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# The Social Context of Cervical Cancer Knowledge and Prevention Among Haitian Immigrant Women

Janelle Marie Menard  
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The Social Context of Cervical Cancer Knowledge and Prevention  
Among Haitian Immigrant Women

by

Janelle Marie Menard

A dissertation submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy  
Department of Anthropology  
College of Arts and Sciences  
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## DEDICATION

Many people have inspired me to pursue and finish graduate study in this field that I love so much. I am grateful to Beth Barnett-Pathak for sparking my interest in integrating social epidemiology and anthropology, and for her thoughtful advice and friendship over the years. Erin Kobetz has been hugely inspirational in myriad ways, as a colleague, a dear friend and mentor, and I am very excited to continue what we have started.

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## **The Social Context of Cervical Cancer Knowledge and Prevention among Haitian Immigrant Women**

Janelle Marie Menard

### ABSTRACT

Cervical cancer is the primary cause of cancer deaths among Haitian women; however, the social context of cervical cancer among Haitian immigrant women has not been systematically examined. The ways in which women assign meaning to this disease, understand its causality and situate it within the broader context of gynecological health are poorly understood. Further, Haitian immigrant women's perceptions of disease risk, including knowledge and understanding about Human Papillomavirus (HPV), the primary etiologic factor in cervical cancer, have not been explored. Few studies have assessed health behaviors, including culturally mediated feminine hygiene practices, among Haitian immigrant women, which may negatively impact gynecological health.

This exploratory study examines these dimensions of gynecological health using ethnographic methods including participant observation, observation, informal and semistructured interviewing and surveys. Ethnographic data contextualize this disease in larger cultural and historical contexts. In addition, these data informed the construction of a 92-item survey, ensuring content validity of the personal questions women were

asked about feminine hygiene practices and the agents they use. This survey, administered to 246 women in Little Haiti, Miami, represents an application of medical anthropology to epidemiologic research. Each survey respondent also was evaluated for cytology and sexually transmitted infections (STIs), including HPV, using a self-sampling medical device.

Quantitative analysis of survey data indicates that prevalent STIs (Chlamydia) are significantly associated with feminine hygiene practices; however, HPV infection and cervical cancer are not associated with the practices. The practices are likely underreported in the survey sample. Qualitative analysis reveals that women's constructions of gynecological health are inseparable from cultural beliefs that emphasize feminine hygiene. Beliefs guide behaviors, which include vaginal douching and intravaginal washing, using plant-based therapies, imported commercial products and chemical compounds. These practices serve the purpose of not only cleaning, but also drying and tightening the vaginal environment for increased sexual pleasure of male partners. Attempts to preserve relationships, and reduce the chance that partners will take mistresses, occur through maintaining intimate hygiene and, in some cases, by other ethnomedical means.

## **CHAPTER 1**

### **INTRODUCTION**

#### **Rationale for this Research**

This research addresses the social and cultural contexts of Haitian immigrant women's gynecological health, with a specific focus on cervical cancer and culturally mediated feminine hygiene practices, which may put women at greater risk of developing cervical cancer. Of all the various forms of cancer, cervical cancer is perhaps one of the most interesting from a medical anthropological perspective. This particular disease allows for a simultaneous and necessary examination of how cultural and structural factors are intertwined and give rise to unequal burdens of disease for women from marginalized and resource-poor situations. Cervical cancer is the primary cause of cancer deaths among Haitian women (Lewis 2004); however, the social context of cervical cancer among Haitian immigrant women has not been systematically examined. The ways in which women in this transnational context assign meaning to this disease, perceive risks, and engage in reproductive health behaviors are poorly understood. Through in-depth explorations of these meanings, local knowledge and behaviors, this research will provide rich ethnographic data to contextualize this disease in the larger immigration and historical context.

## **Theoretical Approach**

This research addresses the theoretical question of how historical, social and cultural processes shape health beliefs and behaviors, and how they become embodied expressions of illness over time. A critical elucidation of the social spaces, historical and cultural contexts in which health and illness manifest is essential to understanding the excess cervical cancer morbidity and mortality experienced by Haitian immigrant women. A biocultural paradigm is especially well suited for making explicit the multi-layered contexts in which this disease impacts women, and how it affects women according to social class, ethnicity, nationality, citizenship and foreign-born status.

This theoretical framework represents a fusion of cultural and material approaches, as it is informed by cultural constructivist and structuralist perspectives, political economy and political ecology. As Dressler (2001) states, "...as anthropologists studying health, we have stumbled into an arena that demands that we understand how structure and cultural construction intersect, because that intersection leaves its mark on the human body" (Dressler 2001:457). This evolving framework in medical anthropological studies permits critical examination of the intersections of biology and culture and resultant effects on human health. This framework is especially relevant for placing disease patterns within historical contexts, social environments, and in recognition of social structures that give rise to social inequality, and thus unequal exposures and burdens of disease



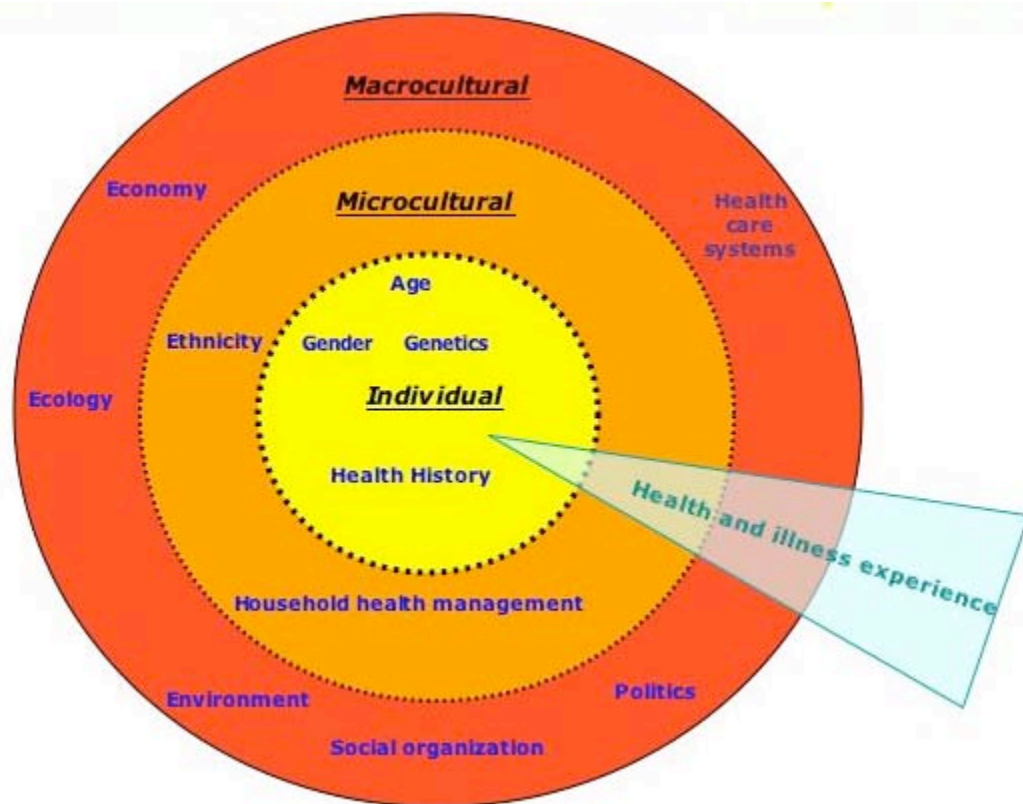
(Leatherman 1998, Leatherman 2005, Oths 1999).

Human social environments are the contexts in which disease risk develops, where notions and practices of prevention are born and therapy options are defined and delineated. They are also the sites where disease risk may be buffered by health-contributing determinants such as social support, fulfilling work, and access to higher education. These environments include physical surroundings, cultural belief systems, social networks, and historically structured gender and power relations (Barnett et al. 2005, Barnett and Casper 2001). Within social environments, culturally mediated etiologic beliefs serve to guide people's understanding about disease, from prevention to treatment (Dressler and Oths 1997). Social environments, then, help to shape the distribution of health and illness across human populations.

In keeping with Dressler's and Leatherman's call for a new synthesis, and McElroy and Townsend's holistic systems approach, a biocultural framework positions social phenomena, including health and illness, within a wider political, economic, and sociohistorical framework and allows for a simultaneous examination of the effects of macro- and microlevel forces upon the health of individuals and populations (Dressler 2001, Leatherman 2005, McElroy and Jezewski 2000, McElroy and Townsend 2004). In essence, it allows for a more complete understanding of the dynamic relationship between biology, culture, illness, and disease risk in social and physical environments and results in more fruitful explanations for unequal disease distributions. Figure 1, on the following page, depicts the interrelated analytical levels of a biocultural model (McElroy and Jezewski 2000). This

theoretical framework is especially relevant to understand health in the context of immigrant women’s lives, where elements of culture and structure constantly and dynamically interact and become embodied representations of these intersections. Indeed, cervical cancer studies are well suited to this perspective, for disease distributions are strongly uneven and invariably correlated with poverty and social marginality on global, national, and local levels.

**Figure 1. A Biocultural Model of Interrelated Analytical Levels\***



\*Adapted from McElroy and Jezewski, 2000

A biocultural approach is also useful for examining and understanding cultural and structural contributions to the distribution of cervical cancer at the population level. This approach is congruent with ecosocial theory in social epidemiology, which emphasizes how interconnected social and biological processes become embodied in individuals, and shape population health profiles over time (Krieger 2001a). The two approaches mirror one another in many ways; however, a biocultural approach more strongly stresses the role of *culture* in human health and illness. The two approaches also serve to foster the growing, common dialogue between medical anthropology and social epidemiology. This dialogue is critical for advancing collaboration to create health interventions, where concepts of epidemiologic risk can be translated into culturally meaningful actions for prevention (Dunn and Janes 1986, Trostle 2005, Trostle and Sommerfeld 1996, Weiss 2001).

This common dialogue resulted in a research collaboration that became part of this dissertation research. I worked with an epidemiologist, using my ethnographic data on agents women used for feminine hygiene practices and ethnoetiologic beliefs about cervical cancer and hygiene, and helped to inform the content of an epidemiologic survey about Haitian women's gynecological health beliefs, culturally mediated feminine hygiene practices and preventive health behaviors. The survey, administered to Haitian immigrant women residing in Miami's Little Haiti ethnic enclave, is an example of how interdisciplinary collaboration is fruitful for elucidating the importance of culture to population health. Survey participation was complemented with cytology screening using a self-sampling device used by

women in their homes. Women's stated health behaviors were then compared with cervical samples testing for HPV, gonorrhea, Chlamydia, cervical cancer and cervical dysplasia. This method is discussed in further detail in Chapter 6, Research Design and Methods.

In sum, a biocultural perspective is valuable for its inclusion of culture *placed within* a broader sociohistorical context, in understanding how health and illness manifest in different populations and cultural groups. Culture is often narrowly conceived and incorrectly blamed for individual-level harmful health behaviors in public health research, while structural inequalities that shape and delimit individual and group behaviors and knowledge go ignored. That is, culture is inappropriately used to explain individual behavior, when it is by necessity a group or shared phenomenon. A biocultural approach, then, places seemingly individualized behaviors into overlapping and broader social, physical, political, historical and cultural contexts, bringing into relief the myriad factors that influence both group and individual health behaviors and population health profiles.

### **The Unequal Burden of Cancer and Cervical Cancer**

While many advances have been made in cancer prevention and early detection, cancer remains a disease of major public health importance. The global burden of cancer was described in a recent World Health Organization (WHO) report in which recommendations focused on lifestyle change (e.g., tobacco, nutrition, physical activity) and increased screenings, particularly breast and cervical cancer screening (Stewart and Kleihues 2003). The

uneven impact of cancer is evident in both incidence and mortality, where both poor and non-whites tend to have lower long-term survival due to less timely access to the formal healthcare system and presentation and diagnosis at later stages (Freeman 2004, Gornick, Eggers, and Riley 2004, Hoffman-Goetz, Breen, and Meissner 1998, Peek and Han 2004).

Additionally, non-white and foreign-born women experience a higher incidence and mortality due to reproductive cancers including cervix uteri (Barnett 1996, O'Malley et al. 1997, Robles, White, and Peruga 1996, Sanghavi Goel et al. 2003), as well as late-stage diagnosis and higher mortality from breast cancer (Gornick, Eggers, and Riley 2004, Peek and Han 2004). Multiple factors contribute to these health disparities, including inadequate access to preventive and follow-up care, exposures to unhealthy environments, lack of appropriate health education and communication resources about cancer screening and treatment.

Further, a relatively recent Pan American Health Organization (PAHO) report on strategies to reduce the high cervical cancer rate in the Caribbean region, primarily through improved public health infrastructures and Pap screening, included startling statistics for Haitian women and cervical cancer (Lewis 2004). According to that report, among all Caribbean populations, women in Haiti experience the poorest cervical health, where it is the leading cause of cancer mortality. Indeed, based on this mortality, this population has the highest age-adjusted cervical cancer incidence in the world.

Furthermore, cervical cancer is a sentinel disease. It is a marker for poverty (Freeman and Wingrove 2005, Palacio-Mejia et al. 2003) and lack of

access to preventive care and resources (Eluf-Neto and Nascimento 2001). It has a greater incidence and mortality impact in ethnic minority and foreign-born/immigrant, and non-citizen women (de Alba et al. 2005, Dignan et al. 1998, Fruchter et al. 1986, Luke 1996, Sanghavi Goel et al. 2003, Seeff and McKenna 2003, Ward et al. 2004) and women with low health literacy (Lindau et al. 2002, Sharp et al. 2002). In low resource settings, it is most often an outcome of the lack of a preventive health infrastructure (Arrossi, Sankaranarayanan, and Parkin 2003, Hoyo et al. 2000). At the same time, beliefs about cervical cancer etiology influence how women think about screening, treatment decisions, and risk in relation to reproductive health behaviors (Chavez et al. 1997, Chavez et al. 2001, Goldman and Risica 2004, Martinez, Chavez, and Hubbell 1997, Scarcini et al. 2003). In this sense, both structure and culture are integrated into the uneven distribution of this disease and the health decision-making strategies of women.

### **Organization of the Dissertation**

Following this introduction, Chapter 2 lays the foundation for this ethnographic study through an historical examination of key themes in Haitian ethnography, immigration, and gender and ethnic identity in the Diaspora. Chapter 3 examines medical anthropological work on health, illness and medical pluralism in Haitian culture. Chapter 4 illustrates the importance of anthropological contributions to cancer studies and ethnographically informed interventions through a synthesis of examples from collaborative,

interdisciplinary research. Chapter 5 presents the case for a biocultural approach to cervical cancer through an examination of the clinical, public health and cultural aspects of the disease and an exploration of cross-cultural feminine hygiene practices that may contribute to the cervical cancer impact. Historical aspects of biomedical gynecological practices are also reviewed for their commonalities with contemporary agents and products women use for feminine hygiene. Research design and methods are presented in Chapter 6. Chapter 7 describes the setting for this research and presents an analysis of findings with the key consultants, preliminary sample of women, and physicians. Chapter 8 presents the findings from the secondary sample of women and from the analysis of survey data. Finally, Chapter 9 discusses conclusions, recommendations for public health application and clinical practice, recommendations for applied anthropology, contributions to anthropology, and suggestions for future research.

## **Summary**

This research contributes to medical anthropological discourse on cultural constructions of illness, experience and behaviors situated in a broader structural context, advancing the dialogue in biocultural theory and immigrant women's health. Cervical cancer, which is at once a biological and social outcome, poses a significant burden of disease and suffering for Haitian women. This research attempts to illuminate how culture, history and gender relations are intertwined and influence the distribution of cervical

cancer, for the purpose of discovering culturally meaningful and effective ways to alleviate women's suffering and death from this disease.



## CHAPTER 2

### ETHNOGRAPHIC STUDIES OF HAITIAN CULTURE AND LIFE IN THE DIASPORA: TRENDS AND KEY THEMES

#### Introduction

Writings about Haitian culture are intermingled with discussions covering themes of colonial and contemporary history, race, social class, politics, religion, education and economics. Many of these writings, especially of the colonial period, are not methodologically ethnographic but are nonetheless important. I give mention to these important genres of work because of their impact on the culture histories of Haiti and influence on scholarship in the Caribbean, including early and contemporary ethnography of Haiti and the Caribbean. Such writings include colonial travelogues and naturalist descriptions (Descourtilz 1809, Moreau de Saint-Méry 1958 [1796-1797]), ethnohistories (Dorsainvil 1934, Leyburn 1941), historiographies (Nicholls 1985, Nicholls 1996, Watts 1987), and literary critiques (Price-Mars 1959) and fall under areas like Latin American Studies, African Diaspora, postcolonial studies, race consciousness, comparative linguistics and literary criticism. Indeed, the writings of influential scholars indigenous to Haiti and the Caribbean saturate these topic areas (e.g., Firmin, Price-Mars, Magloire, Césaire, Fanon, et al.).

Given the colonial influences on the development of Haitian culture and society, and its geographic and political position in the Caribbean, it is not surprising to find intersecting postcolonial writings informed by leading French literary writers and contemporary Haitian social and political science scholars, who shared subversive ideas about culture, society and assimilation after-effects on national identity formation. Some of these writings do transcend boundaries into ethnography and will be discussed here. Key themes in ethnographic work on Haitian culture also reflect the influences within social science studies of the time period from which the observations and writing occurred; as such, the following discussion is organized temporally in an exploration of key themes.

### **Colonial Period to 1800s**

The earliest published descriptions of Haitian culture known at the time of this writing date to the 18<sup>th</sup> and 19<sup>th</sup> centuries. The descriptions largely follow a naturalist approach in a typically colonial and racist perspective, recording observations of customs, moral dispositions and physical traits of a population in a particular geosocial environment. Moreau de Saint-Méry's 1796-97 *Description topographique, physique, civile, politique, et historique de la partie française de l'île de Saint-Domingue* is an example of such work. A Martinican-born kinsman of Empress Joséphine, this work depicted plantation economy and life of enslaved Haitians under French colonial rule. It represented a first attempt to systematically describe the culture and social life of people in then French Saint Domingue, and it is referenced in

early ethnographies of Haiti (see Price Mars 1928, Hurston 1938, Métraux 1959). Descourtiz's 1809 *Voyage d'un naturaliste en Haïti, 1799 – 1803* is another example of naturalist depictions of Haitian social life and culture. The general tone of these works is one that attempts a distanced observation but is constrained by colonial ideological constructions of race and class.

Published writings of the 1800s that covered aspects of Haitian culture were more focused on revolutionary history, were infused with narrow discussions of race and tended toward broader descriptive observations of geography and political histories of Haiti. Thoughtful analyses on Haitian culture appear to be limited through the early to mid-1800s, perhaps due to the economic and political isolation of Haiti after its revolution and to 19<sup>th</sup> century racism in American and European scholarship. But one major exception surfaces in the late 1800s that effectively set the stage for 20<sup>th</sup> century ethnography, and anti-racist and postcolonial writing on Haiti and the African Diaspora: the work of Joseph Anténor Firmin, a Haitian attorney, diplomat, and ethnographer. His *De l'égalité des races Humaines: Anthropologie Positive (1885)* represents a positivist yet critical treatise on the fallacy of ranking human population groups by race, and it presaged later scholarly notions articulated on the social construction of race (Fluehr-Lobban 2000).

Firmin's work was a reaction to de Gobineau's *De l'inégalité des races humaines (1853-55)*, which cited the social and political problems of Haiti as evidence of racial inferiority (Fluehr-Lobban 2000). This work was revolutionary in that it provided cogent arguments based in empirical

observation that challenged the 19<sup>th</sup> century biological reductionism inherent in anthropometry and the polygenist-monogenist debate in anthropology. His work also emphasized a Gestalt paradigm for understanding human similarities and differences across cultures. Finally, Firmin's work was a significant contribution to the foundation of the cultural, political and literary Pan-Africanist studies and publications that would soon follow in the Caribbean, U.S. and Europe.

### **Early to mid-1900s**

Firmin's influence is evident in the indigenous ethnographic work on Haiti in the early 1900s, most notably that of Haitian ethnographer and physician Jean Price-Mars. Price-Mars' *Ainsi Parla l'Oncle* (Price-Mars 1928) is the first systematic study of Haitian people and culture to reach a broader audience influenced by the ongoing contemporary Pan-Africanist studies throughout Latin America and the Caribbean (Magloire 2003). Price-Mars' approach was historical and he sought to elucidate cultural survivals in Haitian culture as evidence of African connection and a formulation of a national identity. Importantly, in addition to syncretic elements of Haitian culture he also recognized the creative and adaptive aspects of culture (Magloire and Yelvington 2005). His systematic study of Haitian culture in the context of history and colonialism heavily influenced the development of Diaspora scholarship and the Négritude movement in the Caribbean and United States (Magloire and Yelvington 2005). His creation of the Bureau of Ethnology in Port-au-Prince in 1941 was an important contribution to

ethnographic study in Haiti. Price-Mars' work was congruent with contemporary theoretical trends in cultural anthropology theory in the U.S., notably cultural relativism. While this was in part a reaction to biological determinism that was a dominant theme in anthropology at the turn of the century, reductionism remained an influential thread in the 1930s with the work of Carleton Coon and contemporaries from otherwise well-respected institutions such as Harvard.

Other ethnographic works about Haitian culture in the first half of the 20<sup>th</sup> century fall along thematic lines of political and religious aspects of Vodou (with various spellings reflecting the primary language of authors, including *vaudun*, *vaudou*, *voodoo* and *vodou*, for example), political economy, class struggle and political expression, art, folklore, dance and music. Some popular works about Haitian culture published during this time period still suffer from the exoticism inherent in 19<sup>th</sup> century travel writings (cf. Loederer 1935), yet others represent important contributions to the early systematic study of Haitian culture and society (Herskovits 1937, Hurston 1938, Leyburn 1941). Both genres of work were stimulated by the U.S. occupation of Haiti from 1915-1934 (Dubois 2001), during which embellished tales of cultural "otherness" were promulgated, as well as a diffusionist theoretical trend in the social sciences that encouraged the search for cultural traits which link a population to a culture of origin; primarily Dahomey, West Africa (now Bénin), in the context of Haiti.

Haitian cultural studies about the much maligned and misunderstood Vodou gain representation during this timeframe. Herskovits, in keeping with

a historicist perspective and general efforts to establish a continuity of cultural traits from Africa to the Americas, continued the dialogue on Haiti with his well-known *Life in a Haitian Valley* (1937). Based on his fieldwork in Mirebalais, his ethnographic study of Haitian country life is saturated with descriptions of spiritual dimensions of quotidian activities, kinship and social structure as well as detailed accounts of ritual life. Herskovits has been criticized for his understanding of syncretism as it applies to religion in the context of Catholicism and Vodou, where he focused on specific items (e.g., *lwa* and saints) as cultural retentions and concluded that this blending of traditions occurred with little conscious thought (Pérez Y Mena 1998). His lack of attention to the dynamic and adaptable aspects of culture, beyond a population's historical past, has brought criticism to his work (Reynier 1999). Despite these criticisms, Herskovits' work contributed significantly to contemporary anti-racist scholarship and stimulated further ethnographic study of Haiti.

