and categorical trends were identified and guided through thematic data analyses. My outlook of being *the other* enabled inherent biases to be regulated while ethical considerations of being captured within the unheard or unseen *other* immigrant status along with being vulnerable as a Black woman in the United States further validates the use of the applied methods for the research study.

I feel one of the major roles of the applied anthropologist is to work as collaborative partners with community and other stakeholders to obtain knowledge, educate and disseminate data on shared topics of interest. In this case, all the actors must work in a cyclical process to emphasize health education, evaluate stakeholders' actions, and motivate change in health-seeking behaviors. Waldram (1998) asserts that "we must strive always to empower those with whom we work with" (1998:243). In turn, this notion transfers the positioning of power and "some control over the research to the researched population" (1998:243). It is imperative for those who were traditionally silenced in the research process to speak through their actions.

## **Chapter Five: The Blurred Lines of HPV and Cervical Cancer Knowledge**

This chapter details the results from the self-administered demographic surveys for focus group participants and the semi-structured in-depth interviews. The demographic survey findings are presented to show how the women in the study responded to questions ranging from their age, race or ethnicity, education level, and sexual practices to their health status. The focus group data present the general synopsis of what young women know about HPV, how they acquired information and knowledge about HPV and cervical cancer, and ultimately how their personal behaviors have been influenced by what they know about HPV and cervical cancer. The semi-structured interviews display the range of perceptions about health knowledge obtained in their birth country, preventive screening practices, and knowledge and attitudes about HPV, cancer and cervical cancer from a Caribbean immigrant woman's perspective. Thematic analysis from the individual interview findings present the emergent themes from the personal and historical perspectives of the participants' knowledge and perceptions of HPV, cancer, and, more specifically, cervical cancer.

I argue how the voices of U.S.-residing English-speaking Caribbean immigrant women are missing from the landscape of immigrant health and health disparities research. MacClancy states "fieldwork allows anthropologists to take little for granted...presumes very little and has to be prepared for even her most cherished preconception to be overturned" (MacClancy 2002:6). MacClancy also states how anthropology "helps to empower the alienated and give voice to the otherwise unvoiced" (2002:13). While reading MacClancy's perspectives on the strengths of anthropological fieldwork and the nature of giving the marginalized a "voice," I have to be

attuned to an emic perspective when preparing to collect data and throughout the data collection phase with the women in the community. The women shared intimate life histories about childhood memories, migration experiences, familial struggles and conflict, individual triumphs, and complex sexual histories.

Nagengast states women are designated, globally, as “repositories of cultural meanings that imply confinement to the private, domestic sphere and second-class status” (2004:116). This public and private sphere is considered highly contentious and problematic when asserting rights of women as a community or individualized voice. Nagengast continues to state that this troubling vision “...contributes to women’s secondary class status in which their lives are debated and decided” (2004:116); therefore, denial of full access to universal freedom. The study participants willfully bared their vulnerabilities and shared meanings with me for the purposes of this study.

### **Demographic and Study Participant Characteristics**

Ethnographic in-depth interviews and the focus group assessed attitudes, available knowledge, culturally specific perceptions, and behavioral practices of the sample group of Caribbean-born women in Tampa Bay. These data collection techniques collected sensitive narratives from the study participants specific to the knowledge, beliefs and experiences of participants, elucidating the cultural context of perceptions and attitudes relating to HPV knowledge, risks and disease concepts. Additionally, questionnaire surveys were administered to determine how women’s attitudes, their knowledge and perceptions of HPV, sexual risk practices and demographic information are correlated.

### **Phase I: Key Informants**

The study was conducted in three phases (please see Table 1). The first phase was obtaining insight on the local Tampa Bay Caribbean population from informal conversations

with key community informants. The key community informants were business owners, civic organization leaders, and health stakeholders in the Caribbean immigrant community. These informants provided insight on how interested the community would be in HPV and cervical cancer. They provided venues, events and occurrences throughout the community where potential study participants could be recruited.

Recruitment flyers and my contact information were provided to the informants to give to other community stakeholders who could assist with alerting the community of my presence, disseminating study information, and recruiting the target population. Recruitment flyers were strategically placed at Jamaican and Trinidadian restaurants near college campuses. Flyers were posted in hair salons that were known to have patronage from Caribbean women.

Announcements were also made at Caribbean-based organizations meetings along with distribution of recruitment materials by key informants. Dissemination of recruitment flyers also occurred via e-mail to Caribbean civic organizations' members through electronic list-servs and distribution lists.

Throughout the study, social media analysis was conducted along with listening to Caribbean radio station segments and reviewing Caribbean media outlets (local/out-of-state/international, online, hard copies). Reviews were conducted to garner additional data on the knowledge and behaviors of the study population.



## **Table 1. Phases of Study - Key Informants, Focus Group, In-Depth Interviews**

### *Phase I. Key Informants*

n=6

Women 5

Men 1

Age: 21-71

(Hair salon owner, USF Caribbean Association President, Tampa Bay Barbados Association President, USF Medical School Caribbean Association President, Jamaican restaurant owners)

### *Phase II. Focus Group*

n=5

All Young Women

Age: 21-22

### *Phase III. In-Depth Interviews*

n=28

All Women

Age: 18-55

## **Phase II: Focus Group**

Phase II of the study involved exploring the beliefs and perceptions about HPV and risks associated with cervical cancer by utilizing a focus group methodology. This method of inquiry not only assisted in editing more questions, but also obtained insight on further formulation and editing of the in-depth interview questions conducted in Phase III of the study.

The focus group discussion with five women was conducted at the USF-Tampa campus in one of the main library study group rooms. Four other women committed to attending the session, but did not show up or cancelled their attendance on the day of the scheduled focus group. I conducted the group in the summer of 2013.

The focus group assisted in providing a foundation of knowledge about HPV, cancer and cervical cancer for the study population. The data obtained from the group also guided the development of the in-depth interview questions. Five focus group participants provided their perspectives about their knowledge about HPV, and cervical cancer (please see Table 2). Their attitudes about health care provision in the United States and the HPV vaccine were also discussed (please see Table 3). The group comprised of single, young women between the ages of 21 ( $n = 2$ , 40 percent) and 22 ( $n = 3$ , 60 percent). The women were either students ( $n = 2$ , 40 percent) or recent graduates ( $n = 3$ , 60 percent). Three group members were employed ( $n = 3$ , 60 percent), and one employed group member indicated her job as a Home Health Aide. Only one employed group member indicated her salary was less than \$20,000 a year. All young women spoke English as their primary language, and most self-identified themselves as Black ( $n = 4$ , 80 percent) or Caribbean American ( $n = 1$ , 20 percent). Regarding country of birth, there were three Jamaicans and one Bahamian. One did not provide a place of birth. The majority of the group lived in the United States less than five years ( $n = 4$ , 80 percent). Health insurance was identified by three members ( $n = 3$ , 60 percent), yet three ( $n = 3$ , 60 percent) of the group participants did not have a specified health provider. Regarding sexual risk practices, while the majority of women were under 20 years old for their first sexual encounter ( $n = 4$ , 80 percent), at least four of the women had less than four sexual partners in their lifetime ( $n = 4$ , 80 percent).

The five young women were asked questions about what they knew about HPV and cervical cancer, including prevention efforts, treatment options and associated causes of the diseases. Responses from the focus group session are summarized after each question below. Identified themes emerging from the group pertaining to their knowledge, risks and beliefs are also described below.

**Table 2. Demographic Characteristics of Participants - Focus Group (n=5)**

		<u>N=5</u>	<u>%</u>
<b>Age</b>	<i>21</i>	2	40%
	<i>22</i>	3	60%
<b>Education</b>	<i>Some college</i>	2	40%
	<i>College graduate</i>	3	60%
<b>Self-Identified Race/Ethnicity</b>	<i>Black</i>	4	80%
	<i>Caribbean American</i>	1	20%
<b>Birth Place</b>	<i>Jamaica</i>	3	60%
	<i>Bahamas</i>	1	20%
	<i>No Answer</i>	1	20%
<b>Years in U.S.</b> <i>Mean= 5.75</i>	<i>3</i>	2	40%
	<i>4</i>	1	20%
	<i>5</i>	1	20%
	<i>11</i>	1	20%
<b>Living arrangements /Marital status</b>	<i>Single</i>	5	100%
<b>Household income</b>	<i>&lt;20K</i>	1	20%
	<i>No Answer</i>	1	20%
	<i>N/A</i>	3	60%
<b>Primary language</b>	<i>English</i>	5	100%
<b>Employed</b>	<i>Yes</i>	2	40%
	<i>No</i>	3	60%
<b>Occupation</b>	<i>Student</i>	2	40%
	<i>Home Health Aide</i>	1	20%

*Question: Have you ever heard of HPV? Have you ever heard of cervical cancer?*

When asked this question, all of the women stated that they heard of HPV and knew that the acronym stood for Human Papilloma Virus. However, some women stated that the HPV term was only heard of a few years ago via the Gardasil HPV vaccine television advertisement

commercial. One participant even recalled the commercial tag being “One Less” woman to have HPV. Another participant stated HPV causes cervical cancer and another group member stated she knew very little. When asked if they knew about cervical cancer, all of the women had heard of the cancer.

*Question: When did you first hear about it?*

Participants initially heard of HPV in their home country and in the United States when they came to attend college. A few young women initially heard of the STI at their annual well-women’s gynecological visit at the university. Some of the women first heard of the phrase “HPV” when they began attending USF. This was the first time hearing of the infection as a freshman at the university, and often their first time in the United States. Some of them may have visited the United States during their lifetime, but never resided in a U.S. city.

*Question: What is HPV? What is cervical cancer?*

When asked about what the women knew about HPV, the range of answers indicated that some knew very little and a few knew the specific DNA strains that cause cervical cancer and genital warts. A group member stated that there was a certain age to take the test for HPV. One woman stated she knew very little.

*Question: Do you think HPV can be prevented? Do you think cervical cancer can be prevented?*

A participant did mention that there was no cure for HPV, and another young lady noted that you had to be a certain age for the test. The group members knew the virus can be prevented, but were unclear regarding how it is prevented. The HPV vaccine was a mode of prevention stated by the group members. Some of the respondents were strongly advised to take the vaccine. At least three of the members had completed the 3-shot vaccine regimen; one member had only two shots and needed to schedule the third shot; and the other member stated that she decided not

to take the vaccine due to her lack of information on the vaccine. However, some were told that the risk of getting HPV and risk for getting cervical cancer can be reduced.

*Question: Do you think HPV is sexually transmitted? Do you think HPV is common? Do you think HPV goes away without any treatment?*

One member did not know it was a sexually transmitted infection, noting an individual cannot get rid of the HPV. A few women were unsure on how common the infection was transmitted, and the entire group agreed that they were not 100 percent sure. One participant indicated her belief that there was no cure for HPV.

*Question: What causes HPV? What are some causes for cervical cancer? Do you think HPV causes cervical cancer?*

Group members mentioned potential causes of HPV being another virus and yeast infections. Most of the group was uncertain about what caused HPV. One participant said she knew at one point but forgot what causes the infection. One group member stated that HPV is stressed instead of genital warts, and the specific strains of HPV are emphasized for public awareness.

Several key themes emerged from the focus group session in Phase II that informed my approach to the semi-structured interviews. The focus group showed a considerable lack of knowledge about the prevention and transmission of STIs, a lack of knowledge about the link between HPV and cervical cancer, uncertainty about the scope of HPV as an STI, and therefore my informants demonstrated skepticism and fear. They also indicated that cervical cancer is a taboo subject in Caribbean societies.

Most of the women heard of HPV, but the infection was not fully understood in the context of knowing what actually causes HPV. There was clearly a need to understand the infection in terms of the epidemiological scope including “what causes the infection,” “how is it transmitted,” “what is the etiology of the disease,” and “who transmits the infection” to put it in

the terms the focus group respondents used. Several responses to the questions exemplified the need to obtain more information about the STI: “I heard of people being diagnosed with HPV and going back to the doctor after the diagnoses and found out it was gone.” The need for prevention messages to women were expressed by statements on self-responsibility and vaccine protection: “I saw it just like the polio vaccine. If you can prevent it, get it.”

Most of the women were not clear on the connection between HPV and cervical cancer. Thoughts were expressed about the need for increasing HPV educational messaging being similar to HIV/AIDS awareness efforts. Confusion about the scope of the infection indicates the need for Caribbean women to understand the entire spectrum of the disease. As one focus group participant asked: “I know you cannot cure a virus...but I have questions like ‘Why does it go away?’”

The participants agreed that when they were advised by clinical practitioners from the USF Health Services Center about the vaccine, no advisement, education, or explanation on the vaccine (side effects, additional benefits, risks) was provided. The students felt that the practitioners pushed the vaccine or used “scare tactics” to force them to take the vaccine. Participants did mention that the health practitioners may have noted that the vaccine reduces the risk of getting HPV and that they may have mentioned that HPV causes cervical cancer. But that they were not sure enforces the point that the education of these focus group participants, despite their status as students and access to student health care services, was woefully incomplete.

The group members also mentioned that the vaccine was made very affordable (via financial aid assistance) by utilizing their student status privilege. Additional questions from the participants indicated that they needed more educational information surrounding HPV, such as associated HPV risks and co-morbidities, gender differences and vaccine acceptability. For

example, two questions asked were: “Is it true that men carry HPV?” and “Is there a relation between prostate cancer?”

Inquiry questions throughout the discussion and at the end of the group session emphasized the skewed perceptions and beliefs about the HPV vaccine, transmission beliefs and fear-based behaviors. As one said, “It’s scary...even if you use condoms you still can get it. Weird! Not only via fluids, skin contact, pubic areas...” Another one said “HPV makes me think of breast cancer.”