Continuing a focus on folklore, and thus Vodou, another notable work, semi-travelogue and comparative ethnography, *Tell My Horse* by Zora Neale Hurston describes folklore and customs of Jamaica and Haiti, with much more emphasis on the latter (Hurston 1938). Hurston describes in great detail the organization of the Vodou deities (Rada and Petro), ritual functions and preparation, and practitioners. This work is one of the earliest to describe Vodou in the context of resistance (Trefzer 2000). She described intersections of Vodou with political and mundane life, and rejected the notion that the deities and *lwa* were merely the Haitian version of Catholic

saints. A student of Boas and thus firmly entrenched in traditional field methods including extended participant observation, Hurston criticized such superficial interpretations of contemporaries and predecessors. Her field accounts also include throughout examples of social class differences in Haitian society with regard to belief systems and Vodou.

Hurston's Boasian orientation to the study of Haitian culture contrasted with the work of her contemporary, Katherine Dunham, which emphasized an experiential component of fieldwork as well as careful observation (Dunham 1969). Dunham's interest in dance as cultural expression in Vodou led her to conduct fieldwork in Haiti around the same time as Hurston. Dunham became an initiate of Vodou, as she describes in her memoir/ethnographic account of her work in Haiti, *Island Possessed* (1969) nearly 30 years after her time in Haiti.

The focus on ethnography of religion and Vodou in Haiti continued in the 1940s with the work of George Eaton Simpson. The influence of cultural relativism and historical perspective is apparent in his work as he explores "The Belief System of Haitian Vodun" [sic] (1945), describing in great detail the various deities he learned about during his fieldwork near Plaisance, noting carefully that interpretational discrepancies he has with other scholars about various *lwa* (i.e., Herskovits, Courlander) may likely be due to regional variations in belief systems.

Finally, contemporary and somewhat similar descriptive, historiographic and ethnographic work that appealed to a more scholarly readership is exemplified in Leyburn's *Haitian People* (1941). A sociocultural

history, it carefully detailed the ways in which sociopolitical histories shaped Haitian cultural institutions of the time, including kinship patterns, religion and class structure and remains one of the most important contributions to the study of Haitian culture.

### **Mid 20<sup>th</sup> Century to Present**

Many of the same themes arise from the second part of the 20<sup>th</sup> century to present, however with decreasing exotic overtones. Revised and at times romanticized descriptions of Haitian culture and social life geared toward a popular or broader audience also emerged in efforts to correct stereotypes about Haiti such as Dantes Bellegarde's *Haïti et Son Peuple* (1953), Métraux's *Haïti: La Terre, les Hommes et les Dieux* (1957) and Rodman's *Haiti: The Black Republic* (1960). Works such as these were corrective in many ways to the exoticized travelogues that preceded them, and they contained descriptions of daily urban and rural life, religion, marriage, historical foundations of cultural institutions, and frequently, drawings and photographs.

In the 1950s and 1960s there was an increased representation in the ethnographic work of Haiti in areas of economic anthropology and focus on traditional anthropological concepts such as kinship and marriage patterns, and rural and urban life. A United Nations development project of the 1950s in southern Haiti afforded many anthropologists the opportunity to conduct fieldwork in this region that undoubtedly stimulated scholarship and popular, updated publications about Haitian social life and culture (Arthur and Dash



1999). Additionally, the research projects conducted under the Caribbean Anthropology Program of Yale University, contributed to ethnographic work on Haiti (cf. Underwood 1960). A rising interest in anthropology to study market systems in peasant societies and systems of labor is evident, with heavy influence from the work of Caribbeanist and economic anthropologist Sidney Mintz.

The 1950s and 1960s also included ethnographies of Haitian culture centered on Vodou. Two prominent examples include Métraux's (1959) *Voodoo in Haiti*, and Rigaud's (1953) *La tradition vaudoo et le vaudoo Haïtien: Son temple, ses mystères, sa magie*. These works represent detailed ethnographic accounts of the religion and its rituals. Vodou's role in Haitian culture and society continues to be a central theme to much contemporary ethnographic work about Haitian culture at home and abroad. Indeed, Vodou is ubiquitous in modern ethnographic work, with variations in areas of focus on the religion, including its social and political significance for both the poor and elite (Laguerre 1989), contested interpretations of its origins (Courlander 1960, Desmangles 1994), and the multiple meanings of aesthetics and expression in its practice. It is this particular focus which truly saturates the ethnographic literature: Vodou and cultural performance representations in art, music and dance (Courlander 1960, Deren 1953, Dunham 1969, McAlister 2002). Maya Deren and Katherine Dunham's more experimental works explored ritual meaning and communication through dance movement and each became a Vodou initiate during their fieldwork. Courlander's more traditional work on ethnomusicology in *The Drum and the*

*Hoe: Life and Lore of the Haitian People* (1960) examines both syncretic and newly created folklore traditions in music and folktales.

Laguerre's *Voodoo Heritage* (1980) continues the study of song in Vodou, with detailed attention to underlying meaning and classification of songs, geographic and social locations of the deities, and liturgical transmissions and oral history. A focus on underlying meaning in music is continued in Averill's (1997) ethnography, *A Day for the Hunter A Day for the Prey: Popular Music and Power in Haiti*. Averill adopts a political-historical perspective, examining Haitian musical forms as modes of communication and tools of resistance in power negotiation by the masses from the American occupation (1915-1934) to Aristide's return in 1993 (Averill 1997). Recent ethnographic study by McAlister (2002) in both Haiti and New York examines the religious foundations of Rara music, its political-economic significance as a medium of expression for the poor, and the transnationality of Rara performances. Thus, cultural representations in lyric, music and dance as they relate to Vodou have been widely studied in an ethnographic context.

### **Haitians in the Diaspora: Ethnographic Accounts and Themes**

The ethnographic literature on Haitian Americans is centered around the themes of immigration, identity, citizenship and transnationalism (DeWees 1995, Glick-Schiller and Fouron 2001, Glick-Schiller and Fouron 1990, Laguerre 1998, Schiller et al. 1987), health and ethnomedicine (DeSantis 1989a, DeSantis 1993, Laguerre 1981, Laguerre 1987a), social

and spiritual functions and meaning of Vodou in transnational context (McCarthy Brown 1991), music in the Diaspora (Gage 1998), sociopolitical context of immigration, illegal residence and refugee status (Stepick and Portes 1986, Stepick and Stepick 1990), acculturation and racism (Stepick 1998), civic engagement (Stepick, Stepick, and Kretsedemas 2001), language, social class and linguistic capital (Zéphir 1997), material culture, language, class consciousness and identity (Oswald 1999), and gender, work and informal economy (Chaffee 1994). A contextualization of Haitian immigration history is important, because the immigration patterns and settlements set the stage for the topics and issues covered by later ethnographic work among the people who settled in the U.S. In the context of immigration, it is also important to understand that legal immigrants, illegal immigrants and non-immigrants (i.e., students, temporary workers, tourists, etc.) all contribute to the demographic landscape and cultural fabric of Haitian American identity. It is beyond the scope of this research to cover all of the ethnographic literature on Haitian Americans; however, key ethnographic works that contributed most significantly to this area of inquiry are examined in the following discussion, especially in the context of immigration and gender.

### **Brief Overview of Immigration History to the U.S.**

There is a long and complex history of social and political relations between the U.S. and Haiti that begins in the colonial period. As a result of the political and social unrest during the Haitian revolution, Haitians began to

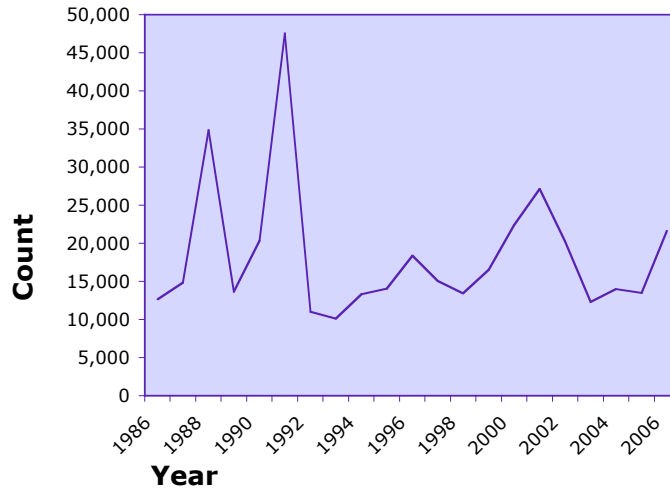
emigrate to the U.S. (particularly to Louisiana) in the 1790s (N.A. 2006). More than 1300 refugees from Haiti (then Saint Domingue) fled to New Orleans, inciting anxiety and fear among local planters of a revolt not unlike that of Haiti and elsewhere in the French Caribbean colonies. These refugees, many of whom were soldiers, contributed substantially to defend U.S. territories in battles against Britain and Mexico (N.A. 2006). The refugees had a lasting political and sociocultural influences including the formation of a strong Black intelligentsia that influenced Reconstruction and civil rights for persons of African descent, continued military contributions, and religious diffusion in the form of Vodou (N.A. 2006).

Contemporary migrations continued for political reasons. Waves of emigration from Haiti to the U.S. correspond with periods of social and political upheaval in Haiti. Emigration in the 20<sup>th</sup> century saw its first wave in the 1920s and 1930s during the U.S. occupation (1915-1934) of Haiti (Zéphir 2004). This wave consisted primarily of Black intellectuals who had the resources to leave. The 1960s and 1970s saw another spike in immigration with the installation of dictator François Duvalier. His 14-year regime of terror and disappearances is blamed for the deaths of 30,000 – 60,000 people and significant economic draining and decline of Haiti (Zéphir 2004). The continued dictatorship with the succession of Jean Claude Duvalier contributed to further substantial emigration to the U.S., both legal and illegal, in the 1980s as Haitians sought political asylum. An estimate of 50,000 – 70,000 Haitians are estimated to have arrived by boat in Miami between 1977 and 1981 (Zéphir 2004).

As in earlier migrations, Haitians have faced significant obstacles and discrimination in contemporary migrations. The massive influx in the 1980s led to significant mainstream media coverage that promulgated stereotypes of all Haitian immigrants as illiterate and poor. Additionally, U.S. immigration policy has been notoriously unfairly applied in the case of Haitians seeking asylum, where Haitians have been systematically denied asylum in their applications. The infamous 1980 Mariel boatlift incident made explicit the government's duplicitous reasoning for accepting Cubans as refugees but denying Haitians entry into the U.S., on the grounds that Cubans were seeking political asylum and Haitians were seeking economic refuge (Stepick and Stepick 1990). Another immigration wave in the late 1980s is evident with the overthrow of Baby Doc and subsequent failed political administrations and social unrest. Based on the most recent population data available, Figure 2, on the following page, graphically depicts these immigration waves over time.

Emigration peaked once again after the political upheavals during the Aristide government and Cédras regime, with an estimated 220,000 Haitians emigrating to the U.S. between 1991 and 1997 (Gammage 2004). More recent political power shifts and coups d'états (e.g., departure of Aristide in 2004, instillation of new leaders who occupied past political posts), coupled with major environmental disasters (hurricanes, tropical storms), have contributed to further destabilization, poverty and hunger in the country, leading to another recent spike in immigration.

**Figure 2. Documented Haitian Immigration Admittances, 1986-2006\***



\*Data for this figure were derived from the 2006 Yearbook of Immigration Statistics, Office of Homeland Security.

Further, patterns of immigration correspond with geographic settlement in the U.S. Haitians who emigrated during U.S. occupation (1920s-30s) and again during Papa Doc’s regime initially settled largely in New York City (Zéphir 2004). The early/mid-1980s and beyond witnessed more direct emigration to Florida as well as increased relocation of Haitians from New York to Florida, currently making it the state with the largest Haitian population (Zéphir 2004).

In addition to discriminatory immigration policy, Haitian-Americans and Haitian immigrants have faced numerous indignities in the U.S., from the Center for Disease Control and Prevention’s myopic proclamation of the “four-H” risk factor characterization for AIDS (hemophiliac, heroin user, homosexual, and Haitian), to legacies of U.S. mass media perpetuated stereotypes, to specific examples of ethnically motivated violence as

illustrated by the crimes against Abner Louima and the detention of Haitian women asylum seekers in a Miami women's correctional facility (Zéphir 2004). This history of immigration, settlement patterns, and social discrimination is juxtaposed with examples of survival and success in spite of multiple obstacles, as evidenced by the growing number of Haitians holding U.S. political offices, increasing numbers of Haitians occupying post-graduate professions such as law, medicine and engineering, and a growing Haitian American middle class in the U.S. These factors combine to influence all aspects of social life including the construction of cultural identity for Haitian immigrants and first and second generation Haitian Americans.

### **Immigration and Ethnic Identity**

Most ethnographic work among Haitian immigrants and/or Haitian Americans contains some discussion, if not primary focus on, the notion of cultural identity as it is created and reconstructed in a transnational, immigration context. In an examination of cultural citizenship, Ong cogently discusses and connects global political economy to the intersection of race, culture and class that combine to produce ethnic identity in the immigrant context in the U.S. Social capital, race, and immigrant participation in economic production and consumption converge as factors that contribute to host populations' conceptions of who can belong and who should not, and how ethnic identity categories are constructed. While Ong's work illustrates these convergences for Asian immigrants, her argument is applicable to the Haitian context as well in that ethnic identities may be seen as dynamic,

reshaped and renegotiated dependent upon social context in the host country.

To emigrate involves learning a new system of social stratification. The categories that stratify (e.g., class, race, gender) may be the same in name from home to host country; however, the meanings, distinctions and definitions of these categories almost always change in different sociocultural and national contexts (Duany 1998). A small, unpublished qualitative study by DeWees (1995) in Massachusetts was designed to assess Haitian adult immigrants' and adolescents' constructions of identity in the U.S context. Although her interview sample was very small (n=8), her participants were drawn largely from a middle class community and some interesting themes emerged through content analysis. First, participants self-identified as Haitian, Haitian-American, Afro-Caribbean, and *nwa* (Black). DeWees found that participants rejected the ethnic category "African American" primarily due to the racism and social devaluation that is perceived with the application of this label. DeWees also found that participants felt that language, specifically speaking Creole, as well as production and consumption of ethnic material culture including music and food, were ways to remain connected to Haitian culture and reinforce a Haitian identity. Finally, a common shared value that all participants cited was an emphasis on the opportunities that become available with education.

Moreover, current Haitian ethnographic work also includes themes of immigration, identity and Diaspora as evidenced by yet other works of Michel Laguerre. Haitian himself, he has conducted ethnographic fieldwork in the



U.S. with Haitian immigrants, in Haiti as well as in other Caribbean nations including Martinique. His earlier work examines migration and urbanization in Haiti in the context of the country's authoritarian government, where rural-urban migration to the capital Port-au-Prince in combination with out-migration to America, Cuba and Canada restructured the urban political class system and created new population demands on the city (Laguerre 1987b). His later work on migration examines transnationality and "Diasporic citizenship" for Haitians emigrating to the U.S., Canada, and other parts of the Caribbean (Laguerre 1998).

His *Diasporic Citizenship* (1998) and *American Odyssey* (1984) are seminal examples of Haitian Diaspora scholarship. In *Diasporic Citizenship*, Laguerre provides a diachronic, political economic perspective on the construction of identity through an exploration of what it means to be a citizen of a nation-state, and the distinctions of refugee and immigrant. He challenges the meaning of citizenship (and its functions) as one traditionally defined by the nation-state, and places it in the context of globalization. He argues that citizenship – and thus identity – goes beyond these traditional boundaries into transnational Diasporic communities. In these migrations, social class and acculturation factors combined to shape identities (rural to urban, peasant to city dweller); and for migration beyond Haiti, ethnic identity shifting as necessary to avoid further stigmatization in the U.S. context. Additionally, Laguerre characterizes transnationality as bi-directional affiliations with national (Haiti, U.S.) political, cultural, social and family contexts, maintained and reinforced by less restrictive and cheaper

international travel and more widely available modes of communication such as fax, telephone, and email. These transnational practices allow Haitian immigrants to the U.S. to continue participation in the affairs of Haiti.

Further, Glick Schiller and Fouron's (2001) *Georges Woke Up Laughing* poignantly illustrates the intersections of citizenship, transnationality and identity. These authors foster a reconceptualization of immigrant to one of *transmigrant*, in an examination of "long distance nationalism." This concept conveys the practices of many Haitian immigrants of remaining actively connected to their homeland through kinship and social networks while adapting to life in the states. Through this concept, the characteristics of uprootedness, exile, and assimilation are rejected in favor of a dynamic, adaptable identity through lived social practices that extend beyond nation-state boundaries.

Another significant anthropological contribution to the study of Haitian immigration is found in the various research projects of Alex Stepick. Stepick's (1998) examination of Haitian ethnicity in the U.S. context critically examines and documents struggles of Haitian immigrants in the U.S. over time, especially with regard to discrimination Haitians faced by whites, Cubans and U.S.-born Blacks. He devotes time to a comparative discussion of immigration laws and effectively describes two distinct systems: one policy for Cubans and a very different one for Haitians attempting to emigrate around the same time periods. Additionally, he relates the importance of the family in Haitian culture as well as remittances, as found in other studies. A major emphasis of this book is his discussion of identity in Haitian

adolescents, both U.S.-born and first generation. Based on labels used by these adolescents (“just-comes” and “cover-ups”), Stepick coins the phrase “reactive formation ethnicity” (p. 72) to describe the process of identity (re)creation in the context of a hostile host environment. He found that some adolescents tried to hide their ethnicity (“cover ups”) and attempted to approximate U.S. Black cultural behaviors, and school performance dropped in this group. Those born in Haiti or who were children of professionals he found were less likely to try to hide their ethnicity and excelled in academics.

Stepick’s other contributions include ethnographic studies of Haitian immigration and population settlement in relation to the U.S. Census Bureau undercount (Stepick and Dutton Stepick 1992a). This work brought to light various reasons why Haitian immigrants were undercounted and provided a corrective adjustment for practical application. His research is also extended to studies of informal economy in Miami (Stepick 1991), situations of Haitian refugees (Stepick and Portes 1986), and acculturation, identity and civic engagement of Haitian immigrants (Stepick, Stepick, and Kretsedemas 2001).

### **Gender in the Haitian Diaspora**

Gammage (2004) offers a historical perspective on the intersection of gender and migration of women within and from Haiti. In a review of census data, INS figures, and some ethnographic work on immigration, Gammage offers that the patterns of out-migration from Haiti to the U.S. obscure the role that women play in the migration decisions, in that most focus is shifted

to the male migration experience due to the proportion of men entering the U.S. first. As noted by Laguerre (1998), Gammage relates that data trends reveal that men tend to emigrate more than women first, and women follow, entering on reunification visas, for example. Although population data are sparse, and they only include those people entering legally, they give some indication of the gendered dimensions of the emigration experience.

The net effect of primary male emigration is an increase in the number of female headed households in Haiti and increased female autonomy in household decision making (Gammage 2004). Women manage the remittances sent by male partners and potentially other kinship networks to secure their own (and/or that of family members) emigration. Gammage (2004) holds that the gendered migration pattern also reflects traditional gender roles in Haiti, where women are the caregivers and nurturers, potentially explaining why women migrate after their male counterparts. However, the migration patterns contribute to shifting identities of Haitian women through the formation of transnational households and new role responsibilities and increased agency (Gammage 2004).

Chaffee's (1994) ethnographic fieldwork for her master's thesis examines the importance of reciprocity, social networks and informal economy in relation to survival strategies of socially marginalized Haitian immigrant women. In particular, Chaffee eloquently documents strategies employed by one Haitian woman, Lucie, using a case study ethnographic approach combined with visual (photographic) methods. Chaffee's work reinforces the points noted previously by Gammage, including how the

immigration experience is gendered, the shifting social roles of Haitian women in the Diaspora, and the centrality of social networks for securing survival in a host country. Chaffee's work also elucidates the importance of religion and respect as tools of resistance against discrimination.

Participation in informal economy sector activities, in addition to formal economy wage labor and ongoing household caregiver responsibilities are at once significant demands and strategies that pave the way for establishing respect, through demonstrations of resourcefulness and resiliency. This notion of social respectability is found throughout much Caribbean scholarship and is important for examining social class and status hierarchies both in the Caribbean and in Diasporic communities (Wilson 1969). Chaffee's work numbers one of only a few ethnographic studies focusing on immigration experiences and social lives of Haitian immigrant women in the U.S.

Glick Schiller and Fouron (2001) include a discussion about the gendered aspects of migration in their co-authored ethnography. Also using a case-example approach, they show the intersection of gender and migration with the example of remittance practices employed by Haitian women residing in the U.S. and the reliance and connection with kinship networks abroad. Through this example, these authors demonstrate how gender hierarchy and women's subordination are challenged and transformed in the transnational context. Their analysis also shows how nationalist ideals are interwoven with cultural notions of gender, family, status and class, and continued transnational movement serves to change traditional gender roles,

social status and family dynamics, through the ongoing acquisition of social capital and resources.

Finally, McCarthy Brown's (1992) ethnographic study of a Vodou priestess in Brooklyn is not overtly focused on gender dimensions of Haitian women's immigration experiences; however, gender is an inherent feature to the study because her focus is on the practices and abilities of Alourdes, a Vodou *manbo* in New York, whose abilities and reputation for treating health problems, bad luck, workplace, love and family difficulties earned her respect and clientele in the local Diasporic community, Canada and the Caribbean. This account provides a thick description of Vodou's many deities and *lwa* (spirits). McCarthy Brown situates Alourdes' life and Vodou practice in the context of her matrilineage, as related by Alourdes, as her abilities were passed down to her from previous generations. McCarthy Brown's ethnography follows an interpretive tradition that is also experimental. She takes liberty to create fictionalized profiles of Alourdes' family members, pieced from details that Alourdes relates. She also becomes an initiate of Vodou herself at the suggestion of Alourdes. This work also indirectly exemplifies how Alourdes achieved power, respect and status through becoming a manbo.