The domain of fear surrounding the vaccine was expressed by statements indicating rumored or hearsay detrimental side effects such as fainting or other actions. One respondent said that they heard that “The vaccine causes you to walk backwards.”

Some of the focus group participants had been exposed to coursework on HPV in their Public Health courses, so their knowledge was evident in the responses provided during the session. Although, even with the collegiate-level HPV education, the members still seemed to lack detailed knowledge to discredit skepticism about vaccine and the causal relationship between HPV and cervical cancer.

Most of the participants agreed that cervical cancer was not heard of or rarely talked about in their home Caribbean nation. This could be due to the diseases link to sexual behavior or promiscuity in the context of disease transmission. As one said, “I feel it’s [cervical cancer] a taboo topic in the Caribbean...not talked about at all.” Another participant stated that she heard of cervical cancer as a teen in her home “...from my mother stressing about routine Pap smears I remember her mentioning it [cervical cancer]. But it wasn’t discussed at school or linked to sex.” One group member felt that her home country of Jamaica is not very open about discussing the disease: “There are not any explanations about it . I went to an all-girls school... and we never

talked about it.” After conducting the focus group, the interview questions were re-structured. At first, I had determined to provide the causes of HPV and cervical cancer to the interviewees. Based on the focus group results, I decided against this approach. The decision to have the listing of the causes of HPV and cervical cancer given by the participants and not by myself was influenced by the group results. Also, I abandoned the question regarding the commonality of HPV and cervical cancer based on focus group discussion due to the similar answers garnered from other questions.

**Table 3. Healthy Lifestyle and Behavior Characteristics of Participants - Focus Group (n=5)**

		<u>n=5</u>	<u>%</u>
<b>Health insurance</b>	<i>Yes</i>	2	40%
	<i>No</i>	3	60%
<b>Health provider</b>	<i>Yes</i>	3	60%
	<i>No</i>	1	20%
	<i>No Answer</i>	1	20%
<b>Age of first sexual encounter</b> <i>Mean=18.6</i>	<i>16</i>	3	60%
	<i>19</i>	1	20%
	<i>21</i>	1	20%
<b># Lifetime sex partners</b> <i>Mean=4.3</i>	1	2	40%
	2	1	20%
	4	1	20%
	10	1	20%

### **Phase III: In-Depth Interviews**

Twenty-eight semi-structured, in-depth interviews were conducted with women between the ages of 18 to 55 (please see Table 4). Interviewees had some college or higher education level at 89 percent ( $n = 25$ ), having attended some college or beyond. Therefore, the educational attainment of my sample was high and I believe not entirely representative of Afro-Caribbean



immigrant women. All participants spoke English as their primary language. The majority of those interviewed self-identified as “Black” (46 percent of my respondents;  $n = 13$ ) or some affiliated Black Caribbean nationality ( $n = 13$ ) (e.g., “African/West Indian,” “Afro Caribbean-Guyanese,” “Black Jamaican”). Participants emigrated from countries including Dominica, to the Bahamas, Belize, Grenada, to Jamaica and Antigua. The interviewees average years of living in the United States was 17.4 with 65 percent ( $n = 18$ ) living more than 10 years in the United States. At least 64 percent ( $n = 18$ ) were not married, 25 percent were married ( $n = 7$ ) and 11 percent ( $n = 3$ ) were divorced or widowed. Over 70 percent ( $n = 20$ ) of the women were employed, and approximately 46 percent ( $n = 13$ ) were making over \$40,000 per year in salary.

Occupations included Instructional Web Designer, Sales Associate, Associate Professor, Speech Pathologist, and Health Care Administrator. Students and Graduate Research Assistants ( $n = 10$ ) were indicated for the student population. The women reported that they had health insurance at 86 percent ( $n = 24$ ), and 68 percent ( $n = 19$ ) stated they had a health care provider. Regarding their sexual risk practices, the first sexual encounter occurred between ages 14 to 30 at 67 percent ( $n = 19$ ). While 56 percent ( $n = 16$ ) of the interviewees had less than four sexual partners in their lifetime, 32 percent ( $n = 9$ ) of the women had more than five sexual partners. Three participants had never had any sexual encounters during their lifespan.

**Table 4. Characteristics of Participants - In-Depth Interviews (n=28)**

	<u>n=28</u>	<u>%</u>
<b>Age</b>		
<i>18-25</i>	<i>11</i>	<i>39%</i>
<i>26-35</i>	<i>4</i>	<i>14%</i>
<i>36-45</i>	<i>5</i>	<i>18%</i>
<i>46+</i>	<i>5</i>	<i>18%</i>
<i>No Answer</i>	<i>3</i>	<i>11%</i>
<b>Education</b>		
<i>High school grad</i>	<i>1</i>	<i>3%</i>
<i>Some college</i>	<i>8</i>	<i>29%</i>
<i>College graduate</i>	<i>12</i>	<i>43%</i>
<i>Beyond graduate</i>	<i>7</i>	<i>25%</i>
<b>Self-Identified Race/Ethnicity</b>		
<i>Black</i>	<i>13</i>	<i>46%</i>
<i>Saint Lucian</i>	<i>1</i>	<i>3.6%</i>
<i>Multiracial</i>	<i>1</i>	<i>3.6%</i>
<i>Black/West Indian</i>	<i>2</i>	<i>7%</i>
<i>African/West Indian Jamaican</i>	<i>1</i>	<i>3.6%</i>
<i>Afro Caribbean-Guyanese</i>	<i>1</i>	<i>3.6%</i>
<i>Black Jamaican</i>	<i>2</i>	<i>7%</i>
<i>Other</i>	<i>1</i>	<i>3.6%</i>
<i>Black/Mixed</i>	<i>1</i>	<i>3.6%</i>
<i>Belizean/Caribbean/Creole</i>	<i>1</i>	<i>3.6%</i>
<i>African/ American</i>	<i>1</i>	<i>3.6%</i>
<i>Black/African</i>	<i>1</i>	<i>3.6%</i>
<i>Black/Caribbean Descent</i>	<i>1</i>	<i>3.6%</i>
<b>Birth Place</b>		
<i>Jamaica</i>	<i>11</i>	<i>39%</i>
<i>Trinidad/Tobago</i>	<i>6</i>	<i>21%</i>
<i>USVI</i>	<i>2</i>	<i>7%</i>
<i>Barbados</i>	<i>1</i>	<i>3.6%</i>
<i>Venezuela</i>	<i>1</i>	<i>3.6%</i>
<i>Dominica</i>	<i>1</i>	<i>3.6%</i>
<i>Grenada</i>	<i>1</i>	<i>3.6%</i>
<i>Belize</i>	<i>1</i>	<i>3.6%</i>
<i>UK</i>	<i>1</i>	<i>3.6%</i>
<i>St. Lucia</i>	<i>1</i>	<i>3.6%</i>
<i>Antigua</i>	<i>1</i>	<i>3.6%</i>
<i>*Washington, DC</i>	<i>1</i>	<i>3.6%</i>
<b>Years in US</b>		
<i>Mean= 17.4</i>		
<i>0-1yrs</i>	<i>2</i>	<i>7%</i>
<i>2-5yrs</i>	<i>4</i>	<i>14%</i>
<i>6-10yrs</i>	<i>4</i>	<i>14%</i>
<i>11-15yrs</i>	<i>5</i>	<i>18%</i>

	<i>16-20yrs</i>	4	14%
	<i>20yrs+</i>	9	32%
<b>Living arrangements /Marital status</b>	<i>Single</i>	18	64%
	<i>Married</i>	7	25%
	<i>Divorced</i>	3	11%
<b>Household income</b>	<i>&lt;19K</i>	2	7%
	<i>20-39K</i>	3	11%
	<i>40-59K</i>	6	21%
	<i>60K+</i>	7	25%
	<i>No Answer</i>	7	25%
	<i>N/A, None</i>	3	11%
<b>Primary language</b>	<i>English</i>	27	96%
	<i>Dialect- Patois</i>	1	4%
<b>Employed</b>	<i>Yes</i>	20	71%
	<i>No</i>	8	29%
<b>Occupation</b>	<i>Student</i>	8	29%
	<i>Health Care Administrator</i>	2	7%
	<i>Administrative Assistant</i>	1	3.5%
	<i>Assistant Professor</i>	2	7%
	<i>Retail/Sales Associate</i>	2	7%
	<i>Director/Supervisor</i>	3	11%
	<i>Immigration Specialist</i>	1	3.5%
	<i>Speech pathology asst.</i>	1	3.5%
	<i>Mortgage Manager</i>	1	3.5%
	<i>Business Manager</i>	1	3.5%
	<i>Project Analyst</i>	1	3.5%
	<i>Web Designer</i>	2	7%
	<i>Research Asst./Intern</i>	2	7%
	<i>No job</i>	1	3.5%

\*This respondent self-identified as being “Caribbean born” although she was actually born in Washington, DC. She was raised her entire life in Jamaica. She returned to the United States to attend university.

## **Common Beliefs about HPV and Cervical Cancer**

Study respondents also referred to behavioral factors such as one's lifestyle, specific kinds of sexual behaviors and partners, they referred to sex partners with cervical cancer, personal hygiene, or the lack thereof, as well as smoking tobacco. One participant felt that it was possible for one's mind to cause cancer. Although one participant did mention that she was unsure of cancer causes, another one said that "Nothing causes cancer. You just get it." When asked if she had heard of HPV or cervical cancer in her home country, one respondent said: "No, they don't talk about it...not openly discussed, or any illness... it's not something you bring up. It would have to have a trigger to start a conversation about it." In general, asking about causes of HPV and cervical cancer generated responses indicating lack of knowledge: "I don't know about causing cancer...like HIV or whatever. I actually don't know anyone with cervical cancer. I don't know much about it, um, but I know it's bad."

My respondents attributed their lack of knowledge to Caribbean contexts which they sometimes rendered as "culture." One study subject said:

"So these were older women, much older. I mean in my mom's age range, 60s, 50s. Now I couldn't say because in the Caribbean, people don't really talk about these things, those were not things that people discussed: 'Oh you have a flu,' 'You were walking outside barefoot.' You know, stuff like that. So with cancers, people, it's almost like something hushed, you don't really talk about it, you just know that somebody is sick and then they're dead some months later."

Another woman indicated that:

"I just think it happens. I mean, I know what you're touching on with that whole HPV, to be honest with you. I didn't even look into it very much because I am very skeptical about the whole shots thing. That may be ignorance....But over the last week and years, I've heard talks of that which we never usually talk about.

Yeah, because ...I just knew that if you contract HPV, or, you know, if

you get the virus, it can cause cancer. I don't know if I thought twice about what type of cancer since I knew lots of things about that. You know something that affects down there? I don't know if I'd given it thought. Is it your ovaries or is it your cervix? Where is it? I mean I think the only time I think of cervical cancer is when I go for my Pap smear and I'm like 'Lord have mercy! Let it [the exam] come back regular [i.e., negative for the disease].'"

One study participant discussed having known about HPV or cervical cancer in her home Caribbean country of Jamaica. For her,

"being Caribbean, more has to do with how you were raised. Maybe the educational level of your parents determines your exposure. So to me if I remained in Jamaica and I went to university or whatever I'd be just as aware as here. You know, I have a cousin who is a doctor in Jamaica, my sister they are all a lot more on top of this stuff than I am. So I think while it's a lot of the ignorance and in the Caribbean is lack of education, you know, a lot of Jamaicans may not have gone through the formal education system but most of the ones who actually went to some kind of college they're on top of everything just like the Americans are. I still have friends there in Jamaica and they're pretty much aware of what's going on and even more to be honest. To be honest with you, Jamaicans are exposed to more world news while Americans are limited to American news, right?

It would have been because, you know, a lot of Jamaicans, all my friends whom I went to elementary school with, yes, you know, they did not grow up with healthcare but because my parents were professionals they had insurance so I went to the dentists, I went to the doctors. You know, I didn't necessarily have to use the clinics in Jamaica because I had. So I think it all depends on your experience, all depends on how you were raised. Were you raised really rural, where, you know, people were raised very rural, where they don't even have running water or they don't have a television. So I was kind of exposed to I think everything. It wasn't Kingston or Montego Bay but, you know, cause there's some parts of Jamaica where it's really rural."

When asked if she had learned much about cancer in her home country before moving to the United States, a participant stated:

"No. And that's the thing. That's a big taboo. The unfortunate thing is when people have terminal or life-threatening ailments, they're like big taboos and, especially when you're young, people never speak about illnesses around kids. They always separated us from adults. Children were very much separated from certain things so when there were adult conversations you had to be excused from it so there was a lot of that. There were examples that I can remember that you heard people passed [died]. You heard about people where they started losing weight dramatically and you don't know what happened and then unfortunately because of [pause] there was a lot of, I guess, cultural things around people working black magic on you. So things were masked under that. Where now you know better, it had to be a cause of something. You know people having

unusual, abnormal growths on parts of their body. You know, I had a cousin who, now thinking back to it, I remember when she was young she had this huge stomach and nobody ever knew what it was. Nobody ever knew what it was. And she passed at age 6 or 7. I don't know whether cancer was the cause of it but I just know that she did. It was never any autopsy results that were done, you just knew she always had this and she passed and that was it. She was maybe my second or third cousin.

The thing too is, here again, in Jamaica versus here, it's such a different thing, because culturally, there is such a divide. There is definitely a divide culturally. There's a divide about certain authority. I think more and more this society is teaching you that you own that time in your visit and you're absolutely fine to ask whatever you want. And, also, again I think for litigation reasons this culture is teaching doctors that they better approach it differently. Jamaica is not there! Jamaica is not there, you know? Where people here say, 'I wanna make sure you asked me that question, I wanna make sure I answered everything' and, yes, so people are taking a totally different approach to it with here. Where in Jamaica, it's very much still in that old system that goes. It's like with the parents. The parents have said it, 'That's how it is! How dare you question or ask it of me!'"