## **Summary**

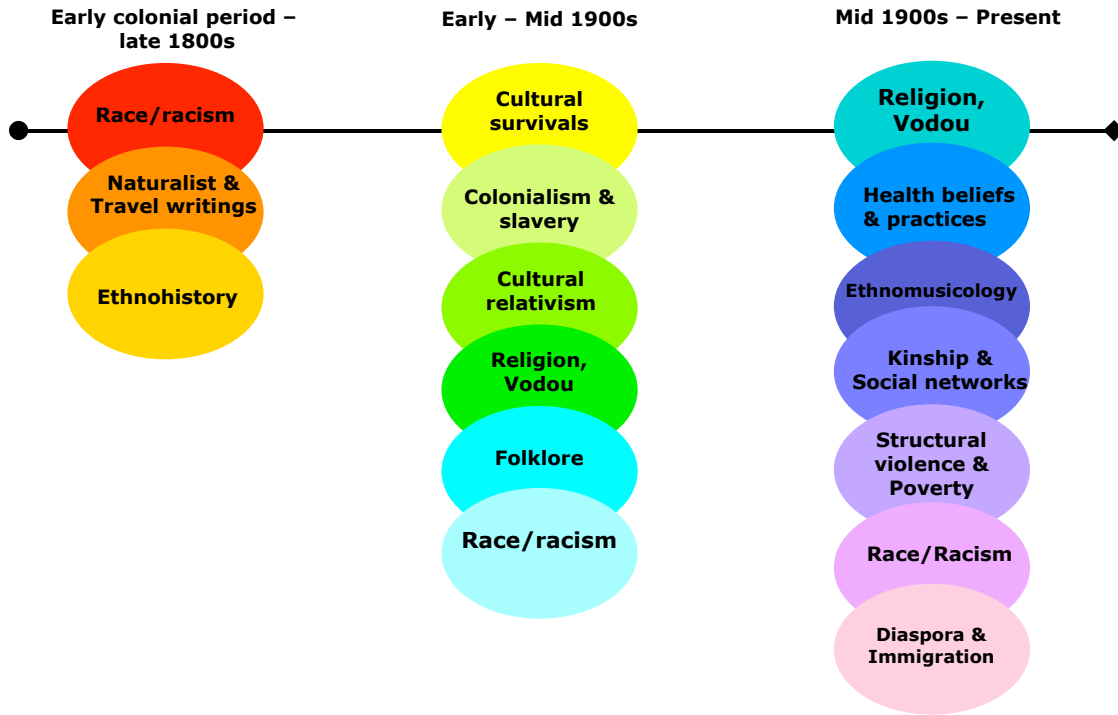
This chapter provided an overview of the key themes in Haitian ethnography from the colonial period to present, including an examination of immigration and gender in Diasporic contexts. Traditional gender roles of

Haitian women have been observed to shift in the immigration context, whereby women may gain more autonomy through increased access to earning potential and higher status for contributions to family migration decision making. The literature available reveals that there continues to be a lack of ethnographic research providing well informed understandings of the lives of Haitian immigrant women.

Further, notions of identity and transnationality are inextricably tied to immigration experiences. Ethnic identity is best understood as a dynamic, shifting concept with variable interpretation within the Haitian immigrant community. Identity is intertwined with long-held, culturally (colonially) mediated perceptions of social class and skin color.

In sum, themes and approaches in ethnographic work on Haiti shift over time in concert with contemporary popular anthropologic methods, theory and the dynamic context of Haitian social life as situated in a wider geopolitical position. A summary timeline, Figure 3, on the following page, depicts these changes, and in some cases, continuities, through time. The following chapter examines characteristics of the Haitian medical system and medical anthropological studies in Haiti and among Haitian Americans.

**Figure 3. Summary Timeline of Key/Topic Themes and Approaches in Haitian Ethnography**





## CHAPTER 3

### ETHNOGRAPHIC EXAMINATIONS OF HEALTH AND ILLNESS: A PLURALISTIC HAITIAN MEDICAL SYSTEM

#### Introduction

The pluralistic medical system in Haitian culture is comprised of both ethnomedical and biomedical elements. This system is brought with people when they emigrate, modified and adapted to a new environment. Local medical knowledge is primarily passed through female lineal and collateral kinship ties. People use biomedicine and biomedical remedies as complements or instead of ethnomedicine. Treatment choice is often based on perceived illness gravity and etiology, as well as on monetary cost. The following sections examine the Haitian medical system and its healers, and relevant ethnographic studies on Haitian health and illness.

#### The Pluralistic Medical System in Haiti & U.S. Context

Before discussing the cultural characteristics of Haitian medical pluralism in the context of immigration, a definition of what is meant by a *medical system* follows. Medical systems are comprised of cultural beliefs and structural components that serve to organize people's understandings of illnesses, determine therapy options, govern patterns and hierarchies of

treatment resort, and ultimately shape the distribution of disease in a given population (Young 1983). Such systems most often contain multiple medical traditions, or ...“distinctive combinations of ideas, practices, skills, apparatuses and *materia medica*” (Young 1983:1206). These traditions, then, define and characterize medical sectors, e.g., a lay, or folk, medical sector, and a professional, or allopathic, medical sector. Further, medical pluralism is a feature of most societies, where multiple medical systems exist alongside one another and may have some shared aspects in both etiologic explanations and practical application of therapies.

Immigration to a new country does not entail ready dismissal of illness beliefs or practices, or even assimilated beliefs after years of residence. Immigrant communities bring with them the illness constructions and behaviors known to them in home countries, and they are adapted for use in a new setting (Baer, Clark, and Peterson 1998, Kemp and Rasbridge 1994). Folk healers are often found in ethnic enclaves that develop in U.S. cities and serve as an important social network for newly arrived immigrants. Often the folk sector is the first source of care, as multiple cultural and structural factors frequently guide and conscript health seeking behavior: incompatible etiologic beliefs, perceived ineffectiveness of biomedicine, language and communication issues, problems with immigration status, fear of deportation, monetary cost, and geographic accessibility, as examples (Baer, Clark, and Peterson 1998, Gany and Thiel de Bocanegra 1996a, Jackson 1998, Kaiser Commission 2003, Kemp and Rasbridge 1994). In the case of Haitian immigrants in the U.S., folk medical practitioners do exist and have been

described in communities with large concentrations of Haitian immigrants, primarily including cities in Florida, New York and Massachusetts (DeSantis and Thomas 1992, Laguerre 1981, Miller 2000, Weidman 1978).

Ethnomedical systems are not bounded by geography, especially in the case of Haitian immigrants, whose transnational ties foster continued associations with Haiti that include aspects of illness beliefs and behaviors, health and health care. The same ethnomedical system found in Haiti has been transported, and adapted, to life in the U.S.; however, there is variability in health beliefs and behaviors especially along social class lines and education levels (Laguerre 1981, Miller 2000). Many of the therapies sought by Haitian Americans and Haitian immigrants to the U.S. are derived from a pluralistic medical system in Haiti, consisting of both ethnomedical and allopathic elements. The ethnomedical sector is an amalgam of African and French traditions forged under slavery from the 17<sup>th</sup> to 19<sup>th</sup> centuries in Saint Domingue (Laguerre 1987a, Leti 2000). Missionaries and international health organizations have also contributed to the pluralistic system with the introduction of Western biomedicine (Brodwin 1996, Farmer 1999a). Thus, this ethnomedical sector also includes allopathic elements from the professional medical sector from cultural borrowing and adaptation of some biomedical therapies. It is a viable, dynamic and adaptive system that continues to exist in Haiti today, and its influence is evident in Haitian households and enclave communities in the U.S. Such evidence is found in the local healers who reside in the communities, as well as in the local medical knowledge that informs people's treatment choices, primarily

consisting of plant-based home remedies (*remed lakay*), such as *thés*, *tisanes*, and poultices.

In Haiti and in many parts of the Caribbean and Latin America, humoral theory explains various illnesses as the result of imbalance (Blumhagen 1982, Coreil 1983b, Dressler 1982, Heurtin-Roberts 1993, Laguerre 1987a). A shared model of human anatomy and physiology is reflected in descriptions of a humoral and hydraulic bodily system where balance must exist in levels, location, and quality of fluids, especially of blood (Farmer 1988). These fluids are also intertwined with the notion that they represent a moral barometer of sorts, where health and morality are intertwined, and disequilibrium may imply immoral behavior (Brodwin 1996, Farmer 1988). A hot/cold schema to food, blood and other bodily fluids, and medications exists alongside these understandings.

Blood is central to nearly all aspects of illness, both chronic and acute, in Haitian ethnomedical beliefs (Laguerre 1981). In the Haitian ethnomedical system, concepts of health are related to good nutrition, adequate rest, prayer and good spiritual habits. Among Haitians and other Afro-Caribbean populations, nutrition is believed to have a strong and direct impact on various qualities of blood, and the ability to be sufficiently rested also affects quality as well as flow directionality of blood in the body (Meyer 1998, Miller 2000, Vilayleck 1996). Also found in many Caribbean cultures is the notion that improperly circulated blood leads to illness. Among Haitians, emotional discord, unexpressed anger, fear and bad luck are thought to make blood rise toward the head and expand (Brodwin 1996, Laguerre 1981). Other

Afro-Caribbean cultures ascribe to this model of blood circulation as well, attributing both biomedically-defined conditions such as hypertension and stroke as well as culturally defined syndromes to the irregular rise and fall of blood in the body (Dressler 1982, Meyer 1998). Teas, tisanes, proper diet and adequate rest, and physician-prescribed medication are frequently cited as therapies for circulation problems.

### ***A Dualistic System of Illness Causality***

Métraux's classic work in Haiti (Métraux 1972) revealed a dualistic system of illness etiology wherein illnesses were attributed either natural/benign (*maladi Bondye* or *maladi péi*) or supernatural/malevolent (*maladi satan*, *maladi majik* or *maladi mò*) causes (Brodwin 1996). Other scholars of Haiti describe this system as well (Coreil 1983b, Farmer 1990, Laguerre 1981, Laguerre 1987a). Brodwin (1996), however, notes that accepted biomedical explanations for disease etiologies (i.e., bacteria as the cause of tuberculosis), do not preclude beliefs that such an illness can be sent upon someone by a malevolent practitioner. Further, therapies chosen generally seem to coincide with illness domain: if an illness is perceived as sent, or if it originates in the supernatural domain (like some psychiatric illnesses are thought to be), treatment will most often be sought from an ethnomedical practitioner who deals in the supernatural. Maladies that are characteristic of supernatural origin tend to have sudden onset and have little response to biomedicine or herbal remedies (Laguerre 1987a). If an illness is

deemed natural, the usual course is to first attempt self-treatment with phytotherapies, often consulting with an elder female family member.

Despite the existence of a naturalistic/personalistic dual system of disease causality in the Haitian ethnomedical system, caution should be taken to not oversimplify the categorization of ethnomedical etiologies, medical sectors or practitioners. Indeed, the boundaries of lay and professional medical sectors overlap in many medical systems, where people simultaneously seek therapies in each sector. Further, lay practitioners are more appropriately distinguished by their association with benevolence or malevolence. This dichotomous distinction is common in Caribbean islands with French colonial histories, but Haiti is unique in its development of Vodou. The next sections will delineate the difference between the various practitioners according to this association of benevolence/malevolence. This association reflects convergent influences from Vodou, Protestant missionaries and Catholicism, which contribute to the current medical pluralism in place in Haiti and frequently observed by Haitian-Americans today.

### ***Benevolent/Benign Practitioners***

In Haiti and other islands with similar colonial histories, practitioners also are defined by how they practice and what conditions they treat. Ethnomedical practitioners who deal with illnesses of natural cause (*maladi Bondye*) frequently use Christian prayer, which is seen as a catalyst, perform rituals, and consult Catholic saints and *anj gadyen* (angels) in addition

relying on empirical experience to prescribe herbal remedies such as teas, tisanes, or poultices (Brodwin 1996). These practitioners are well versed in local medical knowledge and practice and are sometimes described as having *le don*, or “the gift,” illustrating an understanding that their abilities are God-given (Meyer 1998). Unlike malevolent practitioners, clients do not fear these practitioners yet have respect for their healing abilities, and they do not charge exorbitant fees for their services. Examples of such practitioners in Haiti and in Haitian migrant communities in the U.S. include the following (Coreil 1983b, Laguerre 1981, Laguerre 1987a):

*Doktè fey/medsen fey*: herbalist, or literally, “leaf doctor.” A doktè fey may also discern illness origin as supernatural if therapies fail. Consult saints, *anj gadyen*, (guardian angel) and use prayer for augmenting efficacy of their regimens.

*Fanm saj*: midwife; also possesses local herbal knowledge, assists with childbirth and post-partum health.

*Pikirist*: injectionist; a common practice in Haiti and injections of antibiotics and vitamins are commonplace and preferred to pills.

*Doktè zo*: bonesetter; to correct various conditions of bone displacement through manipulation and palpating.

### **Malevolent Practitioners**

Those practitioners who deal with illnesses of supernatural origin (*maladi majik or maladi mò*) are often associated with malefic forces such as sorcery or unappeased ancestral spirits. In some cases they are thought to have entered into a contract with Satan in exchange for healing (and harming) abilities. They are called by different names in the Caribbean islands with French colonial histories, depending on the island (i.e., *quimboiseur*, *gadé zafé* in Martinique and Guadeloupe; *bokor* in Haiti).

However, they have in common the charge that they are said to “serve the spirits.” In Haiti, this is a direct implication of Vodou, for spirits refers to the *lwa*, or familial spirits (Brodwin 1996). On the other islands (primarily Martinique and Guadeloupe), they are said to work with *mauvaises esprits* (evil spirits) primarily to do harm, or alternatively, to undo sent harm that manifests as illness (Meyer 1998, Peronnette 1982). Haitian ethnomedical practitioners frequently perceived as malevolent include the following (Coreil 1983c, Laguerre 1981):

*Houngan*: male Vodou practitioner; may divine cause of illness and prescribe action/therapies. May achieve divination through trance, communicating with *lwa* and other spirits in the complex and hierarchical system within Vodou. Viewed as malefic primarily by devout Christians, particularly Protestants (Brodwin 1996), but do not necessarily consort with evil spirits for divination, nor solely cause harm.

*Manbo*: female Vodou practitioner counterpart.

*Bokor*: practitioner that is thought to only cause harm or undo harm sent by others, not viewed as a healer, but one who consorts with evil spirits and/or the devil.

The centrality of medical pluralism in Haitian culture, the importance of traditional healers and health beliefs, and the ethnoetiologic connections of health to both sacred and profane worlds are evidenced in ethnographic research. The following discussion examines relevant studies.

### **Medical Anthropological Studies in Haiti**

Studies of Haitian health beliefs and *materia medica* in the context of



culture have emerged since the mid 20<sup>th</sup> century as the specialty subdiscipline of medical anthropology solidified. The various development projects initiated in Haiti over the last 50 years frequently involved anthropologists and lent an applied focus to many studies that included a health component. Scholarship produced in the region stimulated further ethnographic inquiry into the context of illness and health in Haiti from varying approaches, as illustrated in the following discussion of relevant literature.

Coreil's extensive ethnographic fieldwork in Haiti has examined biocultural, ecological and structural factors influencing health seeking behaviors, treatment choices and resource allocation in a medically plural, rural society (Coreil 1983a, Coreil 1983c). Using data from participant observation, interviews and surveys, Coreil describes a model of rural health care comprised of folk and professional medical sectors. The model is comprised of three levels of care (primary, secondary, and tertiary), which are organized by illness severity, cost, and practitioners' training and knowledge. Each level includes therapy options in both professional and folk sectors. Primary care is reserved for the less serious, more common illnesses, and treatment is provided by herbalists, injectionists, midwives and/or dispensary nurses. Secondary care, which incurs more monetary cost and time, includes treatment for less common and more severe illnesses by physicians and/or shamans. Tertiary care is reserved for treatment from large urban medical facilities and from *bokors*, or sorcerers.

Importantly, this work emphasizes the heterogeneity of the Haitian

folk medical sector, and the similarities of the folk and professional sectors. Various specialized ethnomedical healers exist to treat illnesses that are personalistic or naturalistic in origin: midwives, bonesetters, injectionists, herbalists and shamans, which included male (*houngan*) and female (*manbo*) Vodou practitioners. This sector provided a significant source of care and served as the primary resort for most rural people, while dispensaries served as a major resource for health care in the professional sector in rural Haiti (Coreil 1983c). Much like the utilization patterns for shamans, physician care was sought when an illness was grave, due to the time and money invested in seeking the services of these practitioners. Thus, the model described of rural health care allows for a more comprehensive and clearer comparison of health care sectors in the Haitian medical system.

In keeping with the theme of intersecting pluralistic medical systems, Coreil describes the adoption and innovative uses of oral rehydration therapy (ORT) among traditional Haitian healers (Coreil 1988). Ethnographic surveys were administered to the various types of ethnomedical practitioners to determine how the healers used ORT to treat childhood diarrhea. The data revealed differential use of ORT by healer type that was further influenced by gender and education level of the healers. That is, midwives and injectionists in particular adopted ORT for treating childhood diarrhea for their patients. This ethnographic work illustrates cultural borrowing from the professional medical sector and adaptation to the folk sector.

Other fieldwork describes explanatory models of the endemic illness filariasis, or *gwo pye* (big foot), in sociocultural context (Coreil et al. 1998).

Specifically, ethnographic methods were used to determine how the disease affected women's daily lives, decipher ethnoetiologies, and discern treatment behaviors for the disease. Women's ability to work, and thus earn a wage, was greatly affected due to compromised mobility. Women with the disease also faced ridicule and discrimination. Women who contracted filariasis before marriage were especially burdened as their prospect of finding a male partner for marriage was significantly decreased. Ethnoetiologies revealed that women understood and treated the disease based on lay models of the illness. Both naturalistic and personalistic elements exist in the lay etiologic model: *gwo pye* is the result of a deliberate attack where a person walked over or stepped in magical powder or the result of *fredi*, (cold), entering the body, or injury. Coreil notes that alternative biomedical explanations for filariasis were gaining acceptance at the time of the research due to exposure to biomedical treatment for the disease. This research made explicit local explanatory models of the illness and placed this vector-borne illness in a broader social context, illustrating its far-reaching effects on women's social and economic well-being. Such work has direct applied implications for informing international health efforts to prevent and treat this disease.

The understanding and classification of healers in the folk sector in rural Haiti is also explored by Brodwin using a meaning-centered approach (Brodwin 1992, Brodwin 1996). Among the various healers, he emphasizes the moral and religious aspects associated with nonbiomedical practitioners in Haitian culture. In an exploration of the secular and non-secular dimensions of these healers, he describes how healers may be differentiated

in ways other than the types of illnesses they treat. For example, while *doktè fey* (herbalists) and *saj fanm* treat primarily naturalistic illnesses (Foster 1976), there remains a religious dimension of their work in that they profess their abilities as God-given, making them morally acceptable as folk sector healers. In contrast, healers associated with Vodou (manbos and hougans) are said to serve the spirits (*lwa*), who give them their power. Thus, medical treatment choice among folk healers also places a moral dimension to illness: those who resort to hougans or manbos are often viewed as guilty of some wrongdoing, and illness is manifested as retribution. Importantly, Brodwin's ethnographic work in Haiti includes examinations of healing *power* in a rural context where there is religious pluralism, e.g., Catholicism, Protestant denominations, and Vodou. Power dimensions then play out in terms of moral authority in healing along these politico-religious lines.

Studies of the health effects of structural violence and poverty characterize contemporary ethnographic work in Haiti. Much of Paul Farmer's work in Haiti is centered on the ways in which social structural processes impact Haitian population health and simultaneously become embodied as illness experience and expression, particularly as they apply to HIV/AIDS and tuberculosis (Farmer 1990, Farmer 1992, Farmer 1999a, Farmer 1999b, Farmer 2003). His work firmly positions the experiences of illness and social injustice within a larger geopolitical framework.

M. Catherine Maternowska continues this theme in her recent work, *Reproducing Inequities: Poverty and the Politics of Population in Haiti* (Maternowska 2006) offers an insightful, critical case study of family planning

in Cité Soleil, an urban slum in Port-au-Prince. This research addresses the questions of failed family planning policies instituted in Haiti by international aid organizations; specifically, why high fertility and low contraceptive use persist, in spite of significant efforts and monies spent on community education. Her work is strongly influenced by political ecology and political economy and illuminates the immediate and long-term effects of poverty, colonialism, and politics on reproductive health strategies. She places reproduction and women's reproductive health squarely with the practice of resistance in a society with a long history of international intervention into every level of social life. She weaves these observations into other culturally mediated gender and power relations in place in Haiti that affect women's reproductive health, contextualizing reproduction in a biocultural framework.

Both historically and today, women's ability to reproduce has significant cultural meaning and social consequences (Allman and Allman 1987, Barnes-Josiah, Myntti, and Augustin 1998, Coreil et al. 1996, Murray 1974, Simpson 1942). Great importance is placed on children. Fertility provides some security in that it creates a connection to the father, often with economic benefits, and it establishes a larger kinship network that may be relied upon in old age for housing and care (Bell 2001, Maynard-Tucker 1996). In essence, fertility is connected to survival, whether it is inside an officially recognized marriage (*marye*), or as part of a cultural practice of conjugal unions called *plasaj*. This word stems from the French verb *placer*, or to place, or to be in a state of *placage*. Historically, such unions involve cohabitation and entail, to varying degrees, economic support from men to

their women partners especially when they have children together (Farmer 1999a, Maternowska 2006, Maynard-Tucker 1996). Some relationships have emotional ties as well.

Cultural norms dictate that men are frequently not monogamous. For example, it is common practice among men in *plasaj* relationships, and even among those who are legally married, to have *fanm deyo*, literally “outside women” (N'Zengou-Tayo 1998). The practice is reluctantly tolerated by women as a means for survival (Maternowska 2006). Indeed, it is emblematic of the deep divisions in gender and power between men and women in sexual relationships, where women have very little control in enforcing men’s condom use, and where intimate partner violence is common (Gage and Hutchinson 2006, Kershaw et al. 2006). Further, intimate partner infidelity and philandering have direct negative consequences for women’s health, and potentially, life span. As Farmer (1999) observed in Haiti, *plasaj* was implicated in the spread of HIV. Other researchers have noted that while sexual unions are entered into for economic reasons among women, they also play a central role in perpetuating other sexually transmitted diseases, (e.g., chlamydia and gonorrhoea) (Fitzgerald et al. 2000, Smith Fawzi et al. 2003).

In keeping with ethnographic studies of women’s health, and specifically women’s reproductive health, an interesting set of ethnomedical studies are centered on a folk illness called *pedisyon*, or arrested pregnancy syndrome (Coreil et al. 1996). The etymology of *pedisyon* is disputed, where earlier anthropological interpretations assigned it to the French, *perdition*, or

roughly, loss (Coreil et al. 1996, Murray 1974). Other scholars offer that *pedisyon* comes from *pedi san*, or blood loss, more specifically (Singer, Davison, and Gerdes 1988). In essence, *pedisyon* is a folk illness that provides a socially acceptable explanation for infertility, or temporary infertility (Murray 1974). When a woman has *pedisyon*, she is in a suspended state of pregnancy, where the fetus is unable to grow and thrive. The symptoms include an inability to get pregnant, and significant bleeding for many days, apart from a woman's regular menstrual cycle.

Ethnographic work in Haiti by Singer et al. (1988) links women's explanations of *pedisyon* with the illness conception of *fibrom*, which is described by participants as hard balls of pooled blood in the womb, which divert nourishment from the fetus, potentially resulting in death. These authors offer that *fibrom* ethnoetiology is illustrative of cultural borrowing from the biomedically-defined condition of uterine fibroids. Indeed, participants indicated that surgery performed by a physician was the only effective treatment for *fibrom*, and that it can be fatal (for both mother and fetus) if left untreated. Given that uterine fibroids cause irregular bleeding and can impact fertility, the construction of this cause of *pedisyon* fits with both ethnomedical and biomedical understandings of *fibrom*/fibroids.

Coreil et al. (1996) examined the distribution and magnitude of *pedisyon* in a national survey of women in Haiti representative of both rural and urban populations. Using a surrogate respondent method, where sisters of women who had died from *pedisyon* responded to the survey, these researchers found that *pedisyon* was common in the adult female population,

and the distribution of the illness differed from rural to urban populations where risk factors for and occurrences of *pedisyon* were greater among urban women. The authors note that this finding is incongruent with the notion that folk illness beliefs are more prevalent in rural populations with lower education and less exposure to biomedicine. In fact, it is a suggested possibility that the magnitude of *pedisyon* among urban women may reflect a medicalization of subfecundity and infertility in women with greater access to biomedicine, placed within a particular cultural construct of illness to explain fertility problems.