One study participant recalls hearing of cervical cancer in the Caribbean. She migrated to the United States at age 27 from Jamaica. She stated, "It was called 'stink' by an older man talking about a woman he knew who had 'that woman's cancer.'"

Regarding knowledge about preventive care, most respondents were first exposed to knowledge about HPV after they migrated to the United States. Some reported that these things were never discussed or heard by the women while in the Caribbean. As one responded said:

"I think I had a basic overview of it. I think when I came here, I actually went to more doctors more frequently here than when I was in Trinidad. And I think from coming here, I have learnt more about the signs, symptoms and checking your breast regularly and that sort of stuff. Like I have heard some stuff. Iif you use antiperspirant deodorant, like that can increase your chances too. But I haven't tapped into research about it....I don't know, I was never exposed to like going to the doctor. It was never promoted. Like I was never told by anyone that you should really go to the doctor until I came up here where I learn that you should do a Pap smear or you should do this."

Some respondents felt that an older generation of women in the Caribbean lacked the knowledge to pass on to subsequent generations. They also pointed to those with a lack of education (associated with lower-class status) lacking that information as well. One said:

“I don’t think that these older women necessarily have the knowledge to tell you. I don’t even know if they know what a cell is or anything like that. And of course most of them didn’t have formal education, most of them, like my mom, only had primary school education and any further education it’s because she read upon stuff or, you know, ask her doctor. But to say that a lot of these women have real understanding about their bodies in general, I would definitely say that it’s probably very limited.

I remember this one person, this was an older woman that died, much older, probably around my mom’s age, and she was the wife of a farmer and everybody knew her. She was very large and they had found out that she had stage cervical cancer and within six weeks she was dead. And one person had said it was so horrible to go visit her because the room had such a stench. And so because of hearing it like that you almost thought that it was something you could have caught if you were near somebody who had that cervical cancer, or if anybody had a stench on them that pungent that maybe the person had cervical cancer as opposed to vaginosis, which you don’t even know. But it was sort of like a scary thing to think about.

I think that there should be a little more clarity on what people are left to do if we’re figuring out these connections between normal sexual practices and this HPV connection. Other than telling me that this is a connection, I don’t know what. I mean I had to abstain from any kind of oral sex for like a whole year because I was so unsure about this and then after a while I was saying well this is kind of ridiculous, ‘Are you going to use plastic wrap or a condom?’ Clearly I am not going to do it because it is not enjoyable, so I just think there is still a lot of uncertainties and kind of in my head I am thinking “I hope they don’t come back in five years and say ‘We were wrong on this’ [laughs]. So just stuff like that. And, also, you think about well, you know, if you’re just finding out about this anomalously, do other people know about this as well? You’re OK in going and finding a medical journal and reading about this because you’re a grad student, you’re used to reading. But how many people are going to go through reading about this? Would people even believe me if I told my male partner ‘Hey, you know men carry HPV?’ Would he just laugh? You know? So all these things. It’s not consistent in terms of how many people are aware. And for the men that do their ‘yearlys,’ are they being told they also can have HPV and they are carrying it and they can pass it on to their girlfriends? You know? All of this stuff. I am the type of person, I like to have these conversations and for people, my partner, to be serious about my concern.”

Study respondents noted how they had learned much from moving to the United States.

As one said:

“I feel in my heart I’m Jamaican but when I think about it I’ve spent most of my life in the States. So, but it’s hard to really my face that. And you go through so many changes because when you first migrate I was in an area that was the population was majority whites, minority Blacks, and I went to a school that was a mixture of Whites Blacks and Hispanics. And Caribbean’s were very few, and you work so hard to assimilate because

you want to be...you want to fit in. And then what? Thank God for college because when you get to college where you learn to embrace your individuality.”

Learning from U.S. resources, can increase access to new knowledge for some women, including knowledge of HPV. One woman acknowledged this:

“Yes, the Caribbean women of my age group or later [she is in her late 40s]...we’re a little backwards. I happen to get a different view on life because I came to the U.S. very early. So my cultural knowledge, it stands with the Caribbean but I was more exposed to the American way of life and the American way of thinking and the availability of resources to learn different things.”

But then she said contradictorily:

“[If had stayed in Barbados] it would have probably been healthier to be honest because of the lifestyle I would have lived there.”

Some of the women believed what was communicated to them through the media and other modes of public and accepted knowledge. Cancer was caused by smoking, or what one puts into their body. Many recalled how neither cancer nor its causes were openly discussed in their nations.

Inquiring about beliefs contributing to causes of cervical cancer questions were asked if the women heard of hard or rough sex causing cervical cancer, large penises causing the cancer or the Pap smear exam causing cancer. These questions were asked, because in my experience in informal conversations with Caribbean women both in Jamaica during my research and in the research for this dissertation, there are commonly-held misconceptions about the causes of HPV and cervical cancer. Very few women in the present study heard about those acts causing the chronic disease, yet some women recalled how specific diseases related to female sexual organs had negative perspectives in their origin countries. Some myths were highlighted in one interview:



“I have had a friend who had cancer of the lymph nodes and they speak about if you jump on a trampoline or go running and it will drain your lymph nodes, then that’s a good thing to do, like sweating, so I just try to exercise and eat healthy.”

Many study respondents reflected on how Caribbean cultural norms influenced the lack of knowledge about HPV:

“I think it’s cultural. There’s a lot of things that my mom or just adults in general, especially adult women, that they kind of think that when you’re older you get to engage in this conversation. It’s not for you to know if it’s ....I guess they don’t think that as a younger woman growing up that it will affect you so there’s no need to but I still think there is some stigma of shame in having a disease and I think anything dealing with your genitalia or your reproductive system or your female parts is often seen as closed door, ‘That’s women’s business,’ ‘Nobody needs to know’ and that it’s sort of tied to some kind of ....not necessarily promiscuity but something that you’ve done in the past to deserve it. You know, I just think it’s cultural, it’s very tacit, nobody says anything, it’s just a sort of understood kind of thing within that type of society.”

I inquired into how Caribbean women conceptualize the causes of the STI and how the infection develops into a chronic disease by asking “What’s your understanding of some of the causes you just mentioned? How does a woman get cervical cancer?” Responses provided insight on whether women really thought about how HPV and cancer impact lives. Many of the women had never reflected on the causes of HPV and its association with cervical cancer beyond the information medical providers shared with them or the information obtained from the commercials about the HPV vaccine. Respondents recalled the causes of cancer that were in the general public sphere about the STI. When asking about cervical cancer, some said they never thought about HPV and cervical as linked.

### **The Meanings of HPV and Cervical Cancer**

When asked “What comes to your mind when you think of the word ‘cancer?’” the women mentioned numerous cognitive reflections and associations that activated their concept of disease. They spoke of their own family members, other cancers, fear and death, behavioral causes, biological causes, along with environmental and social causes. More specifically, the

themes and sub-themes that emerged from the interview sessions included, in their own words, the following emic terms (noted in quotation marks): “the family” (experiences of cancer with family members); “disease/illness” (cancer); “fear,”; “death”; emotional dispositions (“sadness”); behavioral causes (“lifestyle”); biological causes (“genes”); physical essence (“the body”); and “the environment” (including one’s social environment). The history of cancer in one’s family was a group responses linking to the theme of family (“experiences”). Identified cancers like skin, pancreatic, breast, thyroid, cervical, lung, and leukemia were groups of responses from the theme of disease/illness. The theme also emitted “terminal,” “chronic,” and “invasive” disease concepts when the questions were asked. “Dying people” and being “the worst of all illnesses” were concepts associated with fear (death). While emotional (sadness) dispositions were linked to one’s own experience with cancer, behavioral causes (lifestyle) were linked to notions of sex, prevention, alcohol drinking and diet. Images of cells, heredity, genetic connection, “tissue” and “blood” were affiliated with the biological causes (“genes”) theme. Pain, loss of hair, abnormal growth, and lesions/sores were associated with the physical (body) theme, along with “medical treatment,” “chemotherapy,” and “biopsy.” Finally, “the environment” (include the social environment) elicited feelings of minorities’ lacking appropriate resources and testing mechanisms (please see Table 5).

**Table 5. Emergent Themes for Cancer Meanings**

<b>Primary Theme</b>	<b>Secondary Theme</b>	<b>Groups</b>
<b>Family</b>	Experiences with family members	History of cancer in family
<b>Disease/Illness</b>	Cancer	Breast Thyroid Cervical Pancreatic Skin Lung Leukemia
		Terminal disease Chronic disease Invasive disease
<b>Fear</b>	Death	Dying people Worst of all illnesses
<b>Emotional</b>	Sadness	Own personal experience with cancer
<b>Behavioral</b>	Sex Prevention Alcohol(drinking) Diet	
<b>Biological</b>	Cells Hereditary Genetic connection Tissue Blood	
<b>Physical</b>	Body	Pain Loss of hair Abnormal growth Lesions/sores
	Medical	Treatment Chemotherapy Biopsy
<b>Environment</b>	Social	Minorities Lack of resources/testing mechanisms

The causes of cancer obtained from the interviews with the participants were coded into major primary themes, sub-themes or secondary themes, with their notions of the causes of cancer. The identified primary causes and sub-themes were: “environment” (they referred to “chemicals”), “biological” (they referred to “genetics”), “physical” (this included images of the

body), behavioral (“lifestyle”), and “psycho-social” (sometime called “cognitive”) causes. The specific causes for environment (chemicals) included exposure to the following: car exhaust, sun, environmental triggers, and radioactive materials in food. My informants spoke of biological causes in the following terms: “mutations,” “tissue malfunctioning,” and “hereditary” causes. Specific causes for the physical (body) included notions that within bodies with large breasts and fibroids were the causes of cancer. Behavioral (“lifestyle”) causes included drinking alcohol, eating particular kinds of foods, personal hygiene, meat consumption, smoking, sex partners with cervical cancer, and particular kinds of sexual behaviors and partners. The informants spoke of “psycho-social” (and “cognitive”) causes, but were either unsure of those causes or said nothing specific (please see Table 6).

**Table 6. Major Cancer Causes**

<b>Primary</b>	<b>Secondary</b>	<b>Specific Causes</b>
<b>Environment</b>	Exposure to Chemicals	Car exhaust Sun Environmental triggers Radioactive materials in food
<b>Biological</b>	Genetics	Mutation Tissues malfunctioning Hereditary Ingested causes
<b>Physical</b>	Body	Large breasts Fibroids
<b>Behavioral</b>		Drinking (alcohol) Eating/foods Hygiene Meat consumption Lifestyle Smoking Sociocultural Sex partners with cervical cancer Sexual behaviors/partners
<b>Psycho-social</b>	Cognitive	
		Nothing
		Unsure

Some study subjects identified the major cancer types being breast and cervical cancer when asked during the interview. When asked about the major types of cancer specifically obtained by women the following were stated: lung, brain, skin, cervical, uterus, ovarian cysts, blood and lymphoma (of the head and neck). Prostate cancer was even mentioned as a female cancer type (please see Table 7).

**Table 7. Major Cancer Types**

		<i>Top Cancer Types</i>		
	Cervical		Breast	
		<i>Top Women Cancer Types</i>		
Breast	Lung	Brain	Skin	Cervical
Ovarian /Cysts	Uterus	Leukemia	Blood	Lymphoma (head & neck)
Prostate				

Family experiences with cancer immediately connected some study subjects to personal reflections. Reflections of how their mother, father, an aunt, close friend or grandparent was diagnosed with some form of cancer came into the interviews. Noticeable changes in voice intonation or body movement, even lack of eye contact by the participants with myself provided a sense of sentiment that was still being held by the participants. Some participants expressed the emotional relationship with the person who had cancer by stating cancer was “the worst of all sickness,” relating the term to “dying people” and cancer having strong connotations to “sadness.” One participant shared her own experience with a possible cancer scare, and having to have a biopsy made her fearful and think of the possibility of dying from cancer.

Specific diagnoses of cancer were stated when asked about cancer. Breast, cervical skin and lung cancer were mentioned. However, rarer forms of cancer were also evoked such as thyroid, leukemia, and pancreatic cancer. Those who mentioned the rare forms of cancer had family members and friends who succumbed to the diseases.

Displaying how the closely related themes of family and fear resonated with some participants, the interpretation of fear-based concepts surrounding cancer was revealed by one participant, a woman age 35 who moved from the U.S. Virgin Islands to the United States mainland as a 21 year old: “[My] dad had it; died from it in ’06...it’s nasty and transforms loved ones to nothing...sucks the life from you.” She provided examples of how her brother had a major medical issue in the Virgin Islands and he could not get a CAT scan there, so he came to the U.S. mainland and had to have emergency care. She stated that the emergency care was due to the lack of availability of services and patient care in her home country. She tends to shy away for the term “cancer” because of how it makes her feel about her father’s death and her potential cancer scare with ovarian cancer a few years later. She drinks green tea often and drinks lemon juice in the morning as ways of preventing cancer with nutrition. She is not sexually active; not strictly conscious of her person habits towards HPV or cervical cancer.

Biological associations with the term “cancer” emitted evocative terms such as “genetics,” “hereditary,” “cells,” “abnormal growth,” “tissue,” and “blood.” Treatment terminology such as chemotherapy, invasive disease, lesions or sores, loss of hair and biopsy was shared. While affiliated activities to behavioral concepts including sex, diet, alcohol (the amount of alcohol intake), and societal phrases like “not protecting oneself,” “minorities,” “prevention,” and “lack of” a number of resources such as testing and care facilities.

More specifically, environmental or chemical causes were more firmly stated as a matter of fact, different that responses from the cancer meanings. Causes were invoked such as the sun or car exhaust, a general exposure to chemicals, and the common physical environment. Nutritional causes were attributed by my study informants. They referred to the kinds of foods

that were consumed, mentioned and the possibility of radioactive material in food, and also referred to drinking alcohol and excessive meat consumption.

### **HPV and Cervical Cancer Knowledge**

As the medical anthropologists Whiteford and Manderson observe, “Migration is both an international and personal experience” (Whiteford and Manderson 2000:164). When asked about how the immigration process affects cancer knowledge, participants highlight the process is more open in the United States. As one said:

“I think the immigration process affects it in a great way because when you come to the United States, it’s more, um, open. There’s a lot more talk about cancer, you see so many cancer ads on TV. Cancer is an everyday word. You hear about more sexual activities, you know? In Trinidad it’s a lot more closed, you know, people don’t want to talk about things like that, um, so I think it’s for the better [to be open as in the United States].”

When asked if participants ever heard of HPV or cervical cancer back home, very few participants stated their families discussed related cancer experiences to prevention and testing mechanisms. As one woman from Trinidad and Tobago who moved to the United States when she was 6 years old and whom often visits often with family in Trinidad said:

“Well, my grandmother, she’s never had a Pap smear or anything like that her whole life, mammogram, nothing. Um, my mother, it’s only a couple years ago she had her first well woman’s exam, and through that, through going through that she had to have a hysterectomy just the other day. I think now that my grandmother is older and um, she’s more inclined to listen to us, um, and we explain things to her, now she’s more understanding, but back then none of that was brought up, none of that was you know...even now- I can’t name a lot of my cousins who are my age who say anything about well woman’s exams or cervical cancer or anything of that nature.”

Being in the United States has broadened the availability of information and knowledge about cancer and HPV. Now that the women are of reproductive age and able to access doctors with insurance due to their student or employment status, an array of educational resources about cancer and HPV are available. Information was obtained from television advertisements about the Gardasil HPV vaccine. Online resources such as WebMD, Mayo Clinic, and CDC are portals

of information that women accessed to obtain more knowledge about preventing disease, illness symptoms, or disease treatment.

Migrating from their Caribbean nation impacted the women in receiving more information about cancer. Some of the study participants acknowledge that unprotected sexual activity is directly connected to getting HPV. The women learned, primarily in the United States, how the sexually transmitted infection causes cervical cancer. Several study participants reported that they understood that someone is at risk for getting the infection by having sex with multiple partners and by having unprotected sex with men who have HPV. Participants knew that the Gardasil vaccine could prevent HPV if administered early. All of these factors surround the way Caribbean migrant females learn about HPV and how they conceptualize HPV and cervical cancer being connected. Some respondent claimed, however, when they accessed health care systems in the United States that they were made to feel rushed and that this, in turn, diminished their ability to obtain more information and even diminished their motivation to obtain more information. As one former USF student said:

“As a student I felt that like going to the USF Health Services, I felt that it was more of a rushed system. It wasn’t like they were trying to have any connection to you, basically. I felt like, I don’t know, I went to the doctor, I didn’t pay extra, I just used my insurance. Like I just felt disconnected from everything. When I first came, not even from here [the United States], with an accent, etc. put me at a disadvantage because they [U.S. citizens] know how to gain the respect from people. Because I felt like I was not held up to the same standards as if I was from here. So I think that going to the doctor and asking questions and stuff - I mean information is all you want - but they won’t take their time and sit down and explain it to you. So I know I had a bad experience where birth control was not working for me. I went back like five times to the doctor. I don’t know what’s wrong and they just switched me. They were like ‘OK, just try another one.’ So I think that has an effect.”

All of the women interviewed, with the exception of one, declared how the health care delivery system in their Caribbean birth country was not adequate. On seeking healthcare services in the United States, one participant stated that migrating has



“made it easier and more accessible to get like things. Like medicine-wise it’s easier. Like I think like the Caribbean resources are there but it’s not so easy to attain. Like when I’m there, like when I go there, and like I, you know, I look around the environment and stuff I’m like ‘Wow, like, it’s so much easier to get things in America.’ You know? If you’re sick you can get medicine. There’s different types of medicine. Sometimes I’m there and people there they have like a simple cold and it’s like the medicine in Jamaica is expensive and I think ‘OK, if I was, you know, in America I could get this for \$2.’ And it’s way cheaper and I can get it anywhere. And sometimes one store doesn’t have it you have to go like somewhere far to get it. I’m like ‘Wow!’ You know, here it’s more its more convenient. It’s easier.”

Some of my participants stressed the importance of “cultural competency” in choosing a primary care physician. One respondent’s regular healthcare provider was from Africa and familiar with Caribbean women and what she regarded as cultural conditions in Caribbean society. She said:

He used to laugh at me all the time because when I talk with him I am really very straight up with him and he would prescribe all these little things for whatever ails me and I would go ‘Oh no, I know this herb I can drink’ or ‘I know this and that.’ He’d say ‘You Caribbean women and you and your homeopathic medicine. You continue do what you do.’ Because I had developed this, I don’t know, it was a hair bump in the middle of my head. It got infected, of course from the moisture and washing my hair and then sweating and putting grease and doing all this, it wasn’t getting healed fast enough. So I showed it to him and I said, ‘Do you want to recommend a dermatologist?’ He said, ‘No, what is in your head?’ I was like, ‘What are you talking about?’ He said, ‘There’s something yellow on your scalp,’ and I had forgotten that I had taken goldenseal powder and I mixed a poultice and I had put it in my head. Well he gave me antibiotics and but he said, ‘You know what? I’m not going to stop you, you can go what ahead with whatever you mixed up, it looks like its healing so don’t stop doing what you’re doing but I’ll give you these antibiotics also. You know if you want to take them, take them out and continue to do what you’re doing.’ I was like, ‘Yeah all I think I need to do is keep the hair in that area clean, make the poultice, put it on my head, keep it covered and keep it going.’”

One woman referred to what she saw as a general aversion to seeking medical care in the Caribbean, and a kind of fatalistic attitude that is the result of a strict adherence to religious belief – Christianity and other religions:

“A lot of the health care in the islands, it is free and so I guess the extent of research or the extent of testing would be limited unless you were really, really ill. Kind of reminds me of the story of Bob Marley. You know, he died of cancer. It was so shocking. ‘Oh my God, why? He was vegetarian. He was Rastafarian.’ And he reached to the stages where

it was too late to help him and couldn't cure it because he listened to other people say, 'Oh it's gonna go away, don't worry about it. Don't let those people cut you open. Don't let them do this and that.' Because of course, in the islands, to go under surgery is like giving yourself over to death. That was my mother's thinking too. She would always say, 'Oh I'm not going to let anybody cut me.' We'd always say 'Ma, you need to go do something.' She had cataract in her eye. 'Mother, you need to go have that taken out.' 'Oh don't let anybody cut me.' So when she was ill those last couple of years, me and my sister fought and fought and fought and she would not do it. 'Get the heart valve surgery so you could add a couple more years to your life.' 'No, no. If God's ready for me, he's going to take me, don't cut me open.'"

One respondent did discuss how class is associated with the perspectives of Caribbean individuals. She mentioned that her relatives from the Jamaica in New York City often mimic many of the same habits from their country of birth. While friends and family from her home country in Tampa, often more educated and higher-economic status from counterparts in New York, may exhibit more adaptive ideas from their American co-workers or associates. She said:

"I don't think a lot of women shared that they had cervical cancer. They would share that they have cancer. I meant a lot of women who had cancer but they'd never really say what kind of cancer. My ex-husband's aunts, I think two of them died of cancer. His mother died of cancer. He said it was lung cancer but it could have been some other kind of cancer. They didn't say what they had, but they had cancer. So for me knowing that cancer runs in my ex-husband's family that was one of the things I had my daughter to be screened. You know? 'Make sure you go get your Pap's. Make sure you go get yours breasts checked.' And with me having an abnormal mammogram I also do that but most women didn't share that.

My Granny, God rest her soul and I loved her dearly. I used to work with Dr. [name withheld], a very well-known OB-GYN here, and his receptionist. Send my granny had never seen a gynecologist after she gave birth to my mom. I convinced her to go in for a checkup, but she still refused to get a checkup and my grandmother died because she refused to go to the doctor. She's just a real, stern island person. My mother has that same mentality. I'm more about preventive. I've always been about preventive because I believe in medicine and science from since I was young so my mother was good enough to send us to doctors for dentists and immunizations and anything else. W we did it with aloe or whatever, cod liver oil or whatever they want to give us and that's it. Bush tea. We get our bush tea. So she still doesn't believe in it and I tell her those are silent killers and she doesn't do anything about it so it's just for me I have always been on the battlefield when it came to my parents to tell them to go to the doctor 'cause it's a cultural thing, 'cause they just do not believe in that.

I've seen a lot of people from the islands do that. I don't think that they had bad experiences with medicine. I just think that they believe that the natural resources are much better than using things that's artificial. That's the kind of mentality I think they have and I know it's different in America. All my cousins from Grenada, they'd try a home remedy first before they do anything. But by the time they go to the hospital, it's a little too late. My cousin's dad died from cancer that way and I have the trait of sickle cell anemia. My cousin [name withheld] died at 24. He had his first stroke when he was 6 years old and they didn't even know he had sickle cell. So, you know, it's a matter of just trying to be informed. I think that people in the islands believe that if you don't know it then it's not going to bother you. If you don't know things, you don't have to worry about it. And we do worry about it. We're worry warts. So, it's like if you know something's wrong with you, you think you're probably going to get better, you're not going to really be able to think properly. At least that's how I see a lot of people in the islands, when they know something's wrong, they kind of go in denial. It's their culture."

On the perceptions of cancer by a Caribbean immigrant:

"I think in Jamaica there is still that perception of kind of 'the Big C.' I think there is still kind of that stigma, when I was growing up at least. There was that stigma around cancer. I think, you know, people would say, 'Oh, you know, well he's just skinny, he's just sick,' but they'd never want to say that they'd have cancer. And so you never really knew what the illness really was but they might say, Oh well, we're just giving him this herbal tea cause he's not feeling well 'cause he just needs to put some muscle in his back," you know, or whatever. So you never really made the connection. So they'd never say this remedy was necessarily for cancer but they'd say he needs some tonic to make his body stronger or whatever. So when I was growing up there was still that stigma around cancer. You know there were people that I remember. There was a taxi driver who, you know, he just started losing weight, losing weight and I was concerned about his health so I had to ask my cousin what was wrong with him and he said, 'Oh it's just Obeah,' which is voodoo. 'Oh it's probably just Obeah.' I mean, still to this day nobody ever said he had cancer. I, to this day, think he had cancer but it was always like dismissed and it was always attributed to something else. I am not sure how it is now, but I still think there is some of that in terms of the stigma around cancer. I would assume that reproductive cancers are probably even more stigmatized - certainly cervical cancer. I know, while these people did not live in Jamaica they're Jamaicans, that one of my grandmother's nieces she had cervical cancer and she actually passed from cervical cancer. She and her husband lived over in Orlando and I just remember hearing conversations about the fact that she could not sleep with her husband in bed anymore, she had to move to another room. Nobody was really saying what was going on until we learned that she had cervical cancer and so apparently these were nuances in behaviors that when you have this kind of female reproductive cancer that you distance yourself from your husband because you might be bleeding and those kinds of things. So I remember hearing some of that which I thought was very interesting and it caused me to question what type of support you get from your partner while you're going through and then I don't even think there is that connection or that knowledge about HPV and cervical cancer within that context and so I just thought it odd for her to be ostracized and have to sleep in another room and, who

knew?, she probably got HPV from him. You know? So, for me, there was this huge disconnect. But I distinctly remember this situation.”

On what she saw as the lack of education on prevention efforts, one respondent said that growing up and hearing about cancer:

“I was worried that my mom would get cancer. So I always, as I learnt more about it over here, I would always encourage my mom to go get screened for this, or go get screened for that, and she was not very receptive to the idea. She would do the self-checks for the breast cancer but for any other type of screening it was something that you didn’t do. You didn’t go get checked out for those things because that’s just not what you did, you know. It was almost like too embarrassing to go to the doctor if you have a problem with your vagina, so you wouldn’t, you know, you wouldn’t get checked out for it, you wouldn’t get screened for it. And as I started learning more about the different types of cancers than women can get in their reproductive systems – because, I mean, I thought there was only one type of cancer you could get - and then as I started learning more about it I’m like ‘Oh no you can get this kind, you can get that kind,’ and so I really reached out to her and I was like ‘Wow, you know, mom, like there’s a lot of stuff, different types of cancers that you can get, and so you should really go search for it.’ I also remember once I was at my first job in Trinidad and I worked with this lady, she was very religious, and she told me that she believe that cervical cancer came from having unprotected sex from certain men because men had a bacteria in their penis that when a woman had sex with them that’s where the cancer would come from. So that’s another thing that I used to hear.

In Trinidad, well, I know that smoking causes lung cancer. That one I learned. I went to Catholic high school and so a lot of our sex education revolved around like fear in a sense. I remember learning about HPV back home [in Trinidad], I remember learning about HIV and all the other STDs and I know that they said that almost everyone had it, and you can get it each time you have sex, and that it could lead to cancer. So, yeah, so to get the Pap test. That’s another thing. I don’t think they offer Pap smears in Trinidad.”