While the previously described ethnographic research was done in Haiti, many of the same elements can be found in immigrant communities. The following section discusses health seeking behavior in the immigrant context.

### **Health Seeking Behavior & Therapy Options**

Simultaneous resort to therapies and practitioners in both folk and professional medical sectors are common among Haitian immigrants. Therapies sought include plant-based home remedies, commercial products purchased from pharmacies and botánicas, and biomedical treatment for those with access to physicians (Brodwin 1996, DeSantis and Thomas 1992, Laguerre 1981, Lieberman, Stoller, and Burg 1997). If various natural remedies and/or biomedical treatments and practitioners have no or little effect, the illness may be deemed supernatural in origin and thus require resort to an ethnomedical practitioner who works with such illnesses (Miller



2000).

Research on health services utilization in the professional sector among Haitian immigrants is sparse; however, published studies share common findings that cite structural and cultural barriers, such as communication problems, explanatory models of illness that are incongruent with biomedicine, immigration status problems, and monetary cost, as significant impacts on resort to biomedicine for care. Laguerre (1981) describes a Haitian immigrant community that largely has no health insurance, views public health care (e.g., Medicaid, free clinics) as second rate care, and consults private practice physicians (usually Haitian) when needed, resulting in out-of-pocket expenses for health care in the biomedical sector. Other studies, which are found both in anthropology and public health, tended toward disease-specific reports or cross-cultural issues in patient care from a nursing perspective, including explications of illness belief systems (Adonis-Rizzo and Jett 2007, DeSantis 1989b, DeSantis 1993, DeSantis and Halberstein 1992, DeSantis and Tappen 1990, DeSantis and Thomas 1990, Holcomb et al. 1996). For example, much of DeSantis' transcultural nursing work in South Florida examines preventive health beliefs and practices of Haitian immigrants, with implications for clinical practitioners. Her work underscores the significance of medical pluralism for Haitian immigrants, as there is ample crossover in use of both biomedical and home remedies, for attempts to restore health, avoid illness and avoid misfortune. Her work also shows that morality is inextricably linked to illness and to practitioners, wherein guilt or shame may be associated with

acquiring certain illnesses that may be thought of as supernatural in origin, and with the obligations of seeking a folk healer who deals with those conditions. Many people also used home remedies alone and in conjunction with biomedical remedies; however, home remedies were most often the first treatment resort, and were used for regularly for maintaining health and well-being.

Later work by Saint-Jean and colleagues emphasizes that structural factors influence health services utilization in the allopathic sector (Saint-Jean and Crandall 2005a, Saint-Jean and Crandall 2005b). An examination of the relationship between demographic characteristics and health insurance coverage is described based on a survey method in a probability sample of Haitian immigrants in Little Haiti, Miami. Statistically significant associations of attributes such as family income level, length of residence, gender, immigration status and English proficiency were found with health insurance coverage, the primary indicator of access to biomedical care and thus better health outcomes. Using logistic regression, these authors found that education level and immigration status were the strongest predictors of whether or not participants had an annual physical exam, and citizenship status was the single strongest predictor for services utilization in the biomedical sector.

## **Summary**

This chapter presented a discussion of the Haitian medical system (including ethnomedical and allopathic sectors) and health behaviors and

access to care in the U.S. A discussion of medical anthropological studies of health in Haitian culture was also provided. In general, the literature is significantly lacking in systematic studies of population health and health seeking behaviors of Haitian immigrants; however, published studies from the 1980s to 2007 present many of the same problems of access to biomedical care and little change in apparent population health and health seeking behaviors of Haitian immigrants over this time span.

The following chapter provides a discussion of anthropological contributions to cancer related studies, including anthropology applied to cervical cancer.

## CHAPTER 4

### CANCER IN ANTHROPOLOGICAL PERSPECTIVE AND APPLIED ANTHROPOLOGY IN INTERVENTIONS

#### Introduction

Anthropological contributions to cancer-related research are valuable for illuminating aspects of cancer as both a biomedically defined disease diagnosis and as an illness experience that differentially impacts populations and individuals according to social status and ethnicity. A review of the literature allowed for the emergence of natural categories in which different types of studies fell. I will call these categories Cognitive and Structural; however, these categories frequently overlap on many dimensions and are not mutually exclusive. The studies grouped into these categories simply reflect the tone and overall guiding paradigms of the research described.

Cognitive studies include examinations of doctor-patient relationships and communication; negotiations in the clinical encounter (Balshem 1999, Sered and Tabory 1999), illness experience and meaning (Chavez et al. 1995) reflexive/experiential writing (DiGiacomo 1987, Sontag 1978, Stoller 2004), social support and cultural models (Coreil, Wilke, and Pintado 2004, Mathews 2000), perceived causality among patients vs. physician/caregivers (Hunt 1998, McMullin, Chavez, and Hubbell 1996, Wardlow and Curry 1996), explanatory models (Dein 2004), complimentary and alternative medicine

(CAM) use in cancer therapy (Adler 1999, Hess 1996, Hess 1999), and the language and discourse about cancer often illustrated in illness narratives (Garro 1990, Garro and Mattingly 2000, Mathews, Lannin, and Mitchell 1994, Weiner 1999, Weiss 1997). These studies typically examine health beliefs, communications, knowledge and attitudes, for example.

Structural studies include those that focus on making explicit the global to local distribution in incidence and mortality rates by ethnicity, elucidating the historical, cultural and social conditions in which this disease arises and how it is differentially experienced by the poor and by people in different ethnic groups (Balshem 1993, Roushdy-Hammady 2004). These studies are typically informed by a political economic and critical perspective applied to understand the *how* and *why* of disease and the origins of disparities. While there are significantly fewer anthropological studies of cancer that follow this paradigm, they are beginning to emerge more commonly in the public health literature in the area of health disparities and in studies oriented to environmental/geographic racism.

All knowledge and behavior is mediated by and filtered through one's cultural lens. Perceptions about the various forms of cancer are understood in the context of culture, which influence health action, decisions and behavior. Anthropology's unique cross-cultural perspective brings into relief multiple dimensions in cancer studies not addressed by other disciplines. Anthropological contributions in this area are numerous and continue to be useful for understanding belief systems and behaviors in the context of this disease. This chapter provides an overview of some of the primary areas

where anthropology and cancer intersect in current scholarship with a specific focus on the contributions of anthropological methods to effective cancer interventions.

### **Cognitive Studies: The Importance of Beliefs, Disease Discourse, and Experience**

The understanding of culturally mediated beliefs about etiology, prevention and therapies and therapy options for cancer or any illness is a key component for understanding the social dynamics of how people attempt to avert illness, and for informing intervention programs for acceptability and sustainability (Dein 2004). Linda Hunt's work in southern Mexico illustrates the impact of health beliefs on how a family perceived their child's cancer diagnosis and subsequent resorts to various therapies. Through a case study of a teenager with a type of bone cancer, Hunt (1999) makes explicit competing ideologies of illness causality and action from the perspectives of the clinical caregivers to the patient and his family. Only when the teenager was in grave condition was treatment sought from a hospital (owing both to geographic and cost barriers as well as resorts to other therapies in the traditional medical sector initially as guided by what was readily available and congruent with perceived illness etiology. The boy had been kicked in a soccer game, and his leg and foot later became swollen, and eventually infected and infested with maggots. It was then that the family made the long trip to the hospital, where the clinical caregivers perceived the family as unhygienic and neglectful to the boy's condition. Upon examination it was discovered the boy had a type of bone cancer. The family attributed the

disease to witchcraft, claiming the boy who kicked their son during the soccer game also sent upon their son a magical snake (*coral*). The maggot infestation, for the family, was evidence of the witchcraft as for them, it signified a reproduction of the *coral* within the boy's body.

The family did not reject biomedical explanations for diagnosis and the disease process; however, the true etiology was perceived as witchcraft in which the vector was thought to be a magical snake. Treatment in the form of amputation was chosen. In spite of different notions of disease etiology, therapy options were sought in both biomedical and local medical sectors. Thus, both practical considerations (geographic distance, cost) and illness etiologic beliefs were important in determining the family's hierarchy of therapy resort. In the case of chronic and grave illness, medical pluralism is a common practice cross-culturally for illness management and Hunt's work clearly illustrates this concept.

Wardlow and Curry (1996) examined "ethno-etologies" (p. 320) about breast cancer and mammography among low income, medically underserved African American women in Atlanta who were clients at two area primary care clinics. In this clinic-based sample (n=50), the researchers found recurrent themes regarding breast cancer causality that tended toward a naturalistic etiologic explanation (Foster 1976). Women expressed belief about cancer in terms of heredity and diet, but especially causality was understood as related to injury. Specifically, a blow to the breast that results in a bump, knot or bruise, left untreated or otherwise uncared for, was seen as especially predictive of breast cancer. The authors note that this ethno-

etiology reflects women's lived realities of experiencing physical abuse associated with domestic violence.

Regarding mammography, the researchers found that some women distrusted the reliability of mammograms because they didn't get to the root of the breast, where they thought cancer would be most likely to come from. Also, fear of pain and exerting pressure on the breast were elicited as reasons for dislike of mammography. Understanding these perspectives, then, is critical for the creation of health education and screening programs that are acceptable to socially marginalized women.

Mathews (2000) examined illness experiences of women with breast cancer in a support group in North Carolina. Through the group discussions, women negotiated a model of the breast cancer experience by talking about similarities in their treatment and general illness experience. Most women ascribed to a biomedical model of cancer but drew upon their religious background to also cope with the disease and its treatments. Collectively the women in the support group also were able to critique the biomedical system when they compared and shared experiences where they were left unsatisfied with clinical encounters and therapies. Support group members had high religiosity that infused spirituality into their coping strategies and provided a context in which women could assert agency in medical decision making and openly express a wide range of emotions.

Coreil et al (2004) examined the cultural model of recovery and illness among women participants in breast cancer support groups in Florida in order to understand sustained participation in self-help groups. In-depth



ethnographic interviews and participant observation yielded information about a cultural model that included a recovery narrative, group metaphors, benefits, processes and contested domains (p. 910). The authors note that ethnography applied to such contexts is useful for understanding organizational culture, consensus development and/or contesting of cultural models of illness and the transmission of knowledge within a group.

The work of Leo Chavez is well known in medical anthropology for its contribution to the study of cancer in social and cultural contexts (Chavez et al. 1995, Chavez et al. 2001). For example, his work has contributed to the discussion of risk factors and breast and cervical cancer in Latina and Anglo women and physicians (Chavez et al. 1995). Using cultural consensus analysis, these researchers found consistent differences in how risk was perceived across these ethnic groups and physicians. This study also found two distinct cultural models of cancer among these groups: Mexicans, Salvadorans and some Chicanas adhered to a model that attributed risk of these cancers to moral/lifestyle choices and physical trauma and injury; Anglo women and some Chicanas subscribed more to biomedical model of cancer risk, but less consistently as physicians. Intracultural variation in belief was uncovered among the Latina women, and overlap in belief components (ethno-etiological to biomedical models) among Chicana women was uncovered illustrating a biculturally informed understanding of these cancers. This study illustrates the importance of understanding the potential for variation in perceptions within cultural identity categories (e.g., Latina) for public health education efforts.

One unique study that examines both qualitatively and quantitatively Haitian perceptions about cancer is a comparative study by Consedine et al (2004) in which the researchers assess breast cancer knowledge and belief differences in populations of women from different ethnic groups. Importantly, these authors make the distinction that too many other researchers do not: Populations characterized as White, Black/African American, or Hispanic are not monolithic and cultural variation is significant within these constructed categories. These researchers assessed potential differences in belief patterns about breast cancer etiology, treatment options, and knowledge of risk factors between categories that included Caribbean and African American women, Eastern European immigrant and U.S.-born white women, and immigrant Hispanic women from the Dominican Republic. These researchers found that Haitian women, more than the other ethnic groups, held the strongest beliefs that cancer was more likely to be caused by a bruise or sore, that the disease process was determined by God, that chemicals in food caused cancer, that breast cancer is nearly always fatal, and together with Dominicans, they believed that standard biomedical therapies (chemotherapy, surgery, radiation) were as harmful as the disease itself.

In sum, knowing beliefs informs intervention strategies. Successful interventions are created with a deep understanding of a community's cultural perceptions about cancer, its prevention, diagnosis and treatment and are informed about how beliefs help to shape preventive behaviors such as screening (Manderson 1999).

## Structural Studies

Critical anthropology contributions to cancer study are not as numerous as those of a more cognitive orientation. However, with the growth of critical medical anthropology, the stage was set for researchers concerned with the social structural aspects of cancer. Balshem's (1993) *Cancer in the Community: Class and Medical Authority* is one example of a critical perspective applied to anthropological inquiry of cancer. Balshem describes her role as a medical anthropologist/health educator at a major cancer center in a health promotion project with a working class neighborhood in Philadelphia (Balshem 1993). She discusses contradicting perspectives from the academic cancer center to the community. The cancer center researchers stressed lifestyle choices/behaviors as the primary cause of cancer in this community whereas the community blamed environmental contaminants. Further, Balshem describes researchers and health educators' perceptions of this working class community as negative due to lifestyle health choices and low socioeconomic status. These differences in perspectives impacted the community/academic relationship and raised conflict for Balshem in her role as an anthropologically trained health educator. Her efforts to illustrate social conditions of the working poor that inhibit positive lifestyle choices went largely unrecognized in her position at the cancer center. This work also importantly illustrates ethical departures frequently found when anthropologists are employed by institutions in which applied anthropology is marginal, new or otherwise unknown.

As previously mentioned, the critical anthropology of cancer literature is less well developed than cognitive/cultural studies; however, anthropologists have contributed in the areas of physical environmental contributions to cancer risk in the workplace (Doyal and Pennell 1991) and are continuing to provide comment in other areas including the pharmaceutical industry's regulation of anti-cancer drugs (Walsh and Goodman 2002). In keeping with environmental risk themes, Moberg (2002) examined community response to suspicions of cancer causing agents in the environment of a small southern Alabama town (Moberg 2002). Through ethnographic inquiry he concludes that the lack of community action against the chemical plants that are suspected as the source of increased cancer and other chronic disease is due to the community's economic dependence on the plants (for employment) and relative powerlessness to confront both corporations and the state.

In a sociohistorical analysis of Pap smear classifications, Clarke and Casper (1996) examine the changes over time in typologies of classification (4 systems developed) and the social construction of technology. These authors argue that the classification systems reflect knowledge construction and power in both biomedical and social contexts. There remain three primary systems in use today: Dysplasia, CIN and Bethesda/SIL (Clarke and Casper 1996). Each system reflects the dynamics of defining cancer versus pre-cancerous conditions in biomedicine over time and shifting biomedical definitions.

Finally, significant crossover occurs from public health professionals to the anthropological literature that covers structural aspects of cancer study. For example, Nancy Krieger's "ecosocial" perspective (Krieger 2001b) mirrors that of McElroy's political ecology (McElroy and Townsend 2004). While Krieger is a social epidemiologist, her work is regularly accessed in medical anthropology for understanding social environment and world systems contributions to health inequalities. In an analysis of breast cancer incidence in global context, Krieger notes that previous assumptions about breast cancer as more commonly associated with affluent/developed countries are changing, as poorer women in developing countries are experiencing an increase in breast cancer incidence (Krieger 2002). Further, Krieger notes that cancer incidence and mortality differ by ethnic groups in the US: Black women generally have lower incidence (although it is on the rise) than white women; however, they experience higher mortality than white women. Krieger points out that the view of breast cancer as a disease of affluence is dated and the social and economic lives of marginalized Black women in the U.S. provide an illustrative example of this shift.

Studies that include structural and cultural/cognitive variables in their assessment of cancer, and women's responses to it, describe interventions in cross-cultural contexts. These studies, which take into account the macro- and microsocial forces that impact cancer beliefs, behaviors, incidence and mortality, are the most fruitful for applied contexts. It is to these study types that I will now turn.

## **Anthropology in Cancer Control and Prevention: Interventions**

The importance of knowing the community cannot be overstated in the design of interventions, which invariably involve methods that draw from applied medical anthropology, especially in the case of international and/or socially marginalized communities. However, the unique cross-cultural, holistic approach inherent to anthropology distinguishes it from the more linear explorations of disease prevention and control found more often in clinical and public health fields. Further, an applied anthropological approach does not treat culture as a 'barrier,' or maladaptive behavior to be changed; rather, it seeks elucidation through cultural contexts to create interventions that are consonant with cultural frameworks.

The social context of cervical cancer, its prevention, locally constructed knowledge of, and etiological beliefs have all been examined from anthropological perspective in a few studies both domestic and international. As previously noted, this form of cancer lends itself easily to medical anthropological analysis because of its differential distribution cross-culturally and globally, and due to its high preventability. Further, ethnographic methods are key for situating the daily lives, social and system experiences, and sociocultural belief patterns of the focus communities squarely with the goals of any health intervention so that strategies are developed with rich knowledge of communities as guidance. As found in critical studies of cancer, there is much overlap in the intervention literature between anthropology and public health. While several cancer control interventions

have been designed in the public health field using anthropological methods, this literature focuses on those designed and implemented by anthropologists who are part of interdisciplinary teams.

Ethnographic research by Wood et al (1997) exemplifies one way in which medical anthropology research complements public health efforts and clinical needs of medically underserved women from three ethnic groups in South Africa. These researchers explored lay constructs of disease and associated prevention and screening tests. Lay models of disease and ethnoetiologies emerged that illustrated a significant disconnect in women's understanding of Pap test purpose with its biomedically defined purpose. Women interpreted the test as one that diagnosed and treated any STD, replete with a hygienic effect on the womb after the procedure (Wood, Jewkes, and Abrahams 1997). The authors noted the ways in which these cultural models of disease informed health seeking behavior of women considering Pap test screening, which are of obvious importance when applied to the creation of culturally competent intervention strategies.

Another example of an anthropology/public health collaboration using applied anthropological methods is a community/academic partnership in a multipart intervention to control cervical cancer by increasing Pap smear usage in Yakima women (Chrisman et al. 1999). This study approaches a truer example of participatory research, as the call for assistance came from a community tribal member from their Department of Human Services. These researchers used participatory action research (PAR) methods to first discern the primary concerns of community members, as they themselves

defined them. A community advisory board, their Cancer Committee, was a principle component for building tribal capacity to collaborate in research projects to benefit their community. The Committee collectively reviewed a research proposal of a cervical cancer intervention project, Wellness and Spirituality.

The researchers began broadly by asking women about their lives on the reservation, their experience with health services and their thoughts about cancer. This approach generated information that guided the intervention design, based on the perspectives of the women it was to help. Tribal members were included as hired research assistants and consultants. Focus group information led to health education efforts that combined tribal crafts with learning about health, beyond the context of cancer, which better met women's information requests. Women's discussions about their experiences at the health clinic revealed dissatisfaction with social treatment where the clinic staff members were perceived as cold and impersonal. Most notably, the participatory process yielded successes in the intent of the intervention: clinic staff members who were part of the Cancer Committee changed the notification system of abnormal Pap tests from letter format to in-personal consultations to meet the communication preferences of the Yakama women. As a result, follow-up colposcopies increased dramatically from 20% to 100%.

Another important finding in this process was that the general health prevention approach, to get a Pap test to prevent death, was less meaningful to inspire health behaviors. For this community, death was perceived as a



natural cycle of life and instead, an approach that emphasized staying healthy was better received (Strickland et al. 1996). This community based intervention involved tribal members from the initial discussions, which contributed to positive communications and better informed, viable health education efforts. The end effects included increased community capacity for research and decreased attrition in follow-up of abnormal Pap results.

Finally, another notable example of successful intervention in the anthropology of cancer is Debbie Erwin's work in the creation of The Witness Project®. This program is a faith-based breast and cervical cancer intervention guided by behavior change theory that promotes early detection through the use of role-models who are survivors of these cancers (Erwin, Spatz, and Turturro 1992, Erwin 2002). While cervical cancer education is a component, there is a heavier emphasis on breast cancer in this program. The intervention design was informed by ethnographic work by Erwin and colleagues among lower income, rural African American women in Arkansas. The researchers hypothesized that survivors from the same ethnic and social class background would more effectively encourage breast self exam (BSE) regular practice, mammography and Pap test usage through a lay health promoter model.

A model was developed that was culturally congruent with the high religiosity of the African American women in the original ethnographic study. The concept of "witnessing" emerged, relating how an experience was life-changing, and it was adapted to breast and cervical health promotion. The role model survivors specifically address cultural beliefs that could act to

inhibit women from seeking screenings. Programs are typically held in collaboration with churches and congregations on church grounds. BSE techniques are taught through by the lay health promoters and through the use of silicone breast model displays. The program initially aimed to increase attendance at health education programs and awareness of early detection. From the initial programs, the researchers' evaluation data showed an increase in reported BSE, even more frequently than the recommended monthly practice, compared to baseline information gathered at the initial meetings (Erwin, Spatz, and Turturro 1992).

The Witness Project® gained wide acceptance in the rural African American community in Arkansas where it began. Erwin and colleagues later evaluated components of health beliefs, knowledge and behavior practices, demographic items and locus of control, among other variables (Erwin et al. 1996). Statistically significant results were found post-intervention for mammography use, BSE regularity, and BSE in the last month. No changes in beliefs were uncovered, as measured by health belief items in the survey; however, behaviors were impacted through the testimonies of credible role models who survived these cancers.

The researchers again later tested this intervention against a control group of women who did not take part in the program (Erwin et al. 1999). Instead, a Time-1/Time-2 interview method was used in a population otherwise matched on ethnicity and socioeconomic status. (After the Time 2 interview, the women in the control group also received a Witness Program). Erwin and colleagues again found statistically significant results, this time

using a control, where program participants increased their BSE practice and mammography use.

Jackson and colleagues (2000) used qualitative and quantitative ethnographic methods to explore Cambodian immigrant women's constructs of cervical cancer and what it means to have reproductive health. The data were used to create a culturally and linguistically competent cervical cancer intervention that met the needs of Cambodian women who were largely economically disadvantaged political refugees, low English proficient, low literacy and culturally and linguistically isolated in many ways from their host community. In depth ethnographic interviews were complemented with quantitatively oriented surveys in order to elicit and verify information about women's orientations to prevention, ethnoetiological concepts, non-western remedies and healers, gender preferences for health care providers, and knowledge about Pap testing. To meet literacy and language needs, an audiovisual intervention (complemented with lay health worker education counseling) was created in the form of a videotape that addressed cervical health education while infusing important cultural components that reflected how women perceived reproductive health. For example, most women had a strong non-western or traditional orientation to health maintenance, and observing *sor sai kjai*, a three to six month post partum period during which women are thought to be gradually regaining strength and equilibrium after pregnancy (Jackson et al. 2000). During this time they are vulnerable external insult (e.g., eating culturally prohibited foods or engaging in taboo behaviors), which may lead to reproductive disease including cancer.

In recognition of women's worldview, Pap test education was placed within a similar framework as a practice that is done to maintain reproductive health. This research underscores the importance of contextualizing cervical cancer to traditional belief orientations and structural realities of immigrant women. This research also echoes findings among Mexican immigrant women in the U.S. (Chavez et al. 2001) and Native American women (Strickland, Squeoch, and Chrisman 1999) which emphasized the importance of health beliefs in the development of interventions that were consonant with cultural constructions of what it means to be healthy.

Further, Hunter's (2004) ethnographic work in Iquitos, Peru on the experience of cervical cancer for low-income women was informed by a political ecology approach. As in the other research discussed in this section, she elicits local knowledge and understanding of cervical cancer and women's responses reveal ethnoetiologies that guide treatment and screening decisions. Health seeking behaviors were heavily mediated by monetary cost and geographic and time access when women resorted (or attempted to resort) to biomedical sectors for care. Fear components, including fear of the Pap test, the potential for pain, the possibility of discovering grave illness, and fear of organ removal also mediated women's decisions to seek Pap tests. Hunter observes that the discovery of serious illness was particularly concerning to women since it would mean an economic disruption to the household as treatments were very costly, and that the cumulative effects of poverty can also be reflected in the lowered immunity of women she interviewed with cervical cancer. Women also viewed Pap tests as tests for

cancer – not as a way in which reproductive health can be maintained. The author discusses her ethnographic research results in terms of their utility for application to sustainable intervention design, again illustrating how medical anthropological analysis and methods are particularly germane to contextualizing cross-cultural notions of risk and health seeking behavior for women in poverty.

Lastly, Gregg (2003) combined interpretive and political economic approaches to contextualize low-income Brazilian women's experiences with and understanding of cervical cancer. In conditions of extreme poverty, women's survival strategies necessitated using sexuality as a resource for critical economic support from male partners. Women redefined virginity and sexual practices in order to maintain respectability in the context of poverty and unequal power relations between men and women. In so doing, women also reconstituted cervical cancer risk to mean a lack of Pap screening, disassociating sexual survival strategies and risk. Pap testing was widely available from a government intervention program; thus, women could take part in those screenings, but sexual behavior changes were not feasible given the threat to their economic survival.

## **Summary**

In keeping with the conclusions of Chavez et al. (2001), cultural and structural factors are neither mutually exclusive nor competing in their contributions or explanatory power for screening behaviors. Indeed, account of both types of variables is necessary for a more complete understanding of

the dynamics of health seeking behavior. Coupling cultural/cognitive studies with understanding of structural constraints and subsequent case management or otherwise connecting women to care as needed is critical to successful intervention strategy. The following chapter makes the case for a biocultural approach to cervical cancer. This disease is discussed in terms of its medical anthropological, public health and clinical importance.

## **CHAPTER 5**

### **THE BIOCULTURAL CONTEXT OF CERVICAL CANCER**

#### **Introduction**

This chapter begins with a brief discussion of the clinical and public health importance of cervical cancer, illustrating the social and medical impact of this disease by examining its unequal distribution and by situating it from global to local in the specific transnational context of Haitian women. A definition of cervical cancer follows, with a brief discussion of its natural history, etiology and association with oncogenic strains of human papillomavirus (HPV). An examination of known risk factors, both social and biological, serves to contextualize the implications for primary and secondary prevention (screening) and treatment and culturally relevant cancer education. This chapter concludes by linking the medical anthropological aspects and public health implications of this disease. The medical and public health discussions of cervical cancer are necessary background for understanding how the disease progression and its distribution disparity are socially and culturally mediated and thus differentially experienced by marginalized women worldwide. A broader placement of this disease in its various social environments allows for richer medical anthropological contributions to the dialogue surrounding cervical cancer.

## **Disease Significance, Impact and Distribution**

Cervical cancer is a disease of major public health importance with significant impact on women's lives and their families on a global scale. It is the third most common cancer in women globally (NLM-NIH 2004). Across many societies worldwide, women are the primary family caregivers, single heads of household, and simultaneously occupy various additional social roles. A disruption due to serious illness has multiple negative effects on family dynamics, a woman's social role expectations, community position, and earning potential to support a household. Thus, there are myriad social implications found with this disease.

Additionally, this cancer is largely preventable through various screening methods. Cervical cancer tends to progress slowly and is highly treatable with nearly 100% cure if caught in precancerous stages, and an 80-85% 5-year survival rate if the tumor is confined to the cervix or uterus (NLM-NIH 2004). Alternatively, approximately 95% of women will die within a 2-year time period if cervical cancer goes untreated. Many deaths due to this cancer can be prevented through access to early screening and detection with appropriate and timely follow-up care, and in some cases, lifestyle changes. These facts are biomedically significant and socially salient enabling aspects that at once provide a positive outlook at the potential for decreasing death and suffering, and raise a challenge to understanding how this disease remains a common killer among women worldwide. These aspects bring into relief some of the critical components necessary for successful intervention strategies.



Furthermore, the distribution of cervical cancer incidence and mortality is grossly uneven in that it disproportionately impacts women in developing countries and socioeconomically marginalized and ethnic minority women in developed countries (Cronjé 2004, Franco, E, and A 2003, Weissman and Schneider 2005). In global perspective, more than 80% of cases occur in women who live in or emigrate from developing countries where prevention orientations to health are nonexistent or ineffective ((ACCP) 2004, PAHO 2001). Domestically, disenfranchised women – including women with limited English proficiency, low income, low literacy, foreign-born status, no health insurance and no usual source of health care – regularly experience greater incidence and lower survival than women who do not occupy these social categories (Lindau et al. 2002, Navarro et al. 1998, Newmann and Garner 2005, Seeff and McKenna 2003, Sharp et al. 2002).

Current U.S. incidence and mortality statistics for cervical cancer (and most other diseases) are not collected in any systematic way that illustrates in-group diversity in disease distribution. For example, socially constructed categories such as “Black/African American” and even “White” mask rate variations that occur in different ethnic groups occupying the same “racial” category when diseases such as cancer are reported because there is no distinction for cultural background, nationality or immigration status. For ethnically diverse states such as Florida, this system precludes the ability to obtain accurate health profiles of different immigrant populations.

To better understand the health profiles of Florida’s diverse immigrant communities, we must turn to international health statistics initially and

make inferences about population health based on available data and hypothesize about how health profiles change upon emigration to the U.S. We must then follow with more in-depth qualitative examinations of communities' health and disease experiences to accommodate for the health information that is otherwise lacking. Cervical cancer disproportionately affects women in Latin America and the Caribbean (Eluf-Neto and Nascimento 2001, Hoyo et al. 2000, Robles, White, and Peruga 1996). For example, one data source that is particularly relevant to Florida, the Pan American Health Organization (PAHO) recently issued a report on strategies to reduce the high cervical cancer rate in the Caribbean region, primarily through improved public health infrastructures and Pap test screening (Lewis 2004). After regions of Africa and Melanesia, women in the Caribbean and Central American regions experience the next highest incidence and mortality due to cervical cancer (Arrossi, Sankaranarayanan, and Parkin 2003). The following table depicts these rates based on the most recent data available as of this writing, with North America as referent:

**Table 1: Age-Standardized Incidence and Mortality Rates per 100,000 Population by Region, 2002\***

<b>Region</b>	<b>Incidence</b>	<b>Mortality</b>
<b>Central America</b>	30.6	15.0
<b>Caribbean</b>	32.6	16.0
<b>North America</b>	7.7	2.3

\*Adapted from PAHO Cervical Cancer in Latin America and the Caribbean: Fact Sheet 2002

These rates are significant for Florida since the state has large Latin American and Caribbean immigrant communities. Among all Caribbean populations, women in Haiti experience the poorest cervical health. Cervical cancer is the leading cause of cancer mortality for women in Haiti, at 94 deaths per 100,000 population. Based on this mortality, the estimated age-standardized incidence for Haitian women is highest in the world, at 87.3 per 100,000 population (PAHO 2003, PAHO 2008). Comparatively, the estimated age adjusted incidence for the U.S. for the same year was 7.7 per 100,000 population. Currently, the impact of this incidence is unknown for Haitian women in the U.S., in part due to the data reporting methods previously mentioned. However, ongoing research in Little Haiti, Miami, currently reveals crude cervical cancer incidence rates of 38/100,000 women (E. Kobetz, personal communication, September 10, 2008). Finally, Haitian immigrant women's gynecological health issues are largely unknown in the U.S., as are perceptions of screening and treatment.

### **Cervical Cancer in Haitian Immigrant Women**

Cervical cancer is the leading cause of cancer deaths among women in Haiti, where its incidence is 21 times greater than breast cancer (Lewis 2004). While national health statistics in the U.S. do not distinguish Haitians from other populations of African ancestry, several aspects of simply being an immigrant contribute to generally poorer health and health outcomes in a host country. For example, exposure and immunization histories of immigrant populations differ from those of the U.S.-born population, where

the health advantage usually lies with being born in the U.S. Domestically, cervical cancer has a greater incidence and mortality impact in ethnic minority and foreign-born/immigrant, and non-citizen women, and in women with low health literacy (de Alba et al. 2005, Newmann and Garner 2005, Sanghavi Goel et al. 2003, Seeff and McKenna 2003, Sharp et al. 2002). Additionally, immigrant populations generally have less knowledge of reproductive and gynecological health screening and less access to health care services (Kramer, Ivey, and Ying 1999, Scarcini et al. 2003).

Further, current methods of recording health data obscures important differences in health profiles for foreign-born groups (Hahn 1998, Kramer, Tracy, and Ivey 1999). For example, the "African American/Black" category descriptor includes foreign-born and native-born persons of African ancestry from diverse world regions. Persons with Haitian ancestry, then, are absorbed into the "Black/African American" category for reported health measures. The net effect is a higher likelihood of a greater prevalence of cervical cancer in Haitian immigrant women, but a cumbersome system that does not capture the extent of the disease burden due to homogenized ethnic categorization.

Moreover, cancer among Haitians in the U.S. has been given little attention beyond the context of AIDS and its associated malignancies. A 2008 PubMed literature search on "Haitians and cancer" yielded a mere 35 hits, and 27 of the articles (77%) focused on AIDS-related cancers and were relatively dated (18 or more years old). This medical focus reflects a socially significant bias, informed by a persistent, misguided exoticification of disease,

a foreignness-of-germs orientation (Markel and Minna Stern 2002), and ultimately a “geography of blame” (Farmer 1992). Literature searches using other databases yielded similarly sparse results. The lack of published information illustrates the need to better understand the cancer impact among Haitians in the U.S. beyond the AIDS context.

A few researchers from anthropology, public health and cognitive psychology have begun to contribute to studies of cancer in Haitian immigrant communities. Some of this work tends toward knowledge, attitude, perception (KAP) surveys that do not incorporate social context and generally use a “knowledge-deficit” approach (Green 1999, Pelto and Pelto 1997), where lay knowledge is compared to “objective” biomedical definitions (Good 1994, Yoder 1997). Yet, such surveys can suggest important findings to be explored in cultural contexts using ethnography.

For example, David and colleagues (2005) employed a combination of epidemiologic and ethnographic methods in ongoing interdisciplinary research to contextualize breast and cervical cancer impact, experiences and cultural knowledge among Haitian immigrant women in Boston. Preliminary published work illustrates cultural and structural factors at work in the Boston Haitian community. A cultural model of cancer as associated with certain death is present, a lack of understanding of mammogram purpose, and screening and treatment delays were noted (David et al. 2005b). Other recently published work by these researchers shows Haitian women to have lower self-report of Pap tests than other ethnic groups (African American, English-speaking Caribbean women); however, adjustment for demographic

indicators associated with Pap test usage (age, marital status, education level, and income) explained part of the difference (Green et al. 2005). When they examined three variables of 1) usual source of care; 2) health insurance; and 3) female physician, ethnic differences in Pap test usage rates was eliminated, suggesting the importance of structural context and culturally mediated physician gender preference for women's health behaviors.

Thus, the literature reflects a significant gap in anthropological and public health understanding of cervical cancer in the context of Haitian immigrant women's lives. In general, the health status of Haitian immigrants is not well documented, although significant structural barriers to health care (e.g., lack of insurance, legal status, language) have been determined to impact health seeking behavior (Gany and Thiel de Bocanegra 1996b, Saint-Jean and Crandall 2004). Florida is home to a large, diverse and growing Caribbean immigrant population, of which Haitians comprise the majority (excluding the Spanish-speaking islands) even before adjusting for an undercount (U.S. Census Bureau 2000b). Thus, prevention, education and timely follow up care are significant public health tasks for its communities.

In sum, cervical cancer is a unique type of cancer epidemiologically, in that a population level change can be shown in a shorter period of time with the implementation of effective, sustainable screening programs and appropriate, consistent follow-up. Given the relatively low cost of screening and treatment of precancerous conditions, and the generally slow-progressing nature of this disease, an extraordinary opportunity exists to

positively impact vulnerable populations through the use of culturally acceptable and economically effective screening and treatment.

In the next sections, I will cover some of the clinical aspects of cervical cancer and explore known social and biological risk factors for this disease.

### **Biomedical Definition and Natural History of Cervical Cancer**

Cancer of the cervix is the result of cellular change (precancerous to malignant) usually over a long period of time, often many years. It begins in the lining of the cervix, which is the lower part of the uterus. Most cervical cancers begin at the juncture of the endocervix (area closest to the body of the uterus) and ectocervix (area closest to the vagina) ((ACS) 2004). There are two primary types of cervical cancer: squamous cell carcinoma and adenocarcinoma. The great majority of cases (80 – 90%) are squamous cell carcinoma ((ACS) 2004). Adenocarcinomas form from mucous producing gland cells in the endocervix and are much less common. Squamous cell abnormalities that are not regressed by the body's immune system can develop into precancerous lesions, classified by severity in cellular changes.

Medical typology/classification systems in use reflect the natural history of the disease. Precancerous conditions are also called cervical dysplasias and are medically described as mild, moderate and severe. Mild dysplasias are common and usually regress on their own without treatment whereas moderate and severe dysplasias have a greater chance of progressing to malignancy (Zangwill 2004). These precancerous conditions can be present for years. Because most forms of cervical cancer progress

slowly, early detection screening methods are extremely effective in detecting precancerous changes before cancer begins (Bradley et al. 2005). Addressing dysplasias is at once treatment (for current lesions/areas of suspicion) and prevention (of cervical cancer) when lesions are effectively treated. Finally, cervical cancer is staged numerically from Stage 0 (in situ) to Stage 4 (metastasis to nearby organs or other parts of the body), with specific intermediate stages that correspond to the degree to which the cancer has spread (Zangwill 2004).

### **Etiology of Cervical Cancer**

More than 95% of all cervical cancer cases are caused by oncogenic strains of the human papillomavirus virus (HPV) (Lorincz 2003, Zangwill 2004). HPV infection is extremely common in sexually active people, and the lifetime exposure rate is estimated to be 75% of women in the U.S. population ((ARHP) 2005, Zangwill 2004). Prevalence in asymptomatic women in the U.S., based on various studies using HPV DNA testing, is estimated to be as high as 44% (Trottier and Franco 2006). This virus family is the most common sexually transmitted disease worldwide and is comprised of more than 120 types, most of which the body's immune system acts upon and causes them to regress over time with few or no symptoms (Trottier and Franco 2006). The high-risk HPV (HR-HPV) strains that are found with cervical cancer are HPV-16 (accounts for approximately 50% of cases), HPV-18 (roughly 12% of cases), and HPV-31 and HPV-45 account for about 5% of cases (Zangwill 2004).



Co-infection with multiple HPV strains is also possible. One common strain that causes genital papillomas has not been found to be associated with any malignancy. Fortunately most strains (even oncogenic ones) are successfully stabilized or regressed by the body's immune system. It is the persistent and chronic infection with HR-HPV strains that is most closely linked with the development of precancerous lesions and cervical cancer (Trottier and Franco 2006).

Current clinical and social epidemiology of cervical cancer indicates that infection with one or more of the HR-HPV strains is a necessary but not sufficient causal factor (PAHO 2008). Other social and biological factors mediate the extent to which cervical cancer impacts any given population. Such risk factors that are often found with HPV infection include: early age at first intercourse, multiple sex partners, impaired immunity, smoking, multiparity, and early age at first birth ((ACCP) 2004, Kaur and Singh 1992, Trottier and Franco 2006, Zangwill 2004). Examples of social and behavioral factors found in association with cervical cancer are: low literacy, lack of health insurance, no regular source of health care, negative perceptions of cervical screening, ineffective prevention programs, fear that inhibits follow-up colposcopy, gender inequity, feminine hygiene practices, and emigration from developing countries (Basen-Engquist et al. 2003, Boyer et al. 2001, Chavez et al. 1997, Chavez et al. 2001, Kershaw et al. 2006, Martinez, Chavez, and Hubbell 1997, Martino and Vermund 2002, Runganga, Pitts, and McMaster 1992).

## **Prevention, Detection and Treatment in Biocultural Context**

The epidemiological, biological and sociocultural issues related to cervical cancer prevention, detection and treatment are inextricably intertwined. As previously discussed, there is great disparity in the distribution of this disease, which more significantly impacts poorer, socially marginalized, medically underserved women in the U.S., and women in developing countries bear a disproportionate burden of cervical cancer mortality. Early detection efforts have been very successful in curbing this disease in settings and populations with sufficient resources; however, efforts have been less successful in higher risk populations for both structural and cultural reasons.

### ***Primary and Secondary Disease Prevention***

Primary prevention of this disease is the ideal, which is prevention of HPV infection since it is a necessary causal agent in the development of cervical cancer. Currently, there is controversy surrounding condom use and HPV transmission (Epstein 2005). There is no evidence that condoms effectively prevent the transmission of HPV, as any genital contact is sufficient, but there is evidence that they may lower HPV infection risk and reduce viral regression time with consistent use (Holmes, Levine, and Weaver 2004, Moscicki 2005).

The FDA approved a quadrivalent vaccine in 2006 for HPV, marketed as Gardasil® in the U.S., which protects women from infection from the most

commonly found oncogenic HPV strains: 6, 11, 16, and 18 (Hakim et al. 2007). Protection has been determined to last for a period of approximately five years, with some indication of immune memory, affording longer protection and thus sustained efficacy (Herbert and Coffin 2008).

While Gardasil® is on the market, and another bivalent vaccine is in trials (Cervarix®), there are significant social and structural barriers associated with the vaccines. For example, the target age range for immunization is currently between 9 and 26 years. Women older than 26 years may benefit from the vaccine if they have not been exposed to HR-HPV strains or expect to have new sexual partners in the future (Wright et al. 2008). For the younger preadolescent and adolescent populations, this entails obtaining parental consent for the vaccinations, and carries with it many ethical implications about sexual behavior and, among some, fear that the vaccine could encourage promiscuity (Brabin et al. 2006, Lunec 2005).

In addition, the vaccine does not eliminate altogether the need for Pap test usage (de Melo-Martin 2006). Although results from clinical trials indicate that the vaccines are very effective against HR-HPV infection, not all women can be immunized, least likely those at greatest risk, who have no insurance or usual source of care. Currently the vaccine is very expensive, selling at \$360 USD for the 3-dose regimen (PAHO 2008). It is not yet covered by all private insurances, for those who have health insurance. The Vaccines for Children Program (VCF) recently added Gardasil® to its formulary. The VCF is an entitlement program for children under 18 years old who are underinsured, uninsured, Medicaid-eligible or Native

American/Alaska Native that provides free vaccines for eligible children (CDC 2008). Even with this benefit, under- and uninsured children and women are less likely to have a usual source of care and limited access to care (Vetter and Geller 2007). Until vaccines are widely available for multiple HR-HPV strains and prove effective at the population level, secondary prevention through routine screenings remains the standard prevention method.

### ***Disease Detection and Treatment Methods in Context***

The success of cervical screening methods are examined in the literature in terms of sensitivity and specificity. Sensitivity measures how well a test detects true disease, and tests with high sensitivity and negative results are effective at ruling out disease. Specificity measures how well a test rules out true negatives, and a high specificity has few false positive test results. Both of these measures and their associated predictive properties are dependent on population disease prevalence.

Precancerous changes are detectable (with varying degrees of sensitivity, specificity, and predictive values) by routine screening methods including the Pap test and direct visual inspection (DVI) with acetic acid or Lugol's iodine. The introduction of cytology-based screening in the 1940s dramatically lowered cervical cancer mortality in the U.S. and many European countries (Lorincz 2003). However, the conventional Pap test sensitivity in a clinical setting is approximately 50-60% (Damasus-Awatai and Freeman-Wang 2003). The conventional Pap test, then, can have high rates of false negative test results depending upon disease prevalence in the

population.

Newer liquid-based cytology Pap tests (i.e., ThinPrep) increase clinical-setting sensitivity to about 75%. To make these measures clinically meaningful, positive and negative likelihood ratios are needed because they are independent of disease prevalence in the population being tested. However, to evaluate a test's utility for maximum public health impact on detecting a highly preventable and potentially fatal disease such as cervical cancer, one must return to a population-level perspective. Thus, with the Pap test, one of its strengths is found in its repetition over time (Lorincz 2003) to detect changes that progress slowly, affording a wider window of time to catch and treat precancerous conditions before they worsen.

In resource-poor settings, and among disenfranchised populations, the Pap test has significant challenges to its effectiveness: There is the need to maintain the integrity of the samples taken from patient to laboratory; a need for pathology capabilities; a need to relay lab results to patients and in turn secure follow-up care if needed; the cost of securing these services prohibited by cost and other structural barriers. Importantly, the alternative screening tests (i.e., direct visual inspection, or DVI) provide the opportunity for immediate treatment of suspect or precancerous lesions through low-tech options such as cryotherapy that are not cost prohibitive (Jacob et al. 2005, Pollack and Tsu 2005), reducing the number of times a woman must return for follow-up care and the potential for women to not return for care at all (Blumenthal et al. 2005, Bradley et al. 2005, Yang et al. 2004). DVI screening protocols involve colposcopy and chemical solutions applied to the

cervix, which, on contact, make suspect lesions visible. For example, visualization with acetic acid (VIA) involves the application of a 3-5% solution to the cervix (World Health Organization 2002). Suspect lesions turn white, and are visible to the naked eye assisted by a bright light source for examination. Immediate biopsies can be done of visible lesions, which are then treated with excision or cryotherapy (Mandelblatt et al. 2002, Sankaranarayanan et al. 2007). Another common DVI protocol is visual inspection with Lugol's iodine (VILI). VILI screens for suspect lesions, which turn brown with the application of Lugol's iodine. Similar to VIA, the lesions can be biopsied and treated at the time of examination, eliminating a treatment follow-up visit. These "see-and-treat" protocols are widely used in low resource settings such as developing countries (Goldie et al. 2001).

Interestingly, see-and-treat protocols and those using multiple screening methods have also been used in high resource settings in medically underserved populations, although much less frequently than in developing countries. These protocols are informed by the lived realities and social context of the population targeted for prevention and treatment. This perspective is congruent with an emic approach to understanding illness contexts in medical anthropology. In Peru, Jeronimo and colleagues (2005) recently used visual inspection with acetic acid (VIA) as an adjunct screening method with Pap testing in a well-equipped clinic in Lima. All women (n=1,921) were tested at the same clinic visit with both methods and were followed for one year. VIA use increases screening sensitivity, and Pap testing improves specificity.

One key finding from their work concerns lost-to-follow up: Women whose VIA results were positive for suspect lesions (n=132) had a significantly lower lost-to-follow up rate (2.6%) for colposcopy than women who were VIA-negative but Pap-positive (n=80), who had a lost-to-follow up rate of 26.3% (Jeronimo et al. 2005). All women knew the VIA test results within minutes, and if positive, received appropriate education and instructions for follow up; in contrast, women had to wait a minimum of one week to learn Pap test results. Thus, immediate knowledge of abnormality coupled with effective patient counseling is thought to be an effective method to reduce attrition and hence suffering from cervical cancer. This research shows the utility of a multiple methods approach beyond a low resource setting.