### **Beliefs and Health-Seeking Behaviors**

When asked about how immigration affecting the health care services a woman receives when she comes to the United States to obtain gynecological screenings like HPV prevention exams, my study respondents spoke of the barriers, challenges, but also opportunities to increase knowledge about HPV. Some said that there could be challenges to obtaining care in an unfamiliar country or if they had the status as an undocumented immigrant in the United States:

“Um, probably because you’re not as indulged in the culture as the people who actually live here, you don’t know where everything is so you don’t have the exposure, you’re not aware of what options you have as yet. Maybe after you’ve lived here for...probably by the next year you have a fair idea of where everything is.”

Some women even argued that Caribbean migrants are generally healthier than other Americans and that the concern for detrimental health effects is not a concern so it is not a priority.

“I don’t know, we from the Caribbean think that our lifestyles were so much greater or we’ve lived so much better that we don’t need that type of information. It’s not something that would generally affect our daily living. So I say that because I know that most of us think that way. It’s what we eat and how we live and what we do, so we don’t quite take on the seriousness that it may affect us in some way. Probably our offspring, because they were born in this place, we probably need to think about it more like I said with my daughter. But we never know! Because you can be so health conscious and stuff still happens. We don’t know why, so it goes back to that again, because my daughters always say, ‘Ma let’s be vegetarians again. Let’s live organically and this and that or the other and if God has it for you and it’s a lesson to be learned, it’s gonna come and if he wants to teach his lesson, by way of cancer, so someone else can get the message, then that’s how he’ll bring it.’ That’s how I believe it. I really, really believe that. [But] I respect the medical profession and industry. I respect researchers. I respect anything to do with people finding out our “makeup,” what they can do to help us if something happens or we’re ill.”

Some of my informants said that Caribbean immigrant women do not readily go to the doctor and they traced this attitude to cultural attitudes obtained in their home country:

“In the reality and scheme of things, living in the islands, it’s like people don’t go to the doctor unless they really need to, unless it’s something, really, really wrong. That pain or that something has set in where they’re like ‘OK now it’s time for me to go to the hospital.’ But see, here health-care is promoted. It’s drilled into you. It’s like you have to go to doctor here, get a medical check-up, all these things are going on out there, make sure you go to the doctor. And it’s not only about health. It’s about the financial part of life. It’s about the progression that these people that are spending their lives learning these crafts, these trades, want to give back to them too and I understand that.”

Yet, some respondents felt that they faced more health challenges by migrating to the United States. As one said:

“In this world, in the U.S. that we live in, we are exposed to more things; we are exposed to chemicals, they inject the food with something to get it to grow faster, to preserve it

and some people's bloodstream, their life and their tissues, can't handle these things. You may have only ate something one time and because of your genetic make-up it may affect you differently from the person that's lived here all their life and they can eat anything and nothing happens to them. I mean we don't know but like I said that's why I respect the healthcare professionals that take the time to find out these things. So, yes, there is a vast difference and it would be nice for some more of our Caribbean people, young and old, that have come recently from the Caribbean to know and experience these differences, to take a chance and say, 'You know, you're right. I'm in a different place now, I'm not home. I can't go in the garden and pull some 'sera-see' [an herbal remedy] and drink it and be alright. I can't go this and that place.' Because it's the same herbs we use at home. Is the same stuff that they use to make stuff that cure stuff, they just add stuff to it, you know? I know it may take a little longer in the natural form, so however it works, it works."

Some said that the environment in the United States is more "toxic" than the Caribbean, where

"we live right across, the sea is right there, get the fish, they come through they blow the horn. So I think that it's, um, diet and the environment too. I think that they're lots of toxins here, people live along all this. The government does... I don't think they tell you to truth about where you put all this stuff that can cause you to breathe in, or to that is just not healthy for you. Whereas in the Caribbean, we don't have none of that. I mean, it's just a healthier... It's just different, you know? The air is cleaner, 'cause we don't have all that pollution, chemicals, and things are just simpler, you know? Sometimes, you know, they say less is more. You know? That's the truth about... That's why I think that, um, most people don't have all these diseases that we find here. When you look at the average person from the Caribbean, they're just not exposed to that. You know? That's my thing.

As a child I never went to the doctor very much but my mom was a nurse. So she was there and if she needed to take us to one of the pediatricians she did but we never really - I mean beyond the cold or even a slight fever we didn't get sick. We didn't get ill. I grew up, where we grow up we had lots of fruit trees so we eat fresh fruit and vegetables and stuff all the time so there was never really illness. And, you know, a major cut or something where you know you had to go and get it stitched up you know that's sort of a thing but by and large, no, not really sickness.

Many of my respondents felt that one's class and education, plus one's social circle, had a determining role in a kind of orientation to health-seeking behaviors. As one interviewee stated:

"I think... I think it's not the immigration, I think it's your place in life. Like if you're not around health professions, I think that's it for like everybody like I would meet.

Somebody that can tell me about everything about, um, dental care, unless of course somebody in the family is a dentist. So I think it's just where you are in life, if you're not around a health professional I think there's not enough health fairs around, like I've been starting to go there [to] those now and I learn a lot. I get my blood pressure tested and all of that and it's where you need to be and stuff so, you know, the only thing I worry about is losing a few weights and so far like I'm on a 'heal thy' track. I've just been changing my eating habits and stuff like that, and I learned that from going to little, um, training."

A 50-year-old woman from Kingston, Jamaica who moved to the United States at age 27 said: "Class plays a part in herbal remedies with rural vs. urban and older vs. younger people," where older, rural dwellers more likely to rely almost exclusively on herbal remedies. Another subject said: "You know, when I was small my mom believed in douching and I never liked that so I never really did it. So, those are things that they did in the islands that they were cleaning themselves out so they did a lot of douching."

Demonstrating the contrast in healthcare systems one participant from Jamaica who had been in Tampa for two years and who visits home several times a year stressed the differences between the United States and her Caribbean birth nation:

"I think...in America...this probably has to do with it being a First World country, and Jamaica not - being a Third World country you know - that you know it's more efficient. The stuff here, the equipment, you know, medicine and everything is more developed, you know. There's less steps and procedures you have to go through...to get anything done. Like even when I was in the emergency room [in Tampa], I was basically like in and out. I know if I was in Jamaica like, I'd probably be there for a couple of days, you know, 'cause you know, there it's not that their system is bad or anything... it's there... nothing they can do, there's no equipment or medicine or anything. The people, I don't know, like, I guess they're the same, you know. The care, I guess is basically the same... it's just equipment, medicine, procedures..."

Another participant talked about the discrepancies in the health care system she left and what she sees as the U.S. system:

"Oh yes, the healthcare system in Trinidad is awful. And I think that that contributed to the population as well because it correlates all together because if you have a population that is not knowledgeable, then the healthcare system isn't going to be as pertinent. It's awful, like, my mom [chuckles], we always make a joke, "Don't get sick when you go

over there!” because you know my grandfather um, at one point we thought he had pancreatic cancer, and we flew him over here to get help. We didn’t even want him over there.”

While many of the women shared that they do have a regular health care provider that they see for an annual well woman’s exam or physical exams, some women did state they do not visit a doctor regularly. Another perspective from a respondent emphasized the practices of one’s home country being imitated in the United States. She stated that her “culture affects primary care visit habits. Even if a person has insurance.” Highlighting that her family in Jamaica did not go to the doctor, only going if you are really sick or if you need to “treat and illness.” She stated that people would ask “Why are you going to the doctor?” at home as if it was leading to a death sentence. Moreover, here in the United States, her family members still don’t go to a doctor’s office for health care. Her family in New York City goes to the hospital emergency rooms for health care, even if they have healthcare coverage.

On the benefits of being informed about HPV in the United States compared to her home Caribbean nation of Jamaica, one research subject explained:

“Absolutely! Absolutely! Well, for two reasons. Number one is I have access to resources that I never did before. So though the internet is everywhere in Jamaica, I probably wouldn’t have had as easy access to things such as internet in so many different formats than I did before. I’ll give you an example of that. We go to Jamaica, as I mentioned, every year. When we were there in August, my mom and I were out and I noticed this growth on her and it made me really uncomfortable. And then, you know, I am thinking, ‘I need to take a picture of this thing. I need to go on the internet. I need to light it up to see if I could see a similar image.’ So and that was in that context.”

Sexual encounters have changed since coming to the United States. As one young respondent responded to the question regarding the influence of different social contexts on Caribbean migrant women’s sexual attitudes and behaviors in a larger, more anonymous, society like the United States:



“Oh what I know about it? OK, well from what I know from what I learned, it does play a part. The problem is with that a lot of these behaviors that expose you to getting [it], a lot of the behaviors will... OK, so unprotected sex basically can expose you to a lot of things at once because it exposes you to pregnancy, exposes you to STDs, and, um, I do know that there's that link between HPV and, um, cancer because of that. When I was going to high school and they're like, 'Oh you could get it' and 'It causes cancer' and stuff and I know that sexual intercourse has always been, I mean from what I learned, the big scary monster was always getting pregnant, and then as the HIV epidemic came in then you were like 'Oh yeah, you could get AIDS.' But there wasn't so much of an emphasis on the fact that you can get cancers from having sex. There was more of an emphasis on I want children and stuff like that. And then I know that in Trinidad, um, because of our culture, because we have such a fun, lively, 'Let's go party all the time' type of culture, um sex, not only sex but sex with people that you don't know very well, is actually kind of commonplace. And it's not as, um, taboo as it is over here so much.

I would definitely say that me leaving Trinidad, and leaving at a time where I knew everyone, and then coming to Tampa where I didn't know a lot of people, that impacted my sexual behaviors too because I'm like, 'OK, well now I don't have, now I don't know as many people, now I don't have as small of a circle, people won't care of my business,' you know? People won't go back and say, 'Hey, you know, I saw you doing that,' as they would if I was in Trinidad. So you move away to America, because you don't have that circle anymore, um, your behaviors tend to become a lot freer and especially since you're trying to re-establish that circle. So if you had a boyfriend that's left back in the Caribbean and you're trying to get another partner over here, your behavior, your sexual behavior, will tend to be more promiscuous because you're trying to recapture basically what you had to leave behind on the island.”

When exploring risks associated to HPV and cervical cancer an interviewee said:

“When I was younger I would be at risk for different, you know, any kind of sexual disease or sexually transmitted disease. Now that I am older, I realize that “Wow! Yeah.” We tend to forget that we need to protect ourselves and we really need to respect our bodies. I think a lot of times, as younger women, you try to be accepted and, you know, you try to be in the ideal relationship and you do whatever your male partner might want you to do but [pause] I think a lot of us are just not [cognizant of protecting ourselves]. Sometimes I think we're not as informed as we need to be and we're not as educated as we need to be in terms of the risks that are involved in sexual activity and a lot of that I think comes from the fact that a lot of this is not talked about in the home. From my experience, we didn't talk about sexually transmitted diseases. The talk that I had in terms of growing up into womanhood was more so understanding what changes in your body when you get to puberty and menarche and those were the conversations. Conversations did not revolve around sexually transmitted infections and so you kinda learn as you go. In my experience, I learned quite a bit about sexually transmitted infections in college because it was a conversation. I was a Biology major. So I've learned about, I mean, you know, we had discussions about how to protect yourself from

sexually transmitted infections. So I think we do our kids a disservice when we don't talk to them about sexually transmitted infections.

I don't think it was something my grandmother thought she needed to talk to us about because as far as she was concerned, we weren't supposed to be sexually active until you get that ring, so you don't do that until you're married[pause]. But when I think about the sexual act and its relation to cervical cancer I think about lack of empowerment in women, lack of knowledge, this low perception of risk and really the fact that as women, young women, I think we don't get that full introduction and understanding of what it means to protect ourselves and why it's so important for us to protect ourselves and what we need to do in order for us to protect ourselves in sexual situations. You know, I think our parents are still oblivious of the fact that we are sexually active as younger people and so we don't have that conversation."

On sexuality and cancer outcomes, some of my respondents reported that their parents did not speak to them about the connection between sexual activity and cancer risk. As one informant said:

"I knew my parents weren't knowledgeable about that stuff. I mean it was just a given. They didn't [know]. They were pretty healthy people themselves. People talked about what was common. Everybody had high blood pressure, everybody had diabetes. Everybody had a gall bladder or a kidney stone or something. So that was something common that people talked about a lot. 'My doctor said this,' 'my doctor said that.' So that got spread around so everybody knows what to take, what not to take, which teas to take but when you talk about something that did occur but was rare and because it's rare I think there is a greater stigma because it is rare, because now there's probably something – in Creole we say "*mal*" - going on in your family, so that was not talked about. My dad was not somebody that liked going to the doctors. He didn't really care for them and my mom, you know, she had stopped eating meat so she was pretty healthy for her age. So none of us really had issues other than the normal diabetes and high blood pressure stuff so they would not have known specifics about that."

Another participant said that knowing something about the sexual history of one's partner would be important in preventing disease:

"Well, I only slept with my husband and then I had protected sex otherwise, so I do believe because I was a good Catholic that I didn't use birth control so I had to find a way to make sure. It's important to know who your partners are and I don't think a lot of people take the time to do that. A lot of people just fuel the fire first before anything else. And so I've always been a thinker and that's it."