In the U.S., Holschneider and colleagues (1999) worked with a local faith-based group to organize a same-day screening and treatment program for Hispanic women at their local church in Los Angeles. The researchers used cytology-based screening with mobile laboratory processing capabilities producing results in approximately one hour. Non-cytology based screening methods were not used. These researchers found that the single-visit approach was highly effective in meeting the educational and social needs of women who attended the program evidenced by the opportunity to immediately treat various gradations of precancerous conditions, women's high satisfaction reports and improved knowledge of cervical cancer prevention (Holschneider et al. 1999).

These two examples illustrate the bridging of clinical and public health

objectives with the needs of women in various social contexts. This type of intervention strategy, by taking into account women's competing daily needs, increases its effectiveness and women's reported satisfaction while decreasing potential for attrition. Creative intervention strategies are especially needed for women who are the most difficult to reach.

Such strategies are even more necessary and salient when dimensions of culturally mediated health behaviors are potentially harmful, and become the subject of behavior change. The following sections review current research on women's gynecological health behaviors, which are reinforced by culture, history and unequal power in gender relations. An examination of this literature is of comparative importance for illuminating the practices, which may negatively impact Haitian women's health today. Additionally, an examination of archival literature on biomedical gynecological practice illuminates potential influence on choice of agents remaining in lay use today, as documented in contemporary African and Caribbean populations.

### **Gynecological Health and Culturally Mediated Feminine Hygiene Practices**

Culturally defined feminine hygiene practices, such as douching, vaginal drying, intravaginal and vulvar washes are found among women worldwide, including Haiti and among Haitian women in the U.S. These practices largely belong to the level of self-treatment. They tend to be primary resorts for illness treatment, and they are also part of routine hygiene to prevent illness. Published literature on the practices and their



health effects are found primarily in public health and epidemiologic literature, with some also found in social science literature. The current weight of epidemiologic evidence indicates that some intravaginal practices are associated with an increased risk of a variety of sexually transmitted infections (STIs), that give rise to morbidities such as pelvic inflammatory disease (PID), cervicitis, urethritis, and cervical cancer (Cottrell 2002, La Ruche et al. 1999, Martino and Vermund 2002, Rajamanoharan et al. 1999). Meaning is assigned to feminine hygiene practices that take place in broader cultural and social contexts. These practices also help to shape gender and power dynamics in social and sexual relationships between men and women. These facts are important to consider when designing and implementing interventions.

### ***Geographic Distribution of Intravaginal Practices***

While these practices have been documented in a wide variety of world regions and countries, they are most commonly reported in African countries (e.g., Central African Republic, Côte d'Ivoire, Republic of Benin, Democratic Republic of Congo/Zaire, Malawi, South Africa, Zambia, Zimbabwe) (Brown, Ayowa, and Brown 1993, Buvé, Bishikwabo-Nsarhaza, and Mutangadura 2002, Gresenguet et al. 1996, La Ruche et al. 1999, Myer et al. 2004, Runganga, Pitts, and McMaster 1992), Latin America and the Caribbean, including Haiti (Brown, Ayowa, and Brown 1993, Halperin 1999, Kun 1998), and among Latin American and Caribbean immigrants in the U.S. and U.K. (Anderson et al. 2008, Rajamanoharan et al. 1999). Douching practices are

also more common among African Americans and Hispanics than other ethnic groups in the U.S. (Martino and Vermund 2002, McKee et al. 2008, Rosenberg, Phillips, and Holmes 1991, Zhang, Thomas, and Leybovich 1997).

### ***Reasons for Intravaginal Practices***

The reasons for these practices are many, but the literature reveals that similar reasons are found cross-culturally: drying and tightening to enhance sexual pleasure for male partners, for routine hygiene, to prevent STIs, to prevent pregnancy, and to treat perceived infection symptoms such as excess or odorous discharge or vaginal itching (Brown, Ayowa, and Brown 1993, Brown and Brown 2000, Crosby et al. 2000, Gazmararian et al. 2001, Lichtenstein and Nansel 2000, McKee et al. 2008, Reed, Ford, and Wirawan 2001). Brown, et al. (1993) used focus groups with men and women and open-ended interviews with women, to assess attitudes about dry sex and intravaginal practices in Zaire (now Democratic Republic of Congo). Clinical exams complemented interview data, where women underwent gynecologic assessment either as part of routine care or as part of STI treatment at a local clinic. In their sample, both men and women indicated a preference for dry sex to enhance sexual pleasure. Indeed, women with large or wet vaginas were thought by men to be diseased, promiscuous or cursed. In general, wetness was synonymous with illness. The various practices then served to prevent or treat perceived infections as well as dry and tighten the vagina for enhanced sexual pleasure.

Runganga and colleagues (1992) found that the use of agents among

women in Zimbabwe centered on two primary reasons: for male partner gratification, and to keep partners faithful and thus marriages stable. The agents helped women with vaginal tone and decreased secretions, which women perceived as effective. Women also discussed the cleanliness aspect of the practices, which is consonant with the cultural view that secretions of any kind are an indication of illness. Significantly, the authors note that any educational intervention must offer an alternative that is congruent with cultural norms, and that the intravaginal practices must be understood as ways that women felt they had some control over their own sexuality and partner fidelity in a society where gender equity does not exist.

Imade, et al. (2005) used structured interviews with female sex workers and family planning clinic clients in Nigeria to assess the reasons for and frequency of use of lemon or lime juice douches. They found that 75% of the women interviewed (n=300) believed that intravaginal cleansing with lime or lemon juice (either undiluted or diluted with water) before or after sex afforded some protection against pregnancy and STIs, including HIV. Because of its common use in various African countries for these reasons, and its plausibility to create or sustain a vaginal environment with a low pH, lime juice was recently examined in a safety trial to assess its potential for use as a microbicide (see Hemmerling et al. 2007). A safety profile of a lime juice dilution of 20% or less was established, where no significant vaginal or cervical epithelial damage or harmful changes to vaginal flora occurred; however, to be effective against HIV, in vitro studies suggest that a solution of at least 50% lime juice dilution is needed and in an application for at least

30 minutes. The authors note that establishing a dose high enough to be effective, but low enough to be safe, would likely result in recommendations that are impractical for use in non-clinical settings (Hemmerling et al. 2007).

In the U.S., McKee, et al. (2008) used in-depth interviews with Latina women to examine reasons for vaginal douching. Primary themes that emerged centered on cosmetic reasons and on infection control reasons. Women also viewed douching as a normal, healthy habit for effective women's hygiene. Gazmararian, et al. (2001) found similar themes using focus groups of African American and white women from a clinic sample in Tennessee. Women perceived douching as an integral part of a woman's hygiene, and they reasoned that it is a safe practice because douching products are marketed and ubiquitous. These themes continued in findings among American women who took part in a random digit computer assisted telephone survey about women's hygiene practices (n=2,602): Women believed that the use of douches and other hygiene products were safe because they could be easily purchased in any drugstore, and women who douched were more likely to use other feminine hygiene products as well (e.g., wipes, sprays, powders) (Grimley et al. 2006). Importantly, all of these authors point to belief systems and media influence as critical factors to consider when developing educational materials or interventions.

### ***Agents Used and Modes of Administration***

Specific agents used and methods of application and administration vary cross-culturally in response to available agents and perceptions of

disease etiology. As noted previously, the vast majority of agents are part of the realm of self-treatment or health maintenance. In consideration of the variety of agents used, one must rethink the notion of 'home remedy.' Cross-culturally, home remedies are part of the *materia medica* of self-treatment. In the case of intravaginal practices, substances are prepared at home by the women users. Substances vary in constitution from plant parts, teas (infusions), decoctions, cloth or tissue, stones, powders, water, salt, antibiotics, chemical compounds and commercial bactericides. Thus, home remedies may include commercial or pharmaceutical products, adapted to specific culturally mediated uses. In most cases, self-treatment includes use of herbal and non-herbal agents, sometimes simultaneously or sequentially. The following discussion illustrates how agents are used in different contexts.

Phytotherapeutic applications include fruit juices (e.g., lemon, lime) poultices, herbal vaginal inserts, and plant parts (leaves, roots, stems) steeped in hot water for washing (externally and intravaginally), to administer vapors to the urogenital area and to be consumed as teas (Anderson et al. 2008, Beksinska et al. 1999, Brown, Ayowa, and Brown 1993, Imade et al. 2005, Runganga, Pitts, and McMaster 1992). Other, non-plant based home remedies include stones that are inserted whole or crushed into the vaginal canal, liquid dilute chemical compounds, and powders (Brown, Ayowa, and Brown 1993, Gresenguet et al. 1996, Halperin 1999). Yet other liquid-based agents include commercial cleansers and antiseptics, such as diluted solutions of Dettol® and water, Betadine® and water, dilutions of bleach, boric acid and Pine Sol® as external and intravaginal

cleansers (Gresenguet et al. 1996, Lichtenstein and Nansel 2000, Martino and Vermund 2002, Myer et al. 2004, Rajamanoharan et al. 1999).

To illustrate the use of multiple remedies, Runganga and colleagues (1993) examined the use of phytotherapies and other agents for intravaginal application among women in Zimbabwe, and their potential relationship to cervical cancer and HIV. They found that women used a variety of herbal and non-herbal agents specifically for the purpose of enhancing sexual pleasure for male partners by contracting the vagina. Herbal agents included leaves and bark of a wide variety of plants. Non-herbal agents included water, Dettol® (a commercial antiseptic) diluted in water, Betadine antiseptic solution, salt, and tissue. Women were socialized into the practices by female relatives (aunts, grandmothers) and female friends.

Myer and colleagues (2004) found a variety of agents reported as used for hygiene purposes among women in Cape Town, South Africa. These researchers conducted a cross-sectional study of women participants (n=2,897) in a randomized trial evaluating two different cervical cancer see-and-treat strategies. Women completed questionnaires at enrollment and at a 6-month follow up visit asking about sexual behaviors and intravaginal practices. All women underwent gynecological exams as well. Of these participants, 29% (n=831) reported the use of intravaginal agents. Agents mentioned included water, hand or laundry soaps, vinegar, salt/saltwater, tobacco, herbal preparations, vaginal creams or pessaries, household antiseptics (e.g., Dettol®, Betadine®, Savlon®) an industrial outdoor detergent (Jeyes Fluid) that is comprised of tar acids, neutral oil and carbolic

acid. The clinical data revealed that women who reported intravaginal products use were significantly more likely to have trichomonas (a protozoan parasitic STD) and have HIV than women who did not report using intravaginal agents. These findings must be carefully interpreted using this study design; that is, the direction of the associations is not clear. The authors note that HIV infection could cause women to use more intravaginal agents, since HIV results in more frequent vaginal infections among HIV+ women. They also note that personal intimate health behaviors are sensitive and difficult to measure accurately. This reason may account for why most women indicated that the agents were used for hygiene reasons, not expressly for drying and tightening.

Halperin (1999) used focus groups and conducted in-depth interviews among Dominicans and Haitian immigrants in the Dominican Republic. Dominican men indicated a preference for dry, tight sex. Haitian immigrants, who worked on a sugar plantation outside of the capital, reiterated that dry sex is a very common practice among inhabitants of the shantytown. Haitian women interviewed indicated use of a variety of products including chemical compounds obtained in pharmacies and markets and traditional herbal agents. Compounds included alum and potassium permanganate. Women used some agents simultaneously, mixing chemicals and phytotherapies, and others alone. Halperin suggests that the practice of dry sex in Haiti (and its attendant intravaginal practices) may be one of very few areas in the Western hemisphere where the practice exists.

Methods of application and delivery are diverse. Douching involves the

use of water or other liquid-based concoctions (e.g., dilute antiseptics, vinegar and water), most often delivered through a nozzle and bag (Lichtenstein and Nansel 2000). Vulvar washing applies primarily to external genitalia. Intravaginal washing or lavage involves the application of agents internally within the vaginal canal. Lavage is most often done using a finger or a cloth, using liquid-based agents such as chemical dilutions, citrus juices, decoctions or plain water (Brown, Ayowa, and Brown 1993, Imade et al. 2008, Runganga, Pitts, and McMaster 1992). Other internal applications involve using dried leaves of medicinal plants, which are rolled into balls and inserted into the vaginal canal for a prescribed amount of time, or the insertion of ethnomedical powders (Brown, Ayowa, and Brown 1993, Halperin 1999).

A recent exploratory study by Anderson and colleagues (2008) examined douching products and practices among Latin American and Caribbean immigrants in the Bronx, NY. This research is an initial step to design culturally meaningful interventions to reduce douching in these populations. Most people purchased intravaginal products from local *botánicas*, which often serve as primary or sole sources of spiritual and health care for many immigrants, those with and without health insurance. As these authors point out, *botánicas* are at once sites of socialization and sources of care, which are culturally influenced by several Latin American and Afro-Caribbean religious traditions, including Vodou. *Botánica* employees and owners were interviewed in this survey of products and practices. Importantly, the owners were not initially open in discussion of the agents



sold for intravaginal purposes. Some of the agents common in the Caribbean include prescription antibiotics, readily available for purchase at the botánicas.

Interviews revealed themes more broadly related to women's overall health including spiritual well-being. The specific intravaginal agents were viewed as one way of many needed to maintain overall health. Cleanliness and hygiene comprised a theme that was tied to women's sexual health, and corresponding products were found in botánicas such as commercial bactericides (e.g., Lemisol®), phytotherapies (peppermint, chamomile), and Witch Hazel. Alum and aloe vera were mentioned as tighteners, primarily for the purpose of enhancing sexual pleasure for male partners and hiding infidelity. Women used antibiotics primarily as vaginal suppositories for symptomatic relief. The documented antibiotics women used were Acromona (metronizadole, or Flagyl), Nystatin, and Bacantril (miconazole). Remedies could also be found for sale for uterine fibroids, breast lumps and irregular menstruation.

### ***Association with Negative Health Outcomes***

Intravaginal practices have been found to be associated with various negative gynecological and obstetrical health outcomes in epidemiologic studies. The research to date has produced inconsistent conclusions, as many of the studies have been cross-sectional in design, when prospective studies are stronger designs to tease out relationships of causality.

However, broadly, some intravaginal practices such as douching and the use

of drying agents are associated with an increased risk of contracting sexually transmitted infections, including HIV, gonorrhea and chlamydia (Annang, Grimley, and Hook 2006, Fonck et al. 2001, Gresenguet et al. 1996, La Ruche et al. 1999, McClelland et al. 2006, Myer et al. 2005). They are also associated with preterm labor and low birth weight (Cottrell 2006, Misra, Trabert, and Atherly-Trim 2006). The mechanisms by which the associations occur, and sometimes the direction of the associations, are not clearly understood, in large part due to the cross-sectional study designs, which preclude the ability to firmly attribute disease causality to the various types of practices. Thus, current available data conflict on such associations from published (primarily cross-sectional) epidemiologic studies, although the weight of the evidence points to the practices as harmful in varying degrees.

Intravaginal practices compromise the integrity of the vaginal environment in physical and chemical ways, depending on the particular method of practice and its effects. For example, vaginal douching is known to disrupt the balance of endogenous flora, including lactobacilli, which in turn increases the pH of the vagina (Cottrell 2002, Myer et al. 2005). Increased pH is associated with bacterial vaginosis (BV) and increased risk of contracting sexually transmitted infections (STIs), as the vaginal environment is less acidic and less hostile to pathogens (Cottrell 2006, Holzman et al. 2001). Further, BV is associated with increased risk of STIs, especially HIV, chlamydia and gonorrhea (Fonck et al. 2001, Myer et al. 2005). Vaginal mucosa irritation promotes the proliferation of lymphocytes, which are target cells for HIV (Fonck et al. 2001). Some practices also

dehydrate the vaginal mucosa, which renders vaginal epithelium more vulnerable to traumas including abrasions and microtears (Fonck et al. 2001, Myer et al. 2005)

Prospective cohort designs are needed to better understand how the practices affect women's health, whether they increase or do not impact women's susceptibility to STDs, including HPV, which is the principle etiologic factor for cervical cancer. These study designs allow for a temporal association to be evaluated between a potential cause and health outcome. However, the timing, agents used, frequency, exposure over the lifecourse are just some variables heavily determined by culture that impact women's gynecological health outcomes, based on the agents alone. Social factors, including poverty, education and access to care also impact women's health. As a result, even prospective studies are not exempt from problematic interpretations of findings. Few prospective studies have been published in this area, and they primarily focus on the relationship of intravaginal practices to HIV infection. However, interestingly, the results from these recently published prospective studies are inconclusive or indicate no association between intravaginal practices and HIV acquisition. A discussion of these studies follows.

McClelland and colleagues (2006) conducted a 10-year prospective cohort study among women sex workers (n=1,270) in Kenya to evaluate the role of intravaginal practices and incident HIV-1 infection. Women completed a standardized questionnaire at monthly follow up visits along with clinical examination for HIV infection and other STDs and genital infections. These

researchers found that women who cleaned with water or other substances intravaginally before or after sex were at an increased risk of acquiring HIV-1, compared to women who did not do intravaginal washing practices. Further, women who used soap or other agents were at an increased infection risk compared to using water alone. This research did show an association between intravaginal practices and increased risk for HIV infection among women sex workers. They suggest that interventions targeted to the practices have potential for being an effective women-controlled HIV prevention strategy.

Myer and colleagues (2006) conducted a 2-year prospective cohort study among women in South Africa (n=4,089). This study was nested in a larger randomized controlled trial assessing cervical cancer screening methods in the community. At enrollment, women completed a questionnaire in addition to clinical examination for HIV and other STD infections. The questionnaire was designed first using qualitative methods to determine how best to ask such personal questions. A questionnaire about intravaginal practices was administered at 6-month follow up along with repeated clinical exams. After controlling for potential confounders (e.g., prevalent STDs at baseline, sexual behaviors, demographics), these researchers found an association with prevalent HIV cases and intravaginal practices, but not incident cases. They reasoned that this discrepancy might be due to the fact that HIV+ women tend to have more vaginal infections and secretions, thus driving the intravaginal hygiene practices. Further, the women in their sample were older on average (mean age =42 years) than

younger, higher risk groups. Additionally, the types of practices reported among women in the sample were primarily associated with hygiene, not dry sex, thus they involved fewer agents and theoretically less resulting abrasion. These results then are inconsistent with the findings of the previously described study.

More recently, van de Wijgert and colleagues (2008) conducted a multicenter, 2-year prospective cohort study among women aged 18 to 35 years (n=4,431) in Uganda and Zimbabwe to assess relationships among intravaginal practices, BV, yeast infections, inflammation and HIV. Women were clients of a family planning clinic. Each participant was interviewed about intravaginal practices every three months for the study period. Univariate analyses showed an association between intravaginal drying practices and HIV acquisition, but the association was not found in multivariate models. Intravaginal washing was not associated with HIV acquisition. Inflammation did not have an effect on disease acquisition among women in the sample. These researchers did find that women who had BV (HR = 2.50, 95% CI: 1.68 to 3.72) or yeast infections (HR = 2.97, 95% CI: 1.67 to 5.28) were more likely to acquire HIV. Thus, the practices may indirectly contribute to HIV acquisition by upsetting vaginal flora resulting in BV and yeast infections.

Differences in findings may be due, in part, to the populations sampled. McClelland and colleagues sampled from a population of women sex workers, who were at a higher risk of contracting STDs. Myer and colleagues sampled from a general population of women that was on average older than

the higher risk groups, and they were asked at only at one follow up visit (at 6-months) about intravaginal practices and behaviors were assumed to be constant. However, it remains unclear why the physical effects especially of the drying and tightening agents and practices do not contribute more to disease acquisition.

### **Feminine Hygiene and Gynecology in Historical Context**

In the process of describing and understanding the reasons for culturally mediated feminine hygiene practices, a natural next step is to try to discern how similar feminine hygiene practices are geographically distributed, historically located and contemporarily sustained. As previously demonstrated, the published literature on feminine hygiene practices illustrates a common geographic distribution in Africa, the Caribbean, Latin America, and to populations of immigrants from these countries who reside in the U.S. In the case of Haiti, specifically, to what extent the practices of intravaginal washing, drying and tightening are connected to Africa as a cultural practice retained from the colonial era, remains as yet unexplored. However, the reasons for the practices, which ultimately center on female desirability and subsequent economic survival through sustained relationships with men, are not culturally distinct concepts.

It is, however, likely that the choice of chemical compounds and knowledge of their use is, in part, a colonial vestige, as are ideas about personal hygiene and cleanliness. They are also likely, in part, cultural diffusion, as the use of these agents is found in several Caribbean countries,

and agents are available for sale through a variety of Caribbean web stores on the Internet. With these conditions noted, it is important to briefly explore the use of these agents in historical biomedical gynecology.

An archival literature search led to information about common agents and their uses for gynecological conditions in the 19<sup>th</sup> and early 20<sup>th</sup> centuries. Vaginal discharge of any kind was pathologized in these sources, and all biomedical sources explained disease etiology using humoral theory model. For example, in a discussion of uterine conditions, one physician wrote of leucorrhoea (vaginal discharge) as a multifaceted condition, including general bodily weakness or debility owing to a larger, systemic affliction, such as heart, lung or liver disease. Other possible causes included "over-lactation," and "excess in sexual intercourse" (Hewitt 1880:770). Emblematic of humoral medicine of the era, this explanation was also given: "Residence in marshy or damp localities has often been noticed as favoring the occurrence of leucorrhoea" (Hewitt 1880:770). The author attributes causality to these factors, which cause "uterine congestion." The following instructional passage illustrates the prescribed treatment modalities, where intravaginal lavage is referred to as *injections*:

Injections are of great utility in all cases. The water employed is best used a little warm; a pint may be injected twice a day. Medicated injections containing alum, zinc, tannin, infusion of tea, nitrate of silver, are frequently employed. Medicated pessaries are also advantageously used in some cases. Most of the agents used are astringent in character; their action is usually limited to the vagina and os uteri; antiseptic injections are frequently employed when the discharge is offensive; tincture of iodine (one in ten of water), diluted carbolic acid, Condy's fluid, &c., are used under such circumstances (Hewitt 1880:770).

The agents mentioned here, which include alum, iodine, carbolic acid and Condy's fluid (potassium permanganate solution), have been found to be used among Caribbean immigrant women in the U.S. for feminine hygiene purposes (Anderson et al. 2008). These agents are not standard treatment modalities of contemporary gynecology.

Medicine of this era is heavily influenced by concepts of personal hygiene and humoral theory. Colonial medicine pathologized the Caribbean physical environment as a major source of illness for the people exposed to the tropical climate (Quinlan 2005). There was an emphasis on race, class and susceptibility to disease, which inevitably used concepts of purity and pollution to delineate Europeans and Africans, accordingly, in keeping with the racist ideas that permeated medicine of the era. Much medical investigation was devoted to how bodies adapted to new tropical climates in the context of colonial territories (Quinlan 2005). Emphasis on air as a source of sickness, and on perceived blood qualities (e.g., thick, dirty, salty, high) as results of such exposure, are complemented with recommendations of methods to restore bodily balance, including controlling exposure to certain climates, as essential to the therapeutic process. The following passage from a scholarly publication from 1880 poignantly illustrates this perspective, applied to gynecological health:

Lastly, whenever patients, the subjects of chronic uterine inflammation, have been much enfeebled by the persistence of the malady and the treatment necessary for its subjection, some after-treatment with a view of restoring the strength of the patient becomes



essential. Thus a change from town to country or to the sea-side, where bathing may be had, is followed by a marked advantage (Priestley 1880:798).

The centrality of hygiene to health in colonial era medicine was the result of a growing emphasis on personal health. In a racist, colonial medical model, Africans were often viewed as inherently polluted. Quinlan (2005) notes that hygienic concepts were used to reinforce social agendas of the plantation system, where planters were encouraged by physicians to teach slaves about personal hygiene – not for any other purpose than to maintain a healthy workforce. The preoccupation with hygiene is also evident in gynecology of the era. To illustrate, one physician cites cleanliness as a treatment for cervical abrasions: “Practically it is found that cleanliness, with rest and careful attention to the constitutional condition which may have been the cause of the local ailment, is sufficient for the cure (Priestley 1880:797).

These archival sources shed light on how therapies from historical, biomedical gynecology may have an influence on contemporary Caribbean and African women’s choices of therapy for gynecological health. While these influences are historical, it is unequal power in present-day male-female relationships that helps to shape and sustain women’s gynecological health behaviors, which may put women at greater risk for not only cervical cancer, but for a multitude of infections and other gynecological problems.

## Summary

The issues related to cervical cancer disparities, screening, and treatment are complex and best understood using a biocultural paradigm. Such a perspective allows for the placement of this disease in multiple social, cultural and economic contexts for a clearer understanding of what factors contribute to its existence and to its prevention among women worldwide. This disease has altered generations of kinship dynamics, networks and household economic strategies domestically and across the various borders of countries where Haitian families reside. The social and demographic effects of this disease, and for far too many, the illness experience itself, take place in multiple, transnational spaces, thus connecting global and local health realities (Manderson and Whiteford 2000).

Factors that put women at greater risk for cervical cancer and cervical infections include an array of intravaginal practices. Cross-culturally, these practices serve many purposes. To achieve some level of personal intimate hygiene is just one element: the gloss of “feminine hygiene practice” is imbued with meaning that alludes to culturally mediated reasons for and specific practices of women’s intimate health, most often tied to pleasing a male partner, with real economic consequences for the women. In all social contexts, gender and power dimensions are significantly present and guide the types and frequencies of intravaginal practices. Thus, when explored together, the medical anthropological, clinical and public health issues surrounding cervical cancer’s uneven distribution and experience poignantly illustrate that this largely preventable disease is most often a clinical

manifestation of sociocultural and political realities of women residing at the margins of world societies.

The following chapter presents the research questions, design and methods used in this ethnographic study.

## **CHAPTER 6**

### **RESEARCH DESIGN AND METHODS**

#### **Introduction: Research Questions and Objectives**

This research examines the cultural construction of cervical cancer knowledge, risk, prevention and its relation to behaviors, especially culturally mediated feminine hygiene practices, in the transnational social context of Haitian immigrant women in two Florida cities. Treatments for cervical cancer are extremely effective when the disease is detected early. Primary prevention (vaccine) and secondary prevention (Pap testing) are effective methods to prevent the development of cervical cancer; however, access to these methods is problematic for many immigrant women. Currently, there are no known systematic examinations of the broad sociocultural context of cervical cancer among Haitian immigrant women in the U.S. Given this lack of information, the immediate and long-term impact of this disease on Haitian women and families, this research addresses these questions:

Q1. How do cultural and structural factors combine to shape knowledge, discourse, and belief systems about cancer and cervical cancer etiology, risk, prevention and treatment among Haitian immigrant women?

Q2. How do cultural and structural factors intersect to influence women's health behaviors associated with cervical cancer prevention, detection, and for some, therapy?

This research addresses these questions by systematically examining explanatory models, perceptions of susceptibility to, prevention of, risk for, and treatment options for cervical cancer, self-report of prevention behaviors (e.g., Pap test, and/or culturally defined prevention practices), and structural factors (e.g., economic, geographic and political dimensions of access to health care) in consideration of the transnational social context. Specific objectives are as follows:

- O<sub>1</sub>: Locate health priorities, cancer knowledge and health behaviors in cultural and structural context;
- O<sub>2</sub>: Elicit and analyze explanatory models (EMs) of cancer and specifically, cervical cancer;
- O<sub>3</sub>: Examine significance and prevalence of culturally mediated feminine hygiene practices that may impact women's risk of cervical cancer;
- O<sub>4</sub>: Elicit information about male-female relationships (gender & power) that may impact women's cervical cancer risk; and,
- O<sub>5</sub>: Provide data to community based organizations (CBOs) for use in intervention design & implementation.

### **Data Collection Methods and Samples**

A proposal for this research was reviewed and approved by the University of South Florida Institutional Review Board (IRB) prior to any data collection (Appendix A). Multiple qualitative methods were used in data collection for this research. Each method is discussed with sampling strategy, questions driving the use of the method, and how data were analyzed.

## **Literature Review**

In order to critically situate health, illness, and specifically, cervical cancer, in the lives of Haitian immigrant women, I conducted an extensive review of archival, historical and contemporary literature. Topics reviewed include historical and contemporary ethnography on Haitian culture; Haitian immigration history and politics; gender and ethnic identity in Haitian culture; medical anthropological studies of health, illness and medical pluralism in Haitian culture; anthropological contributions to cancer related studies including interventions; historical gynecological practices; and, cross-cultural feminine hygiene practices that impact gynecological health. Further, information learned in a PAHO report (see Lewis 2004), which examined the burden of cervical cancer in the Caribbean, generated a thorough literature search and synthesis on the social, cultural and clinical issues associated with cervical cancer generally, and where available, in the Haitian and immigrant context. Most literature was found through the use of these databases: Social Science Citation Index (SSCI)®, AnthroSource, PubMed®, CINAHL® and Popline®. Google Book Search® permitted review of archival sources through digitized copies of historical (e.g., 1850s to early 1900s) gynecology articles and books, now available in full copy in the public domain due to expired copyrights. The literature was read and comprehensive written syntheses were completed for the aforementioned topical areas. This review of available literature helped me to conceptualize and refine research questions and objectives.

## ***Participant Observation & Observation***

Participant observation is the hallmark of ethnographic fieldwork. Active participation in community life, health and cultural events was a constant throughout the course of the research. I had been involved in local Haitian community activities and life since 2004. Activities included serving as a community liaison for cancer education outreach endeavors for the cancer center where I was employed, volunteer work with the CBOs, assistance with grantwriting and fundraising activities, and less formally, attending musical festivals (*bal*) and private functions at friends' homes. Formal participant observation occurred from January 2007 to April 2008. Participant observation took place on organizational and individual (household and family) levels. For example, participant observation involved taking on varied roles with two CBOs, including grant writing, assistance with planning and implementing health education and outreach events in the community and in church settings, by being a board member, assisting one CBO with the drafting of an application for 501(c)(3) status, taking part in local Haitian radio programs about cervical cancer and HPV, and serving as an employee of one CBO.

With both CBOs, I was actively involved with the planning and implementation of annual cultural and health events, including three years with Haitian Heritage Festival in Tampa, and two years with the Caribbean Health Fair in Orlando, each attracting more than 2,000 participants. The level of comfort that was established allowed for unobtrusive observation at invitations to households for dinners, social gatherings, health events, and in

general day-to-day interactions. Observations were also made during visits to two markets in Orlando (a Haitian grocery store and a Caribbean botánica) where an assortment of items, including home remedies and phytotherapies, could be purchased. Observations were recorded through verbal dictation to a microcassette recorder, and fieldnotes were written after observations and interactions. The recordings and notes were later transcribed into Word documents for electronic storage and review.

Participation in community activities complemented my home life. Two years after I became involved with community volunteerism and work, I married a Haitian American man whose extended family resides in Orlando and Tampa. My home life has since included many family gatherings with affinal kin on weekends and for special occasions, including holidays and salient rites of passage such as birthdays, baptisms, first communions, and a funeral.

### ***Semistructured Ethnographic Interviews***

Semistructured interviews were conducted with key respondents, adult Haitian immigrant women, and Haitian physicians. These qualitative in-depth interviews took part in two phases, where preliminary interviews with a convenience sample of 20 women and six key respondents resulted in data that guided the content of interview guides for a second sample of women. Each of these samples is discussed below. Attempts were made to interview Haitian ethnomedical healers; however, these attempts were unsuccessful, even when introduced by a trusted contact. Additionally, several women I



interviewed, and asked for healer introductions (specifically for manbos and hougans), politely refused my request because I was pregnant at the time. The women indicated that such a state left my baby and me “too open” to danger if associating with these practitioners; that is, while they may have some skill to heal, they also have power to harm. The other type of healers, the *doktè fey*, or *medsin fey* (herbalists) are not commonly found in the community but are consulted on visits home to Haiti, or available in Miami. Most women explained instead that plant knowledge for therapeutic practice was obtained from female family members. The following sections describe the research procedures, how samples were selected, the purpose and content of ethnographic interviews, and how data were analyzed with each sample.

### *Key Respondents*

Semistructured and unstructured interviews were conducted with six key respondents to gather direction for content for other interview guides for use among other samples. Verbal informed consent was obtained prior to the semistructured interviews, which took place at respondents’ homes. Although the interview guides were relatively short, interviews lasted between two and four hours, as questions asked generated detailed responses and ensuing conversations (Appendix B). Key respondents were trilingual (Creole, French, English) and one key respondent was semi-bilingual (Creole, and some French). Interview responses freely flowed between languages, and I let the participant guide the language choice. I did not tape record the

semistructured or subsequent informal interviews, but instead took detailed notes during and after each interview and orally recorded observations to microcassette.

Key respondents were selected based on my personal relationships with them that developed over the course of four years of community involvement. They were chosen for their insight into their communities and culture. Information elicited included questions concerning opinions of community strengths and challenges, opinions about pressing health concerns in the Haitian community, beliefs about cancer etiology, ethnomedical healers in community including those associated with Vodou, appropriate French and Creole terms to use when talking about health, illness and cancer, and general advice and suggestions for conducting in-depth interviews with Haitian women and for other key contacts in the community. Semistructured interviews were followed with multiple unstructured interviews and conversations throughout the course of fieldwork as needed to verify my understanding of recurrent themes and sociopolitical aspects of immigrant lives that impacted health. Written and verbal fieldnotes were typed and transcribed into Word documents for electronic storage and review. Interview notes and fieldnotes about conversations with key respondents were reviewed for common themes and emic descriptive information about the community using HyperRESEARCH™ 2.8 for Mac. Information learned was used to create interview guides for other samples, and in guiding my interactions with people when talking about health, illness and cancer.

### *Adult Haitian Women (Preliminary sample)*

In order to establish cultural domains and explanatory models in women's health, reproductive health, cancer and cervical cancer, 20 semistructured ethnographic interviews that included freelist techniques were completed with a purposive sample of adult Haitian women at the two research sites. This sample size was chosen for its suitability to establish cultural domains of a given topic (Weller and Romney 1988). This sample was comprised of adult women aged 18 or older, who were born in Haiti but now live in one of the two research sites (Tampa or Orlando).

A convenience sampling strategy was chosen because obtaining a random sample of Haitian immigrant women at either of the research sites was not feasible. There are no ethnic enclaves or neighborhood concentrations of Haitian immigrants at either study site, nor were enumeration lists for churches (the most common group-organization of Haitian immigrants) readily available to introduce randomness in any fashion. The convenience strategy also was the best fit for the characteristics of the community, which is one with a significant proportion of marginalized members, and many with questionable legal residency statuses. I relied heavily on my established relationships, my key respondents and directors of the CBOs to connect me with women to contact for an interview. While these individuals often introduced me to women to ask for an interview, if women did not have time or were not interested in taking part, they were generally forthcoming about their reasons for not taking part. For example, two women indicated a willingness to talk with me, but asked for additional time since

they had newborns. Also, if women to whom I was introduced did not return my telephone calls after three attempts, I did not try to contact them further, thinking that they likely did not want to take part, but perhaps had reservations about telling me so. This situation occurred with three women I attempted to interview.

The interviews took place in women's homes, at times convenient for them. The interviews lasted from an hour and a half to roughly three hours, depending on participants' response styles to questions in the interview guide (Appendix C). Many women wanted to explain their answers or provide detailed examples to illustrate their points, and women frequently asked me to stay for lunch or dinner, carrying the conversation further. Additionally, interviews were not tape recorded, following the advice of key respondents, who strongly recommended foregoing tape recording due to the potential of an participant being in the country illegally and potentially creating fear. Instead, copious notes were taken during and after the interview, complemented by my observations orally recorded on microcassette.

Following key respondent suggestions, a waiver of written informed consent was requested and obtained from the IRB. Written consent presented challenges on two fronts: 1) concerns with immigration status and participants' fear of signing anything, and 2) literacy levels. While the IRB insisted that a study information sheet needed to accompany verbal consent, the ability of some participants to read and truly understand them was questionable. As a result, each woman was given several opportunities to ask me questions before, during, and after the interview. The study

information sheets contained the required elements of informed consent, the contact information for the IRB and my contact information. They were provided in Creole, French and English. I gave women a stapled set of these sheets in all three languages during the consent process, because language use is inseparable from social class, and a few women may have indicated they were fluent in French or English but actually were not. Written Creole also presented a challenge in that it is largely a spoken language; far more people can speak it than can read it.

The interview guide was modified slightly after the first three interviews, where it became apparent that the questions about male-female relationships and the cultural practice of *plasaj* should be placed closer to the end of the interview. Data saturation was reached at 15 women, where no new information was learned. This sample was also deliberately heterogeneous in order to capture a wider range of possible items and to improve external validity. Women were assured anonymity, and all data were de-identified. In exchange for participation, women received a calendar with Haitian art, and decorative note pads and pens. I also provided women in Orlando with a brochure describing the health and social services offered through CMWP, and any relevant information pertaining to upcoming health fairs.

Each interview assessed basic demographic information, such as age, education and income levels, and length of time lived in the U.S. In addition to collecting these demographic data, open-ended interviewing included freelisting techniques to elicit illness domains including what constitutes

health for a woman, gynecological health, cancer and cervical cancer. Freelists are key to establishing cultural domains prior to conducting further ethnographic research, to ensure that questions to be asked are culturally relevant and that a researcher and respondent have a shared understanding of a particular domain. This method involves asking people to list all items they can think of for a particular category. Examples of questions asked include, "In your opinion, what are all the things that women can do to stay healthy?"; "What are all the illnesses that you think are important for Haitian women to know about?"; "What are all the things that you can think of that cause cancer?" and, "What are all the things that you have heard about to prevent cancer?" Lists that result are reflective of local knowledge and variation in knowledge.

Freelist questions were complemented with open-ended questions adapted from Kleinman's eight questions to elicit explanatory models (EMs) of illness (Kleinman 1980). These questions, in their original form, are geared toward patients, or toward people suffering from an illness. Some of these questions were suitably adapted for use in interviews with Haitian women who were not patients or necessarily suffering from any illness. Examples of adapted questions are: "When you think of cancer, what comes to mind?"; and, "Please tell me what you have heard about cervical cancer"; "What do you think causes cancer/cervical cancer?"; "How serious is cancer/cervical cancer?" and, "How can cancer/cervical cancer be treated?" These adaptations were useful starting points to learn about women's worldviews about health, illness, cancer, and more specifically cervical

cancer.

Qualitative information was also elicited about traditional therapies and home remedies that women use for gynecological health. Opinions about relationships with men were assessed for the significance they have to women's gynecological health, including thoughts on the cultural practice of *plasaj* and what women think and can do about infidelities of their partners. Finally, as part of an applied dimension of the research, women were asked for their preferences for obtaining women's health information, e.g., through audiovisual means, radio, print or one-on-one health education. This information was valuable for the two CBOs.

In the freelist analysis, answers were tabulated according to the number of women who mentioned each item, and then ordered according to the frequency of mention. For the open ended questions, grounded theory techniques were used to analyze responses to each adapted question (Bernard 2006). For each question, textual responses from each woman were typed and placed consecutively to into one document. All response passages were read and reviewed for themes. Passages were coded using an inductive approach and *in vivo* codes were used whenever possible, where code phrases were kept in the terms and language used by the women participants. Fieldnotes and observations recorded to microcassette were transcribed into Word documents for electronic storage and review in conjunction with the written interview response data, and were also analyzed for salient themes using HyperRESEARCH™ 2.8 for Mac.

### *Adult Haitian Women (Second sample)*

Data from the preliminary interviews, ongoing observation and participant observation informed the construction of an interview guide to be used with a secondary sample of 15 Haitian women (Appendix D). A sample size of 15 was chosen based upon data saturation at this number during the preliminary interviews with women. Women were interviewed in their homes. Each interview lasted from 2 and a half to 4 hours, depending on a woman's response style. When the interviews were finished, women frequently invited me to see plants they grew in their yards or on porches that were used for a variety of ailments, part of the repertoire of *remed lakay* (home remedies) common to many Haitian households.

I relied on key respondents, employees of the CBOs, and women from the preliminary sample to help me to recruit additional women to interview. These interviews were slightly longer, and certainly more personal, addressing issues of health beliefs, feminine hygiene and dry sex practices, plasaj, and Vodou practitioners who deal with health issues (manbo, houngan). By virtue of the topics addressed, it was necessary to be introduced by someone whom women viewed as a reliable friend. Based on the advice of key respondents, women who took part in these interviews received a \$20 gift card to a local mass retailer suggested by the director of one CBO.

Further, this method of recruitment proved critical during a three-month period (October – December, 2007), when the U.S. Citizenship and Immigration Services (formerly INS) was conducting surreptitious "sweeps" in



one research site city. I only learned of this issue when I had difficulty with recruitment and spoke with a key respondent for advice. She told me several stories of recent incidents of Haitians being sent to Krome Detention Center in Miami to await deportation. I also learned at this point that, for some, entry into the U.S. meant taking on a false identity. These very real fears made recruitment extremely difficult for these three months.

In addition to basic demographic information, women were asked, in greater detail, about aspects of their health beliefs concerning gynecological health, cancer, cervical cancer and opinions about *plasaj*. Preliminary interviews revealed a range of products that women used for feminine hygiene. As a result, women were also asked detailed questions about a feminine hygiene practice called *twalet deba*, or *lavmen*, in Creole, given its central place in women's intimate and sexual health and potential relationship to cervical cancer and abnormalities such as cervical dysplasia. The questions were designed to discern exposure details about the various products, which included, plant-based, chemical compounds and commercial agents. Questions addressed preparation and application specifics, when in life women begin the practice, and frequency of use over the lifecourse. With women's permission, photographs were taken of the plants and other items when possible.

The interview guide was modified slightly after the first four interviews, where it became apparent that asking women about their own most recent gynecological problem, and what they did to treat it, made women very uncomfortable to discuss. Two of the four women disclosed the

information. Therefore, this question was not asked of the remaining women in the sample. All remaining questions approached gynecological health questions in a general sense, and they were phrased to women their opinions rather than about personal behaviors. However, some women offered opinions about agents used for feminine hygiene by way of personal example. Interviews were not tape recorded, but extensive field notes were taken during and after each interview. I complemented these notes with verbal observations recorded to microcassette immediately following each interview. Responses were analyzed using grounded theory to assess patterns and themes in responses. Fieldnotes and interview notes complemented the process.

### *Haitian Physicians*

This convenience sample consisted of five Haitian physicians. I relied on personal social networks to select physicians to interview. The physician perspectives were sought to complement those of the non-physician participants from the other samples, and may provide insight into challenges faced by clinical practitioners who screen for, diagnose and often treat cervical cancer and precancerous conditions. As medical professionals, these individuals have the dual knowledge of Haitian ethnomedical terminology and beliefs and corresponding (as possible) biomedical explanations and terms. Questions addressed their perceptions of women's health issues in Haitian immigrant women and the prevalence of cervical cancer (Appendix E). All but one interview took place in their offices. Interviews were not tape recorded,

but written notes were taken to record responses. Each interview took approximately one hour to complete. Fieldnotes were orally recorded to microcassette following each interview. Responses were reviewed and analyzed for common themes.

### ***Surveys: Adult Haitian Women in Little Haiti, Miami***

Information learned from the in-depth ethnographic interviews served as an informative, qualitative complement to ongoing epidemiologic research on cervical cancer among Haitian women in Little Haiti by Dr. Erin Kobetz, an epidemiologist with the University of Miami Sylvester Cancer Center. Little Haiti is an ethnic enclave in Miami where the majority of residents are recently emigrated, tend toward lower English proficiency and lower socioeconomic status (Zéphir 2004). Ethnographic information and observations and knowledge of health in Haitian culture in this research were useful to assist in the construction of a closed-ended, 92-item survey (Appendix F). Ethnography particularly contributed to information about the phytotherapies, chemical and commercial agents women used for feminine hygiene. The survey was administered to a nonprobability quota sample of 250 women residing in Little Haiti as part of a larger community based cervical cancer study and intervention program conducted in conjunction with a Haitian CBO based in Little Haiti. This program, called *Pap Tès Lakay* (Home Pap Test), included educational, research and screening components administered through lay community health workers (CHWs) who were native to the Little Haiti community. Surveys were orally administered in

Creole by CHWs in women's homes. Women who took part in the surveys also took part in cervical screening for HPV, chlamydia, gonorrhea and cervical abnormalities. The screening was done through a cervical self-sampler called the Fournier Device, which is an FDA-Approved medical device that is used collect cervical samples in a home setting for cytology and STD testing (Castle et al. 2006). This self-administered device lends women privacy and better access to biomedical health care for this preventive screening. CHWs were trained to conduct the surveys, teach the women participants how to administer the Fournier Device, and preserve the biological samples for laboratory submission.

A convenience sampling strategy was used to recruit women to taking part in the study. CHWs approached women at Laundromats, grocery stores, salons, markets and other public places in Little Haiti to explain the study and determine eligibility. Women under 18 years of age or with prior history of hysterectomy were not eligible. Women who agreed to take part were scheduled for the survey and home cervical sampling, and informed consent was obtained for each woman prior to administering the data collection tools. This research was reviewed and approved by the Institutional Review Board (IRB) at the University of Miami Miller School of Medicine (Appendix G).

The surveys asked women questions that assessed understanding of cervical cancer and Pap testing, as well as use of ethnobotanical, chemical and commercial products for feminine hygiene.. Data from the surveys were coded into SPSS 13.0 and analyzed quantitatively to assess patterns in use of home remedies as hygiene products and knowledge of Pap screening in

this larger sample of women. For example, nonparametric tests were used to determine measures of association between demographic variables, use of feminine hygiene products and cytology results. Coupled with the survey data, information learned from the cervical cytology samples gives a clearer picture of how the population is impacted by specific strains of HPV, which is significant information for public health promotion of Pap screening and of the new HPV vaccination, Gardasil®. These hypotheses were tested using these survey data:

H<sub>1</sub>: Women who have lived in the U.S. longer are less likely to engage in feminine hygiene practices.

H<sub>2</sub>: Women with higher education are less likely to engage in feminine hygiene practices.

H<sub>3</sub>: Women who speak primarily or only Kreyol will be more likely to engage in feminine hygiene practices.