**Table 8. Healthy Lifestyle and Behavior Characteristics of Participants - In-Depth Interviews (n=28)**

		<u>N=28</u>	<u>%</u>
<b>Health insurance</b>	<i>Yes</i>	24	86%
	<i>No</i>	4	14%
<b>Health provider</b>	<i>Yes</i>	19	68%
	<i>No</i>	9	32%
<b>Age of first sexual encounter</b> <i>Mean=16.8</i>	<i>Around 14-15yoa</i>	2	7%
	<i>16</i>	2	7%
	<i>17</i>	4	14%
	<i>18</i>	5	18%
	<i>19</i>	6	21%
	<i>20+</i>	6	21%
	<i>N/A</i>	3	11%
<b># Lifetime sex partners</b> <i>Mean=3.3</i>	<i>0 to &lt;10</i>		
	<i>0</i>	3	11%
	<i>1</i>	4	14%
	<i>2</i>	6	21%
	<i>3</i>	2	7%
	<i>4</i>	4	14%
	<i>5</i>	1	4%
	<i>6</i>	4	14%
	<i>7</i>	2	7%
	<i>8+</i>	2	7%

Speaking on how cultural influences impact health-seeking decisions and practices, one interviewee detailed:

“My parents were so anti-doctors, it wasn’t funny. Their home remedy was the only things they think you should take. My mother still thinks that if you take aloes, aloe would cure you. That’s it so, no, those things were never discussed. I had always had an interest in science so for me I would always read and was always curious about things like that and I believe that holistic approaches are very good but I also believe medicinal approaches are good as well and the combination of both makes it much better. So, no, I think the first time I heard about it was from the doctor because, most of the time, you hear about syphilis, gonorrhea, the biggest thing was AIDS and, you know, once I found

out that my husband was not being nice and being promiscuous, I had all those tests done. But I did not know about HPV. I mean the Human Papilloma Virus. We know people had cold sores that are caused by that so you'd never think that that was there. You also knew that people could get warts on their hands and they could also get warts in the genital area but those are all unknown facts. That fact that there was a connection with that virus to cervical cancer was relatively new to me and then, once I found out, I did a lot of reading and then I know that there are things but there are so many different strains of the virus and the Pap smear only detects a certain number. I think six of them so they don't really have the full spectrum and there is virus that mutate all the time. It can be undetected, even though the Pap smear has some detectability. So, yes, I did my homework. I got diagnosed [she discovered she had contracted HPV].”

A number of my informants indicated that they were cognizant of the food they consumed. As one respondent said: “I eat my vegetables...’cause I hear tomatoes help prevent cancer so I try to eat tomatoes and broccoli...and drink lots of water...don’t eat too much dairy stuff.” This 20-year-old young woman from Trinidad and Tobago who had moved to the United States just two months before our interview said when asked if she has a health care provider that she purposively does not go to the doctor. The last time she went to the doctor’s office was when she was back home in Trinidad and only received the required immunizations. If she has the flu she just handles that sickness from home. She said: “I am not a sickly person...if I get a sore throat I would just gargle with some lime...I don’t like to take too many pills. I don’t want my body to get accustomed to it.” She comes from a family that believes and practices in natural traditional remedies to eliminate body ailments, therefore she practices the same behaviors. “My mom drinks like bush tea, herb tea, every day. I don’t like all the teas. But I don’t drink milk. I’ve never really, ever since I reached a certain age. I don’t drink like coffee and stuff. I just drink water and juice.”

## **Conclusion**

The voices of Caribbean migrant women recorded and reported reveal material historical social and cultural processes of identity formation – these are gendered, sexed, classed, and

racialized bodies – and their transformative experiences of migration. These voices reveal the apprehension of particular knowledges about HPV transmission and cervical cancer derived from family contexts in the Caribbean as well as these women’s exposure to various forms of medical education and treatment in the United States. From these women we learn about their health-seeking beliefs, perceptions, and practices, from prevention to treatment. As such, we are able to obtain a glimpse into what turns out to be a rather incomplete and uneven knowledge apprehension and subsequent knowledge production regarding HPV transmission and cervical cancer – *these are the blurred lines of knowledge*. This evidence shows the value of conducting this investigation in the first place.

To reiterate, the research questions guiding my fieldwork were as follows:

1. What are common beliefs about HPV and cervical cancer among immigrant Caribbean women?
2. What does HPV and cervical cancer mean to immigrant Caribbean women?
3. In what ways have cultural beliefs and individual experiences influenced knowledge about HPV and cervical cancer?
4. How do these beliefs influence behaviors and prevention practices?

The questions put to my informants were directed at answering my question. Indeed, their responses mapped onto these questions quite nicely as seen in the ethnographic reportage above. Let us review the questions in light of the answers provided in the responses of the informants.

**Research Question 1: What are common beliefs about HPV and cervical cancer among immigrant Caribbean women?**

Many of my informants were familiar with the terms “HPV” and “cervical cancer.” Most women did not hear about HPV or cervical cancer in their home countries. If the diseases were discussed in their home country it was not at home or in healthcare institutions. The knowledge

exhibited by my informants about HPV did not vary from existing literature that suggests that many women are not aware of what the STI actually entails although the concept is heard often, they did not know how detrimental the STI is to one's health, and did not understand exactly how the STI is linked directly to cervical cancer.

Cervical cancer elicited more feedback due to the various meanings surrounding cancer more generally. However, the majority of participants were not comfortable with what they say as the accepted knowledge, even for those who already received the HPV vaccine.

Even when some of the younger informants who were college students at the time of the interview and had heard the messages about cancer, cervical cancer, STIs, and HPV, were still not totally "sold" on the idea of HPV causing or contributing to cervical cancer. This revealed how a lack of trust in general medical knowledge is present in this population. By actually having the vaccine and not truly believing that the shot is for what it is intended for demonstrated the lack of confidence in traditional Western medical practice and knowledge. Many instead exhibited that cultural folk belief systems or home remedies were trusted along with the accepted biomedical knowledge. Some of my informants stated that U.S. society was unhealthier than life in their home country. Many of the women reported that they will return back to their home country after their studies or later in life after their sojourn in the United States. Some depicted their beloved homeland in nostalgic ways.

Associating risk or risky behavior is subject to one self-identifying as someone who participates in a behavior that puts them at risk. Probing the women about what types of behaviors put them at risk were also accounted for and women who perceived themselves at risk from being sexually active or having some previous experience with cancer considered themselves to be at risk for HPV or cervical cancer. Some of the respondents acknowledged that

just being sexually active caused them to be at risk. HPV as a contributor to cancer risk was not voiced. The STI was not in their consciousness public sphere and therefore did not warrant any thought or concern. Cervical cancer or cancer was never discussed in their life so there was no cause to think about risk or even the association of sexual behaviors contributing to a disease that had no relevance to their life. Alternatively, cancer messages including prevention and treatment options were more abundant in the United States in various contexts compared to their Caribbean homeland and incited worry or created fear-based feelings. There was much discussion suggesting that the advertisement and awareness of diseases in the U.S. public sphere was in reality a strategy of monetary gain on the part of health care providers. Some respondents claimed that the economic advantage of health care providers and pharmaceutical companies was what was really behind campaigns for vaccination.

Some of the participants associated ideas of “promiscuity” and lack of hygiene to obtaining cervical cancer. Ideas relating gynecological health to a woman’s virtue were discussed. Some of the older (women over 40) or those who migrated to the United States later in life (after 21 years old) distinctly recall (when probed) how “women sicknesses” were viewed the Caribbean nations. Heavy religious affiliations were attached to women’s behaviors and social standing. These beliefs and feelings were visited on women’s bodies. One informant recalled how a woman in her community in her Caribbean homeland was ostracized due to her sickness, being called “stink” which marked how nasty or unholy she was as a woman, not deserving to be integrated into society.

**Research Question 2: What does HPV and cervical cancer mean to immigrant Caribbean women?**

This investigation shows how knowledge is transferred from the birth country to the new home country. The processing of new knowledge is conveyed through the messages about cancer

mediated in media outlets like the news, commercials, and through social media. Prevention messages are transferred from routine health check-ups with practitioners or clinicians or in formalized settings like university classrooms. Word-of-mouth is one of the most poignant modes of education on cancer, especially important involving marginalized populations like these immigrant Black women who depend on their close networks for information. My informant pool provides many examples of how cancer knowledge is obtained. It also shows how cancer knowledge is prevented from being passed on in their home Caribbean settings.

Navigating the healthcare system in the United States is of vital importance to the healthy status of the women. Many felt that access to the U.S. medical system increases the chances for individuals to live a life without disease or sickness. Yet, by contrast, others felt that one's life can be negatively impacted by being an immigrant in the United States by not being acclimated to the processes of making appointments for well-care visits, knowing how to obtain health insurance, or accessing prevention education on STDs and cancer.

These women attributed the causes of cancer to environmental and chemical exposures, genetics, and social and behavioral activities. As mentioned previously, a few study informants had a disdain for what they saw as "the American lifestyle" where they saw a higher incidence of disease as compared to their home country where they attributed this to chemically-infested food and cheap, unhealthy food.

At the same time, some of my informants possessed a high degree of knowledge about the origins and spread of HPV and its link to cervical cancer. Some attributed this to their undergraduate public health courses or to what they read on the internet or learned from a media outlet. My informants noted, however, that media streams and technological advances are global and much of the information that is available in the United States is also in their home country.



In general, the study population was a highly educated population and often knowledgeable about reproductive health topics. Future research should be considerate of those women who are not as educated as this group of participants. The study revealed how these women have knowledge facilitators such as education opportunities and employment-provided insurance, and how they received educational messages through many means and how, in turn, they proceeded to operate their transnational network by sharing that acquired knowledge with relatives back in their home countries.

**Research Questions 3: In what ways have cultural beliefs and individual experiences influenced knowledge about HPV and cervical cancer?**

Inquiring about the experiences with the health care system in the United States compared to their birth countries garnered information on how difficult the varying economic and structural barriers are in small Caribbean islands to full knowledge and preventative care. Some of the most poignant findings emerging from this study are the barriers that my respondents saw to a full and complete knowledge of the source and spread of HPV and cervical cancer. When asked about the causes of cancer, the responses revealed how some Caribbean women interpret nutritional and dietary intake as a major contributor to cancer and illnesses. A few respondents questioned their prior education about HPV and the HPV vaccine.

Some informants expressed their faith in the use of traditional herbal supplements to reduce the risk of disease. Others clearly placed their trust in biomedical prevention agents like vaccines and in biomedical treatments. When some of the women indicated that they avoided particular foods because of their supposed deleterious effects on health, I began to question these women's actual knowledge of nutritional associations with all disease.

Structural factors like educational level, economic level, and location of residence contributed to individual exposure to HPV information.

My informants commented on the stigma of cancer in Caribbean societies. They expressed how cervical cancer education is not discussed if at all until a well-woman's visit with a medical professional, and that even still it is very limited.

**Research Question 4: How do these beliefs influence behaviors and prevention practices?**

All of the women in my study knew about the Pap smear being a test for women. The majority of women did not know that the test is administered to check for abnormal cells on a woman's cervix. Some women thought the test specifically tested for HPV, some women thought that the test checked for cancer, while others had no idea what the screening test actually checked.

The informants thought that in the United States there are many messages perpetually targeted and integrated into the daily lives of American women that urge them to have an annual gynecological exam. The majority of the study participants had a Pap smear by a healthcare provider in the United States. Oftentimes, their first time was when they attended university if they were a student or at the urging of a female confidant.

For those who had a private care physician, the test was conducted by that provider and paid for by their health insurance. Few women in my sample were without insurance. This was because my sample included what I take to be an overrepresentation of full-time students with access to university health care facilities and formally employed women with insurance benefits through their employers. However, most women who reported having had the Pap smear testing procedure reported their experiences with the test as "uncomfortable," and they reported feeling "uneasy." However, some reported that they became more comfortable taking the test over time and "learned to deal with" the more test procedures conducted.

Some of my informants reported that sexual encounters can be altered in the United States compared to being in the home country due to the lack of familial connections and a lack

of a sense of belonging to the United States. Many of the women were very open about their sexual activity practices and expressed that they use prophylactic devices, but more so as a protection against pregnancy and other STDs such as HIV/AIDS.

### **Summary of Findings**

Throughout the dissertation I advocate for the fusion of a new CMA and political economy framework that is interpretive, providing an appropriate platform for exploring HPV and cervical cancer knowledge in the study population. In addition, this approach helps us understand how cultural beliefs, meanings, practices influence health-seeking behaviors regarding HPV. The awareness that this approach provides can allow women to be actors in their own right as they navigate the intersections of social and cultural constructs and political-economic structures in their daily lives. Their narratives illuminate how the social networks maintained with family and friends in their home country allowed the women to still be “at home” and operate as Caribbean women in Tampa. Yet, at the same time, newly created social networks and situations merged with pre-existing ideas, beliefs, and behaviors that may not have been available in their home country (e.g., online access to health information and treatment options). Political and economic transitions were enacted by the women in their experiences of operating in a class-based system that highly values and rewards capitalist markers of success (e.g., job, income, education). Structural and cultural factors such as immigration status, educational level, insurance and job status, as well as sexual behaviors, and attitudes about HPV coalesce to determine the experiences of these women and reveal how their daily lived experiences of being Black Caribbean immigrant women affect the meanings, knowledge, beliefs and screening practices of this population residing in Tampa Bay.

The Caribbean diaspora in the United States is truly transnational, as so in the subject population for this research. As Laughlin (2008) notes that Caribbean people leave their islands of birth and taking elements of their respective cultures into “the wider world, creating new connections and fusions.” This was evident with the medical pluralism displayed in the simultaneous use of home-based herbal and folk remedies along with biomedical practices to prevent disease or illness, such as obtaining HPV vaccinations, enduring cancer screenings along with prescription drug intake for ailments. These transmigrants have established a new set of meanings about disease for Black Caribbean immigrant women, in their new space and in their newly ascribed social role in the United States. Their perception of preventive behaviors was altered due to the lack of knowledge and education about HPV, cervical cancer, and the concept of sexual disease transmission. Nevertheless, this new platform continuously forges and sustains the multi-stranded relationships these women have domestically and abroad, where the cultural models of their country of origin still play an active part of their life in the United States. Laughlin (2008) invokes the Caribbean poet and scholar Louise Bennett who called this “colonization in reverse” or a form of “creolization as elements of an already hybrid Caribbean culture go forth to negotiate with other cultures to create new and unpredictable hybrids.” This is just what my study population of Caribbean migrant women does.

The experiences of embodiment are embedded in the historical Caribbean cultural constructs encompassing these women’s physical, emotional, spiritual, and mental encounters in their daily journeys. Through their narratives and cultural constructs, these women locate their experiences and health-seeking decisions based upon previous and current professional, familial, business, personal, and sexual relationships, all while charting a new course operating as Black immigrant women in contemporary American society. Whether it is recalling memories as a

young child hearing about a woman who was called “stink” because she had a “woman’s disease,” or reflecting how one’s own previous health experience with biomedicine influenced decisions on following up on negative test results, their experiences and meanings of sickness guide future action and decisions about their individual bodies, all while negotiating this intersection of power, immigration, and health-decision making.

## **Chapter Six: Conclusion**

### **Contributions to Medical Anthropology**

As many anthropologists argue (e.g., Schensul, et al., 1999; LeCompte and Schensul 1999), if anthropological theory, methods, analytic procedure, and results are clearly described in local context then the potential for reliability and generalizability is enhanced. It is hoped that this research enhances the CMA approach by incorporating, not merely tacking on, a new interpretive dimension that allows us to simultaneously understand political-economic forces that account for health beliefs and behaviors while at the same time understand our subjects' understandings through an interpretive procedure – Roseberry argues that “Interpretation cannot be separated from what people say, what they do, what is done to them, because culture cannot be so separated” (Roseberry 1988:1028) – and thus becomes a generalizable model that can guide future medical anthropological research. An interpretive CMA approach such as the one I have provided here conceives of symbolic representations not as unconnected from the wellings up of power and structural constraints, but rather as constituted by and constituted of material social relationships located in ongoing historical processes. These include the large-scale processes of migration, transnationalism and the maintenance of transnational social and familial ties, culture change, and economic and social integration, along with more individualized forms of health-related beliefs, perceptions of disease risk, and health-seeking behaviors.

Because the topic of my dissertation research is not confined to medical anthropology, but, however, is of central concern to such disciplines as public health, nursing, psychology, and sociology, I am also concerned with the translation of my theoretical approach to those domains.

The field of public health is multi-disciplinary and offers insightful models for application beyond anthropology for this research project. There are numerous theories that account for exploring health behaviors and health promotional efforts to improve health, reduce of disease risks, and management of illnesses. Many of these frameworks relate to health behavior and health promotion perspectives adapted from social and behavioral science disciplines including psychology, sociology, anthropology, and consumer and marketing behavior (Glanz et al. 2002). At the same time, I believe that the interpretive CMA model that I am proposing can provide a corrective to at least two standard approaches in public health research, namely the Health Belief Model (HBM) and Theory of Reasoned Action (TRA). The HBM was created to explain and predict health behaviors. This model was created by in the 1950s by social psychologists working for the U.S. Public Health Services focusing on the attitude and beliefs of individuals (Glanz et al. 2002). The model addresses intrapersonal or individual “cognitive-behavioral” levels of influence. These levels of influence guide healthy decision-making practices for an individual to practice a health behavior, supply adequate information to increase knowledge to change a behavior, and to obtain perception of attitudes that affect behavior (Glanz 2002). The HBM framework provides the context to comprehending how an individual will take a health-related action if a negative outcome can be avoided, if a person expects a positive outcome if a recommended action is taken, and finally, if the person believes that a healthy activity can be conducted (Glanz et al. 2002). However, it is apparent that this model cannot incorporate the political-economic structures that account for broad health outcomes into an explanatory framework because it assumes that behavior is generated primarily by ideas, that individuals have agency (this is the problem of “voluntarism”), and that individuals act in rational ways (this is a form of rational choice theory).

Similarly, the TRA framework considers the difference between attitude and behavior towards health practices. This framework primarily relates to voluntary behavior. Additionally, the model suggests the best predictor of a health behavior is the intention one has to perform a certain action. Intention is considered to be the “cognitive representation of a person’s readiness to perform a given behavior” (Ajzen 1991). It assures an individual’s behavior is determined by the intention to perform an action and that intention forms the attitude toward that behavior and subjective norms. The model upholds that intention is determined by a person’s attitude toward a behavior, their perceived control over behavior and their subjective norms or beliefs.

Incorporating medical anthropological perspectives into these popular and widespread health behavioral constructs and their aligned paradigms from concerned disciplinary traditions will enrich these traditions and provide further explanatory power. The interpretive CMA approach that is advanced here has the potential to critically illuminate the dynamics of sexual health-related practices and decision-making processes by immigrant Caribbean women residing in the United States. A CMA approach which is aligned with political-economic perspectives within anthropology and which is critically interpretive demonstrates the necessity of accounting for the efficacy of structural forces as well as the operation of symbolic systems and cultural styles in trying to understand health-related beliefs, perceptions, and health-seeking behaviors in the population in question.

### **Advocacy and Anthropology: Applied Anthropological Implications**

Practicing advocacy within the discipline has long been debated. As a student of anthropology who intends to promote advocacy through research I have to take into account issues related to practicing or applying advocacy within my work. As Graham states, “anthropologists who study populations suffering from human rights abuses and forms of



injustice have an ethical obligation to seek ways to improve these conditions...this discipline has an obligation to promote social justice...Anthropologists who work with vulnerable, indigenous and other marginal communities have a special responsibility to engage in support of these groups, or advocate on their behalf” (2006:4). Of course, it is possible in some cases that groups do not desire to have an advocate. One also must be suspect of advocacy when the researcher’s values and position are being imposed instead of the values and positions of the affected group. Research that attempts to arrive at solutions requires negotiation, sharing of power and making joint decisions that are advocated by critical theorists and ethnographic researchers. As Lather (1986) highlights, research that stimulates local communities and groups to identify and help solve their own problems is indeed “catalytic” and, in that sense, has “catalytic validity” (Lather 1986). Therefore, anthropological advocacy is not straightforward, nor is it easy. As Nagengast and Vélez-Ibáñez note, the “relationship between activism and research is sometimes thorny for anthropologists” (2004:17). Anthropologists can protect and promote human rights by incorporating their skills into activist work. By negotiating research goals and benefits (e.g., incentives, compensations) with the target community, recommendations for health services and social services can be effectively incorporated.

This dissertation research contributes to interdisciplinary approaches in reducing the disparities of the impact of the diseases in the Caribbean Diaspora. Most importantly, the study contributes to literature applying anthropological perspectives and methodology to narrow the gap in available literature relevant to migration, Black Caribbean immigrant women’s health, and cancer health disparities. The findings reveal transnational cross-cultural factors affecting risk perceptions in the United States, specifically Tampa Bay. The lack of current available professional literature targeting the elimination of the disease for this population demonstrates

the need to integrate medical anthropological application into the discourse of eliminating cancer health disparities throughout Tampa Bay, the state of Florida and essentially the United States.

Additionally, the field of public health is multi-disciplinary and offers insightful models for application beyond anthropology for this research study. By identifying the relevant themes of HPV and cervical cancer in the targeted population, integrated efforts toward reducing HPV-associated outcomes and increase prevention initiatives in the origin home Caribbean countries can also be accomplished (e.g., radio advertisements, soccer game sponsorship announcements, integrated messages in soap operas).

Contextualized efforts toward reducing disparities of HPV and cervical cancer can begin by developing culturally-tailored intervention programs addressing the identified themes of obtaining gynecological health services, acquiring education and knowledge about gynecological health, tackling barriers for those seeking cervical cancer screening and HPV testing, improving knowledge about HPV vaccine and motivating factors affecting the acceptance or denial of the vaccine. These factors can be communicated through national social marketing and educational campaigns while recognizing how cultural norms, transnational factors of politics and the economy integrally affect health-seeking behaviors in both Caribbean countries and the United States.

Medical institutions, hospitals and public health departments which serve this target population are charged to elevating the health status of patients who are potentially at risk for HPV. In developing nations, the local community health clinics are most often the common provider of gynecological services. Clinicians and health care providers are the frontline communicators of prevention messages and the research substantiates how the participants abide by the advice of their doctors. Health marketing campaigns can aid Ministries of Health to

implement culturally-appropriate prevention messages during well-woman visits, prenatal care appointments along with educational materials developed for dissemination at STI testing stations.

Outside of the medical community, valued stakeholders in the community are most fundamental in promoting the messages of abstinence or testing when discussing STIs prevention. While there are women who visit local community health clinics, some women do not visit health institutions. There is a segment of women who are still very modest and traditional in morals and respectability; primarily situating knowledgeable advice from their respected faith-based venue or religious institution was not discussed in every interview, however there was a recognized tone of viewing promiscuity as negative and being virtuous and purity as an aspirational concept, rooted heavily in strong religious affiliations of Caribbean consciousness. Marketing messages from within a religious institution, with the leader of the church (e.g., pastor) recognizing that his/her high risk congregation needs to reduce any risks of disease, would be a most effective strategy.

Meanwhile, taking my responsibility seriously, I have publicized the findings generated from this study in professional, clinical and community-based settings, domestically and abroad. I attended and presented dissertation research at numerous scientific conferences and workshops. These research venues assisted in developing my research agenda and narrowing the scope of my dissertation research, but they also, more importantly, provided information for various audiences. During fieldwork in Jamaica for a project on medical migration in 2008, I was able to network and facilitate vital relationships with potential stakeholders (e.g., Ministry of Health officials, University of West Indies-Mona faculty researchers, and regional health departments) in this dissertation study and obtained informative preliminary data.

I initially presented the research proposal at the Caribbean Cultural Studies Association Conference in Kingston, Jamaica in 2009. I attained critical feedback on the methodology and population criteria. I was also able to facilitate discussion amongst colleagues throughout the Caribbean that guided my research on focusing on HPV knowledge and perceptions among Caribbean Diasporic populations in the United States. While in Kingston, Jamaica, I met with investigative researchers who examined HPV genetic expression in Jamaican women, and who explored knowledge and attitudes about HPV vaccination in college-aged women.

It is vital that academic research be tailored to play a role in the application of knowledge. The dissertation abstract was submitted and accepted for presentations at the American Cancer Society Health Disparities Conference in Las Vegas in 2009, the Penn-ICOWHI 18th Congress on “Cities and Women’s Health: Global Perspectives” in Philadelphia in 2010, and the Caribbean Exploratory NIMHD Research Center’s Fourth Health Disparities Institute in St. Thomas, U.S. Virgin Islands in 2011. Preliminary results from the qualitative data that were collected for the dissertation were presented at the 13th NIH RCMI International Symposium on Health Disparities in San Juan, Puerto Rico in 2012. The findings have also been presented at the McKnight Doctoral Annual Conference in Tampa in 2014. I was also an invited special session presenter at the 4<sup>th</sup> International African-Caribbean Cancer Consortium Conference in Philadelphia in 2012. The presentation of preliminary work in these academic and professional venues situated my research to be shared in the public sphere with colleagues focusing on reducing cancer health disparities and improving the health outcomes of immigrant populations within the United States.

It is imperative that the community who is being influenced by this research receive the results of the data collected about this targeted population. Community-led discussions have

been presented throughout the Tampa Bay area. I presented the research proposal at two USF Caribbean student-affiliated organizations (medical school organization and undergraduate organization) highlighting health education and prevention efforts in the college-aged population of the local Caribbean Diaspora. She also presented a paper based on the research at the conference of the Institute on Black Life at USF titled “Activism Matters: Scholarship, Engagement, and Action!” in February, 2016. Subsequently, I have provided educational materials on HPV for Caribbean health fairs and workshops.

Future research efforts should involve strengthening existing partnerships with academic research organizations and community entities to implement the Community Based Participatory Research (CBPR) framework to guide interdisciplinary actions to reduce the disparities of HPV and cervical cancer in the Caribbean Diaspora. According to the W.K. Kellogg Foundation Community Health Scholars Program, CBPR is a “collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community, has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities” (Community-Campus Partnerships for Health 2013). This approach acknowledges how social, political and economic structures contribute to health outcomes. Incorporating this perspective into future research will assist in utilizing natural community advocates or community health advisors/workers to decrease health inequities in their respective locales and lay groundwork for policy development.

By training community health workers or lay health advisors to implement a train-the-trainer curriculum on HPV education in Caribbean communities, domestically and globally, can contribute in engaging participatory action toward educating, empowering and increasing the

knowledge of sexual health prevention and practices. Educational fora will be implemented via non-profits, faith-based institutions and university organizations locally.

### **Limitations of this Research Study**

While this study makes contributions to anthropological theory as well as applied knowledge, there are nevertheless several limitations to this research project. First, while this study obtained insightful narratives from 33 study participants (the five focus group participants plus the 28 interviewees), the sample size was relatively small and the results of their feedback cannot be generalized for the entire population of Caribbean immigrant women. And although the sample size was appropriate for qualitative exploration and garnered culturally-derived themes, the results do not speak for all Black Caribbean immigrant women in Tampa, in the state Florida, or the United States. This study population was a highly-educated group and had an elevated socioeconomic status.

Secondly, the qualitative results and quantitative survey data were self-reported. Data obtained through the process of self-reporting can be biased based upon what the participant wants me to know or alter responses to what she thinks I need to hear about her, especially with her behaviors (e.g., the number of sexual partners). Recall bias should also be considered. Some participants moved to the United States over 20 years ago and recalling memories and experiences from a distant timeframe may not be accurate.

Snowball or convenience sampling bias could have hindered the study by producing findings from women who were not randomly sampled from a large population. The study sample population was specifically targeted and participants were selected based upon word-of-mouth recruitment or at selective venues.

Lastly, I had to be cognizant of researcher bias by abandoning preconceptions on what expected responses she anticipated or what type of people she would interview. I was keenly aware of her position as an applied researcher and therefore strived to establish a strong rapport with the individuals and organizations she recruited to participate in the study. Contemporary American discourse situates the agency of Black immigrant women in a liminal space where they are not seen or heard and essentially lost due to their residency status, racial-ethnic identification, and gender.

Knowing that the “voices” and experiences of the English-speaking Caribbean population are often masked by African American or Black American cultural scripts, I was strategic in achieving reciprocity and empathy for transparent ethnographic inquiry. This research project was appropriately framed to empower Black immigrant Caribbean women to begin initiating self-hood and independence in transnational communities, in their home countries and improve gynecological health-seeking behaviors.

Chávez (2003) recognizes that immigrant behaviors and cultural beliefs can be protective and paradoxical to the biomedical literature, often noted as the “healthy immigrant status.” However, Nazroo (2007) found that the overall health status of Caribbean-born immigrants in the United States and England was better than Black and some White Americans. Nevertheless, one cannot help but to ask to what extent is the Caribbean population more protected or even more vulnerable than other Black populations in the United States? Are Caribbean-born populations better or healthier than U.S.-born Blacks in Florida? How vulnerable are these immigrant women compared to U.S.-born Black women? Answers to these questions are unknown and require further exploration. My dissertation research attempted to explore answers to these broader questions.

## **What Does It All Mean?**

While this research study illuminates the complex lived experiences of Black Caribbean-born immigrant women in the United States, it goes beyond this population and even goes to the personal. As a young-college aged woman myself being diagnosed with this infection prior to the pharmaceutical company educational campaigns of the late 1990s, I was confused. “What was this thing called HPV?” “How could this occur?” “What was the cause?” “How long had I had it?” “Could the diagnoses become deadly?” All questions an unassuming undergraduate student would ask and want to know the answers to yet knew nothing about or wanted to ask. I found myself not knowing what actions could have prevented the health outcome if more education was provided about the infection, or even if a discussion with a healthcare provider, better yet, possibly candid discussions about personal behavior with family members, which could have influenced my collegial decision-making. The unfamiliarity and vulnerability experienced by me and so many others are the reason I advocate and continue to initiate works for those who are in similar states of ignorance or shamefulness – offering a sense of solidarity and action for the silenced ones.

My own personal experience with HPV diagnosis, along with the narratives expressed by the study participants, all intertwine within the experience of being a woman of color who has been affected by HPV or cervical cancer. Whether the stories cross waters, span beyond national borders, or extend beyond transcultural barriers, their memories and lived experience context warrants recognition in the landscape of immigrant health and sexual health education. Through these narratives their unified voice is resonating, being heard and accepted as a viable perspective in the scholarly arena.



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## Appendix A: USF Institutional Review Board Approval



DIVISION OF RESEARCH INTEGRITY AND COMPLIANCE  
Institutional Review Boards, FWA No. 00001669  
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799  
(813) 974-5638 • FAX (813) 974-5618

June 19, 2012

Maisha Standifer (Kambon)  
Community and Family Health  
12901 Bruce B. Downs Blvd., MDC 30

RE: **Expedited Approval** for Initial Review  
IRB#: Pro00006911  
Title: Exploratory Study on Caribbean Immigrant Women and HPV

Dear Maisha Standifer (Kambon):

On 6/18/2012 the Institutional Review Board (IRB) reviewed and **APPROVED** the above referenced protocol. Please note that your approval for this study will expire on 6/18/2013.

Approved Items:  
Protocol Document(s):

<a href="#">Disseration proposal</a>	6/13/2012 3:41 PM	0.01
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### Consent/Assent Documents:

Name	Modified	Version
Adult Consent form granted a Waiver of Informed Consent Doc.		

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110 and 21 CFR 56.110. The research proposed in this study is categorized under the following expedited review category:

## Appendix B: Participant Recruitment Flyer



Are you from the Caribbean islands?

Would you like a free \$25 Wal-Mart  
gift card?

### **You can get a gift card if you are:**

- Black Caribbean
- Female
- 18-60 years old
- Live in Tampa Bay area

I am conducting research on HPV and cervical cancer with Caribbean-born women who live in Tampa Bay and want to interview women for this study “Exploratory study on Caribbean-Born Women and HPV Meanings” (eIRB#6911)

Please call Maisha Standifer if you are interested  
@ 813.974.7039 or send an email to [caribbeanwomenstudy@yahoo.com](mailto:caribbeanwomenstudy@yahoo.com)





## Appendix C: Informed Consent Form

Dear Participant,

You are being asked to take part in a research study for the dissertation titled “*Exploring the Sociocultural Context of Risks Associated with HPV in Black Caribbean Immigrants Living in Tampa Bay, Florida.*” I want to find out how knowledge surrounding HPV is transmitted and associated with risks and behaviors associated with cervical cancer.

In the first part of this project, I am conducting focus groups to learn more about the risks and behaviors associated with HPV and cervical cancer. In the second part of the study, I will conduct individual personal interviews to learn more about individual’s knowledge, and meanings associated with risks and behaviors linked to HPV and cervical cancer.

Your comments are important to me. This information might be used to inform health education programs targeting this population.

The Principal Investigator for this study is Maisha Standifer, who is a USF Anthropology graduate student working on her dissertation under the supervision of faculty advisor Dr. Kevin Yelvington.

I am asking you to take part in this study because we feel that you can give important information. You are asked to spend about 2 hours of your time to take part in a focus group. A focus group is a small group discussion that includes 8-10 people. You will be asked about HPV and cervical cancer and associated behaviors, risks, perceptions, and healthcare choices you make. Because of the group setting, absolute confidentiality cannot be guaranteed. However, we ask that you keep what is discussed during the group confidential and not disclosed to others outside of the group.

In the interviews, you are asked to spend about 2 hours of your time to take discuss your experiences and knowledge about cancer and associated behaviors, risks, perceptions, and healthcare choices you make. There are no right or wrong answers.

We will audiotape the group discussion and the interviews, so that we will not miss any of the comments and ideas that are shared. Everything you say here will be kept confidential. You will not be linked to any of the comments that you make.

There may be no direct benefit to you by taking part in this study. There are no known risks by taking part in this study.

You will receive a \$25 gift card at the completion of taking part in this group discussion or interview. Participants will take place in two focus groups that will last for two hours. At the completion of these two hours, there will be no further time requirement for participants. You will be asked to participate in either a focus group or individual interview, not both. You will only be asked to participate one time. A total of 40 participants will be a part of this study.

It is up to you if you want to take part in this study. You can withdraw at any time. If you decide not to take part in this study it will not affect your relationship to any social organization or the university.

If you have questions about your rights as a person who is taking part in a research study, you may contact the Division of Research Compliance of the University of South Florida at (813) 974-5638.

The results of this study will be used for the completion of research toward a PhD in Anthropology. Results of the study will not include your name or any other information that would personally identify you in any way.

Please feel free to contact us if you have any questions or concerns, and thank you for your time.

Sincerely,

Maisha Standifer, MPH, PhD(c)  
813.210.1250  
[mkambon@health.usf.edu](mailto:mkambon@health.usf.edu)

## **Appendix D: Demographic Questionnaire Survey Instrument**

### **Self-Administered Survey Questions**

#### Demographic Characteristics

What is your age?

What is your educational level?

-High school graduate

-Some college

-College graduate

-Beyond graduate school

What is your race/ethnicity?

Where were you born?

How long have you lived in the U.S.?

What are your living arrangements?

-Single

-Married

-Divorced/widowed/separated

What is your household income level (total income)?

What is the primary language spoken in your home?

Are you currently employed?

What is your occupation?

Do you have health insurance?

Do you have a regular health care provider?

What was the age of your first sexual encounter?

What is the number of lifetime sexual partners?

Questions are derived from the following studies and their validated instruments:

Chavez et. al 1997  
McMullin et al. 1997  
Daley et al. 2008  
Chavez et al. 2001  
Luque et al. 2011  
Luque et al. 2010  
Menard 2009

## **Appendix E: Interview Guide – Focus Groups**

### **Questions on Knowledge, Beliefs and Risks (Focus Group)**

Have you ever heard of HPV?

When did you first hear about it?

What is HPV?

What causes HPV?

Do you think HPV be prevented?

Do you think HPV sexually transmitted?

Do you think HPV is common?

Do you think HPV goes away without any treatment?

Do you think HPV causes cervical cancer?

Have you ever heard of cervical cancer?

When did you first hear about it?

What is cervical cancer?

What causes cervical cancer?

Do you think cervical cancer can be prevented?

What are some causes for cervical cancer?

### **Questions on Behavior & Lifestyle**

What is a Pap smear test?

Have you ever had a Pap smear test? If so, how long ago?

What was your experience?

Have you had a medical checkup in the last year?

Did you seek medical care in country of birth?

Do you currently seek medical care?

What services do you receive from your healthcare provider?

What are your experiences with your provider?

Any questions you would like to ask me?

Questions are derived from the following studies and their validated instruments:

Chavez et. al 1997

McMullin et al. 1997

Daley et al. 2008

Chavez et al. 2001

Luque et al. 2011

Luque et al. 2010

Menard 2009

## Appendix F: Semi-Structured Interview Questionnaire – Individual Participants

### In-Depth Individual Interview Questions

#### *Introductory Questions*

Where were you born?

How long have you lived in the Tampa area?

How long have you lived in the United States?

-----

When I say the word “cancer”, what comes to mind?

Probe: What do you think of when you hear the word cancer?

What do you think are some of the causes of cancer? (Probe until listing is provided)

What are some of the cancers that women get? (Probe until listing is provided)

What’s your understanding of some of the causes you just mentioned? How does a woman get \_\_\_\_ cancer?

Probe: You mentioned \_\_\_\_\_ causes cancer. Can you tell me more about that?

Probes: Why do you believe that \_\_\_\_\_ causes cancer? What do you believe? Where did you hear about these causes? Were these causes ever talked about in your home country? How so?

I’ve read/heard several things that may contribute to women’s cancer like hard rough sex, large penises, too many sex partners. Have you heard about any of these causes? What have you heard?

Probe: Have you ever heard of an infection or virus causing a cancer?

Probes: If cervical cancer is mentioned-

What does the word “cervical cancer” mean to you?

What do you think are some of the causes of cervical cancer? (Probe until listing is provided)

What were you told about cervical cancer in your country of birth?

Probes: If HPV is mentioned-

Have you ever heard of HPV or Human Papilloma Virus?

What do you think are some of the causes of HPV? (Probe until listing is provided)

What does the word "HPV" mean to you?

Probe: How do you get HPV?

Did you ever hear about HPV in your country of birth?

Probe: If so, what were you told about HPV?

Probe: Do you believe that? What do you believe?

Probes: If more discussion is warranted for HPV and cervical cancer-

Do you think cervical cancer and HPV are connected?

Probe: If so, how are they connected? Do you think one is a possible cause of the other?

How would you know if you had cervical cancer?

How would you know if you have HPV?

-----

Do you think you are at risk from a cancer?

Probe: Which one? Can you tell me more about why you think you would be at risk?

\*Can you look at this list and tell me which things do you believe help you get cancer?

-Show list of possible causes

Can you tell me more about why you picked this one on the list?

Are you familiar with any test for any cancers women get? If so, what are the names of the tests?

Probe: Have you had any of the tests before?

Probe: How do you feel about them? What is your experience with the tests?

Probe: Does any experience stand out as being positive? Does any experience stand out as being negative?

Where do you get tested for cervical or HPV?

Do you have a regular healthcare provider?

What are your experiences with the health care system?

How were the experiences different in your country of origin?

Probes: Can you tell me more?

Where do you get your health information from?

Based on your experiences how do you feel immigration status affects the information you receive on cancer?

Probe: Female cancers? Cervical cancer? HPV?

Probe: How so?

### *Sexuality*

Can you tell me more about sex playing a part in some of the female cancer mentioned earlier?

Probes: Do you think many sex partners play a part in getting cancer? Female cancers? Cervical cancer?

Would someone be at risk if they slept with several people? How so?

What else might play a part in getting a female cancer, like cervical cancer?

If a friend told you that she had a female cancer like cervical cancer what would you tell her?

What would you think of her?



Do you feel you might get a female cancer one day? Why? Tell me more.

Do you believe there is a cure for female cancers? How so? Tell me more.

Do you use to anything to prevent female cancer?

Probe: If so, what do you use?

Are there any traditional remedies or activities used?

If so, what are they?

### *Conclusion*

What would you like to know about any cancers?

Probes: Female cancers like cervical cancer? STIs like HPV?

What have you heard about cervical cancer, STI or HPV in the U.S.?

Did that differ from what you heard in your country of birth?

Is there anything else you would like to tell me?

Is there anything you would like to ask me?

Questions are derived from the following studies and their validated instruments:

Chavez et. al 1997

McMullin et al. 1997

Daley et al. 2008

Chavez et al. 2001

Luque et al. 2011

Luque et al. 2010

Menard 2009

## **About the Author**

Maisha N. Standifer's training as a medical anthropologist has allowed her to provide unique insight into health research focusing on disparate populations, women and medically underserved groups. She is particularly interested in focusing on the intersections between culture, health, and community-based education. Mrs. Standifer works throughout the Diaspora in the United States and globally, intending to narrow the gap in research and literature surrounding knowledge production in the areas of health disparities and health equity. Her future work intends to produce community-based participatory research to create culturally-tailored interventions that will empower disenfranchised populations to make healthy informed decision-making life choices. Maisha Standifer received a Master's Degree in Public Health from the Rollins School of Public Health at Emory University and received her Bachelor's Degree in Sociology from Spelman College.