H<sub>4</sub>: Women who have ever had a Pap test, or who have had a Pap test within the last three years, will be less likely to engage in feminine hygiene practices.

H<sub>5</sub>: Women who have STIs, including HPV, and who have cervical abnormalities, are more likely to engage in culturally mediated feminine hygiene practices.

H<sub>6</sub>: Women with high-risk HPV infection will be more likely to engage in culturally mediated feminine hygiene practices.

## Summary

Qualitative data collection methods, including observation, participant observation, unstructured and semistructured interviews were conducted in this field research. Qualitative methods allowed for sensitive health information to be elicited, along with key features of participants' worldviews

about cancer and cervical cancer, and what constituted health and illness. Information gathered from these methods was used to assist in the construction of a closed-ended survey for administration among a large sample of women in Little Haiti. Data were analyzed qualitatively for the interviews and quantitatively for the survey. Triangulation of methods allows for a more complete picture to emerge illustrating the social context of cervical cancer in the lives of Haitian immigrant women.

The following chapter describes the setting for this ethnographic research, and it presents the findings from the preliminary phase of research that included interviews with key respondents, physicians, and the preliminary sample of women.

## CHAPTER 7

### RESEARCH SETTING & CONTEXTUALIZING HEALTH PRIORITIES, ETHNOETIOLOGIC BELIEFS AND PRACTICES

#### Introduction

This chapter presents the research setting and the initial findings related to women's health priorities, explanatory models of cancer and cervical cancer, and ethnoetiologic beliefs about aspects of gynecological health. Ethnoetiologic beliefs refer to cultural beliefs about disease causality, which shape local knowledge and worldviews about health and illness. These initial findings guided deeper inquiry, with a secondary sample, into culturally mediated feminine hygiene practices, and their role in male-female relationship dynamics and potential for harm in women's gynecological health.

#### Research Setting

Fieldwork took place in two major metropolitan areas in Florida, (Tampa and Orlando) comprised of a total of five counties. Fieldwork in Tampa was carried out in Hillsborough and Pasco Counties. The Orlando area research site is comprised of three counties: Orange, Osceola and Seminole. It was not uncommon to hear that people settled in one of these two cities after first emigrating from Haiti to New York or Miami. At the time of my

fieldwork, each city (and its suburbs) were home to Haitian immigrants, but neither city had clearly delineated ethnic enclaves, such as what is found in Little Haiti, Miami. People were quite dispersed, living both at the centers and peripheries of the two cities. Mixed inner city neighborhoods in Orlando also had a significant Haitian population.

### ***Economic and Social Characteristics***

Employment varied along social class lines among Haitians in each community. Among professionals in each city, the most common careers were clearly in law, engineering, medicine and nursing. Trades included taxi cab driving, auto mechanic and detailing shop ownership, restaurant ownership, grocery store and botánica ownership. I observed that many women were Certified Nurses Assistants (CNAs), and were employed in hospitals and nursing homes. In Orlando, it was very common to find Haitians of lower socioeconomic status working in non-benefited positions in the hotel and tourism industry, including housekeeping, kitchen work, dishwashing and maintenance. Informal economy work included babysitting, baking, and selling homemade items, vegetables and plant-based remedies at local markets.

Each city had some resources and information made available in Haitian *Kreyol* by print, radio and television. Tampa's Haitian community is generally more recently established and smaller than Orlando's, and the availability of resources in *Kreyol* is more limited. However, at the time of this fieldwork, one FM-SCA-band radio station existed on and off, depending



on funding. Subsidiary communication authorization, or SCA-band radio stations are legal and are heard by the public only through a special SCA-band radio receiver. I purchased one of these radios for \$30 from a community member. The programs most often were religious in nature. Occasionally, I heard of various pirate (unlicensed) Haitian radio broadcasters in both cities, with short-lived radio transmissions that were ultimately shut down by the Federal Communications Commission (FCC), operating from mobile antennas attached to homes or personal vehicles. Also, during the course of fieldwork, one regular Caribbean television program developed in Tampa that was directed by a member of the Haitian community. Orlando had an established Kreyol television program and approximately 15 Haitian radio stations during the time of this fieldwork. Both stations are AM frequency transmissions and legal.

The audio and audiovisual outlets in both cities are especially critical conduits for communication, especially with people who have low English and Spanish proficiency, the two most commonly spoken languages in the two cities. They are also key communication channels with people with limited literacy. Printed information in Kreyol is limited in both cities, and many people speak but do not read Kreyol.

### ***Getting Connected***

My involvement with the Haitian community began in Tampa in 2004 through an introduction by a community gatekeeper. This involvement had both professional and personal objectives. Professional objectives, as part of

my employment with a local major cancer center, included exploration of ways to partner with the community on cancer prevention activities, serving as a liaison between the community and cancer center to bring mammography screening to an annual Haitian cultural festival and coordinating a layer of health-related services of local hospitals and health centers for the festival. Personal objectives included significant volunteer time for assisting the community based organizations with capacity building activities, including assistance with grant applications for specific projects, taking part in donation drives for items to send to Haiti following a major hurricane, and assisting with the creation of a booklet detailing key resources in the community, such as health and social services, Haitian restaurants and other businesses. These activities helped to build rapport and trust and to steep me in local community life.

### ***The Importance of Community Based Organizations (CBOs)***

CBOs are key resources for people in the Haitian community for information about where to obtain help with immigration issues, health problems, domestic violence, food assistance, and other social services. They also serve as a critical network for cultural events and more informal gatherings. My fieldwork began with a number of CBOs in Tampa. Over time, relationships among the various CBO leaders shifted from periodic partnerships to isolation, to infrequent, cautious collaboration. They often competed for the same resources, and claimed to be doing the same or similar community work.

Indeed, at the beginning of fieldwork, there were eight CBOs in Tampa directed by Haitian immigrants, which had directives of improving education, health and social services for Haitians in the wider community. I did not understand, at first, why so many CBOs existed. One key informant made it clear: "It's like 1804 all over again. Each person thinks that his ideas are the ones that will revolutionize things in the community. And Haitians don't trust each other, either." The CBO that I came to work most closely with in Tampa, The Haitian American Alliance, Inc. (HAA), formed during the course of fieldwork, in efforts to bring all the CBOs together for project-driven activities. Ultimately, its democratic, collaborative objectives, and subsequent successes at obtaining grant funding and solidifying partnerships with health and social service organizations, made it suspect among other local Haitian CBOs to some extent, and collaboration with other organizations for the annual heritage festival remains a delicate negotiation process.

The Center for Multicultural Wellness and Prevention, Inc. (CMWP) is located in Orlando, Florida. This CBO is a well-known, trusted resource for Haitian immigrants (and other populations) in Orlando, providing assistance with a variety of health issues for screening and treatment (HIV, cancer, children with asthma, heart disease, obesity and diabetes), and assistance with public housing needs, in Kreyol, Spanish, French and English. The organization's motto is, "Facilitating Access to Services in Central Florida." It is directed by a public-health trained Haitian physician. My role with CMWP evolved from one of a volunteer and pro bono grant writer to one of employee, where my paid work included grant writing, coordinating a breast

cancer education and outreach project for Caribbean women funded by the Florida Department of Health, and serving as a project evaluator for a colorectal cancer education project for Haitian men, funded by the Centers for Disease Control and Prevention. With CMWP, I also took part in the development and delivery of Creole community educational radio programs about cervical cancer and HPV.

The CBOs at both research sites were acutely attuned to the pulse of their respective communities' needs, and each was a trusted resource. The relationships with these CBOs were critical to establish my presence in the community. These affiliations lent me credibility and trust in the wider Haitian communities of the two research sites. I was often invited to a variety of social gatherings: informal parties; formal community fundraising activities; infant baptisms; church services; soccer games, and dinners at people's houses. These interactions served as sites for informal conversations and opportunities to improve my Creole language skills.

### ***Population Profile of the Two Metropolitan Research Sites***

Florida is the gateway to the Caribbean, and home to more Haitian immigrants than any other U.S. state. Fieldwork was conducted in a total of five counties in the metro Tampa and Orlando areas. For the Tampa area, in Hillsborough County, there were 34,128 foreign-born persons of Caribbean ancestry, of which 2,370 (11%) were born in Haiti (U.S. Census Bureau 2000a). From the same data source, Hillsborough County is also home to 3,181 persons claiming Haitian ancestry. Approximately 74% of persons of

Haitian ancestry in Hillsborough County were born in Haiti. For Pasco County, Haitians represent 12% (n=162) of the total foreign-born Caribbean population (n=1,711). Pasco County is home to 224 persons claiming Haitian ancestry for census purposes. Approximately 72% of Haitians in the county were born in Haiti. Key respondents from this research site balked at these figures when I presented them. Respondents indicated that a significant undercount must exist due to immigration legal status fears and language barriers.

For Orlando, According to the 2000 U.S. Census, in Orange County there were 41,956 foreign-born persons of Caribbean ancestry. This figure represents roughly 33% (N=128,904) of the total foreign-born population in Orange County for Census 2000. Approximately 32% (n=13,227) of the Caribbean-born population in Orange County was born in Haiti. Regarding ancestry, 16,473 persons claimed Haitian ancestry in Orange County for the 2000 Census. The other two counties have smaller proportions of Caribbean and Haitian immigrants. In Osceola County, there were 6,227 Caribbean foreign-born persons of which 569 people (12%) claimed Haiti as place of birth. For Seminole County, there were 6,632 Caribbean foreign-born persons of which 718 (11%) claimed Haiti as place of birth.

As with Tampa, these figures do not factor in an undercount, a common problem of enumerating Haitian immigrants (Charles 2001, Stepick and Dutton Stepick 1992b). Key respondents from this research site also disagreed with the Census numbers, citing that there are significant numbers of Haitian immigrants who work in the hotel and tourism service industry,

who were likely not counted due to immigration fears and language barriers. Thus, these figures provide a snapshot of the population proportions at the two research sites, but they are likely highly underestimated for the 2000 Census.

This discussion of the research setting provides a social and geographic backdrop against which the research results from the preliminary phase may be considered. Prior to the discussion of initial findings, the population profile and sample characteristics are described.

### **Preliminary Sample of Women: Demographic Characteristics**

The preliminary sample of women (n=20) was selected to be deliberately heterogeneous in demographic characteristics so as to capture a wider range of possible responses about women's health, cancer and cervical cancer concepts. Findings from interviews with this preliminary sample elucidated key cultural constructions of health, illness, cancer, and cervical cancer. These data subsequently guided the creation of a more detailed interview guide that was administered to a second sample of women. Data saturation was reached at 15 women in this sample, when no new information was learned.

### ***Personal and Household Measures***

The following table summarizes demographic characteristics pertaining to age, religion, marital status, fertility, household composition and education level.

**Table 2. Personal and Household Characteristics of Women in Preliminary Sample (N=20)**

<b>Age in years</b>	<b>Range</b>	<b>Average</b>		
	25-67	39		
<b>Number of children</b>	<b>Range</b>	<b>Mode</b>		
	0-5	3		
<b>Number of people in household</b>	<b>Range</b>	<b>Mode</b>		
	2-7	5		
<b>Religion</b>	<b>Catholic</b>	<b>7th Day Adventist</b>	<b>Baptist</b>	
	13	4	3	
<b>Marital status</b>	<b>Married</b>	<b>Separated</b>	<b>Divorced</b>	
	12	5	3	
<b>Education level attained</b>	<b>Middle School</b>	<b>High School</b>	<b>Some College</b>	<b>College Degree</b>
	3	6	4	7

The average age of women in this sample was 39 years. The majority of women reported having 3 children and a mode of 5 people in the household. Most often, a household consisted of the woman participant, her child or children, her partner and either her mother or her partner's mother. All women claimed Christian religious affiliations, both Catholic and Protestant denominations. The majority of women were married and cohabitating with their husbands. Only two married women stated that their husbands did not live with them at that time. Approximately half of the women (n=9) had a high school education or less.

### **Language and Literacy**

Concerning language use and preferences, the language spoken most at home was Kreyol, but French was the preferred reading language. The preference for French reflects its use as the language taught in the Haitian school system, and that Haitian Kreyol's orthography is relatively young. The following table depicts the distribution of language use among women in the sample.

**Table 3. Language Use and Preference among Women in Preliminary Sample (N=20)**

	<b>Kreyol</b>	<b>French</b>	<b>English</b>
<b>Language spoken most at home</b>	16	0	4
<b>Preferred reading language</b>	0	16	4
	<b>Kreyol, French &amp; English</b>	<b>Kreyol &amp; English</b>	<b>Kreyol, French, Spanish &amp; English</b>
<b>Languages spoken</b>	17	2	1

### **Immigration**

The length of time women lived in Haiti prior to emigration (to the U.S. or elsewhere) ranged from 9 to 37 years, (mean = 19.25 years). The length of time women lived in one of the two research cities ranged from 1 to 16 years, with a mean of 9 years. At time of emigration to the U.S., women ranged in age from 9 to 42 years, mean = 21.6 years.



## ***Employment and Household Income***

Concerning employment, women often held multiple jobs simultaneously in both the formal and informal economic sectors. Fifteen women (75%) worked 35 to 70 hours each week for pay, with an average of 45 hours. Three women (15%) worked 20 hours per week. One woman was retired, and another woman was unemployed. Formal economy professional jobs of women in this sample included law, accounting, higher education and public health. Formal economy non-professional jobs included certified nurse assistant (CNA), clerical work in chiropractic offices, hotel housekeeping, retail sales, and clerical work in local schools and Haitian churches. Informal economy pay included babysitting.

Income is a sensitive topic, but it is also a valuable descriptive variable. I followed the advice of key respondents who suggested I provide range categories from which participants could choose their annual household income. Reported incomes ranged from \$10,000 to \$65,000 annually. The following table illustrates income among women in this sample.

**Table 4. Income Distribution among Women in Preliminary Sample (N=20)**

	<b>\$10,000- \$19,999</b>	<b>\$20,000- \$29,999</b>	<b>\$30,000- \$39,999</b>	<b>\$40,000- \$49,999</b>	<b>\$50,000- \$59,999</b>	<b>\$60,000- \$69,999</b>
<b>Number of women</b>	4	4	6	3	2	1

### **Health Insurance & Use of the Formal Health Care System**

With regard to medical health insurance, the majority of women (n=18, 90%) indicated they had some form of health care coverage. Forms of insurance included public types (Medicaid, Medicare, County Health Plan), and private insurance as an employment benefit. The majority of women (n=17, 85%) also stated that they had a regular physician or clinic they could go to if needed. The following table illustrates women's insurance statuses and source of health care.

**Table 5. Health Insurance Status & Source of Healthcare by Women in Preliminary Sample (N=15)**

	<b>Public only</b>	<b>Private only</b>	<b>Combination</b>	<b>Uninsured</b>
<b>Number of Women</b>	7	10	1	2
	<b>Regular source of care</b>	<b>No regular source of care</b>		
<b>Number of Women</b>	17	3		

Importantly, having health insurance or some form of health care coverage (e.g., public) did not mean that women regularly accessed the biomedical system. There were numerous barriers that women described. For example, 8 women mentioned that they had very little time to go see a doctor when needed, even though they had health insurance. "M' bezwen travay. M' pa kapab vwe doktè nimpot ki le m' vle." (I have to work. I can't just go to see a doctor any time I want to). Additionally, women stated that

they were hesitant to visit the doctor because they were afraid that their employers might find out personal health information. When probed for clarification, women made it clear that they did not trust that their medical records would be kept private, especially if insurance claims had to be processed. This director of CMWP confirmed this finding, stating that this belief was common among many people served by her CBO.

### **Salient Domains: Locating Women's Health**

The concepts of health, illness, cancer, and more specifically, cervical cancer, were examined in the larger context of women's health through freelists and responses to questions designed to elicit explanatory models of cancer and cervical cancer among the women interviewed. This was an important initial step to approaching the more complex questions associated with women's beliefs and knowledge about cervical cancer and its attendant risk factors. The freelists provided insight into women's cognitive orientations to key domains of this study, including maintaining health, what illnesses are important, cancer causes, types and treatments. With freelists, the number of times items are mentioned by women are counted. Women had multiple responses for most freelisting tasks, thus, the count is far greater than the number of women in the sample.

To begin, women in the preliminary sample were asked to list all the things they could think of that a woman could do to stay healthy. Women had some variation in phrasing that illustrated the same concept. These phrases were grouped according to concept. The following table illustrates

number of women who mentioned each item, and the items are ordered in terms of frequency of response.

**Table 6: Frequency Distribution of Ways Women Can Stay Healthy Freelisting Task**

Items Mentioned	Count (n=20)	%
Eat healthy/have a good diet/eat fresh foods	16	80
Maintain personal hygiene/stay clean/keep your body clean inside and out	16	80
Have a close relationship with God/Pray/Go to church	14	70
Have well behaved children/have harmony in your family/don't have arguments with family	13	65
Make frequent visits to the doctor/get regular check ups/follow doctor's orders	12	60
Exercise frequently/take walks every day	11	55
Take teas/tisanes regularly/drink your teas daily	11	55
Have a good social support network/have a good social life/have many friends to help you	10	50
Don't have too many sex partners/don't be promiscuous	10	50
Keep your mind healthy/have good mental health/don't stress	9	45
Don't eat canned food/avoid eating canned food	9	45
Get educated about health/learn about your health	7	35
Stay away from drugs & alcohol/don't drink or smoke	6	30
Have a loving relationship with your partner/don't fight with your husband	6	30
Get enough sleep	5	25
Avoid abusive relationships (with men)/don't stay if a man hits you	3	15
Be involved with community	1	5
Know family history of illnesses	1	5

These frequencies are good indicators of how salient each item is to the sample of women interviewed. This task illustrates that having a good diet, personal hygiene, religiosity/morality and family harmony are the most significant concerns of women in the sample. These items are followed with seeking regular care from a doctor (60%), exercise (55%) and taking teas or tisanes regularly (55%) in terms of saliency for women in the sample. One respondent stated, "You have toxins in your body that you need to cleanse sometimes. Like using *l'huile de ricin* (castor oil), *Senekot* (Senekot commercial laxative), *tè senè* (Senna tea, a laxative), *l'huile olive* (olive oil)." And as another woman put it, "You have to keep your body clean, just like you keep your house. If you neglect yourself, that is when you get sick." This reference to cleanliness involves internal and external dimensions. Women explained that periodic purging of the body's system (e.g., intestinal), showers, and proper intimate hygiene (*twalet deba*, or *lavmen*) are key to maintaining ones health. Thus, for women in this sample, health is highly intertwined with notions of bodily nourishment, morality and cleanliness.

Women were also asked to name all the illnesses that they thought were important, in terms of awareness and education. Table 7, on the following page, illustrates the results of the freelist task. This task yielded both expected and unexpected results. Clearly, this population is heavily affected by hypertension and diabetes, and their relative frequency of mention is emblematic of experience of seeing these illnesses affect themselves, kin or others in their social networks.

**Table 7: Frequency Distribution of Illnesses that are Important to Be Aware of Freelisting Task**

Items Mentioned	Count (n=20)	%
Hypertension/la tansyon	18	90
Diabetes/le sik	17	85
Cancer/kansè	16	80
AIDS/le SIDA	14	70
STDs/maladies sexuelles	14	70
Fibroids/fibrum	13	65
Malnutrition/not eating healthy	12	60
Depression/la santé mentale	12	60
Heart disease/heart attack	12	60
Breast cancer/kansè nan sen/cancer du sein	9	45
TB/tibikiloz/la tuberculose	9	45
Sickle cell anemia/l'anémie falciforme	9	45
Malaria	7	35
Cervical cancer/kansè nan matris/kansè nan kol matris	5	25
Eyesight/eye problems	4	20
Dental/oral health/having painful teeth	2	10
Problems if there is no prenatal care	1	5

Cancer in general is a concern of populations cross-culturally, as are AIDS and other sexually transmitted diseases. Other illnesses listed reflected knowledge of conditions in a developing country and a population of primarily African descent: tuberculosis, sickle cell anemia and malaria. However, the frequency of mention of *fibrum*, or uterine fibroids, was unexpected. Discussion about this topic with key respondents revealed that a significant number of Haitian women suffer from fibroids. Discussion with a physician respondent also echoed this observation: "African American women are 20 to

25% more likely to have uterine fibroids than other women.” A quick literature search revealed that women with a specific genotype related to polymorphisms of an estrogen receptor gene do have a higher rate of uterine fibroids. The prevalence of this genotype was observed to be significantly higher in women of African descent (35%) than in Hispanic (16%) or white women (13%) (Al-Hendy and Salama 2006). Respondents also noted that fibroids were thought of as cancerous, perhaps because they are sometimes referred to as “fibroid tumors.” Lastly, five women (20%) specifically mentioned cervical cancer; however, it was not clear among three of them that *cervical* cancer was distinguished from uterine cancer, as they used the phrase *kanse nan matrix*, which is technically uterine cancer, in further discussion.

While, intuitively, freelists are thought to elicit items from respondents in some unconscious order of importance, this may not apply to eliciting perceived illness severity unless directly asked. I wanted to know what illnesses women thought were most serious, of those they named. I followed up the former freelisting task with a successive freelist asking which ones women thought were most serious, in order. Table 8, on the following page, illustrates women’s responses. Both prevalent and life threatening illnesses were named: AIDS, hypertension, cancer and diabetes, among the top four, followed by fibroids, mentioned as one of the most serious by 13 of the 20 women (65%). Because the freelist drops quickly from 13 women mentioning ‘fibroids’ to 3 women mentioning the next item (depression) as one of the most serious illnesses, this gap indicates that the cognitive domain

of 'serious illness' is not as large as that of 'illness.'

**Table 8. Successive Freelist Task of Which Illnesses Named are Most Serious**

<b>Items Mentioned</b>	<b>Count (n=20)</b>	<b>%</b>
AIDS/le SIDA	18	90
Hypertension/la tansyon	17	85
Cancer/kansè	16	80
Diabetes/le sik/le diabète	14	70
Fibroids/fibrum	13	65
Depression	3	15
All of them/toutes les maladies	2	10

### **Eliciting Explanatory Models of Cancer**

In efforts to gain an emic perspective on cancer, I first approached key respondents and asked their opinions of how cancer was thought about in Haitian culture. All 6 key respondents offered that it is seen as fatal, and depending upon one's education level, it may be seen as a sent sickness (*ekspedisyon*). Further, sent sicknesses are metaphorically spoken of as devouring a person: *li manje li* (it eats him/her). I asked if cancer had another name or terminology in Kreyol. Most key respondents indicated that it is known simply as *kansè*; however, one key respondent offered that it is sometimes spoken of as *sè*, or the letter "C," for fear that speaking the word would opens one to affliction.

Women in the preliminary sample were asked to name all the different types of cancer that they could. The purpose of this task was to better understand how women thought about cancer, and to discern how



perceptions might be similar to or vary from the biomedical model of the disease in its many forms, with attendant levels of severity. This freelisting task produced a range of responses in types listed, from no different types distinguished by four women, to 8 types mentioned by one woman. In total, 16 women in the preliminary sample named 12 different types of cancer. Four women did not distinguish between different cancer types. The following table illustrates the types named and frequency of mention.

**Table 9. Frequency Distribution of Types of Cancer Freelisting Task**

<b>Cancer Types Mentioned</b>	<b>Count (n=16)</b>	<b>%</b>
Lung	10	62.5
Breast	9	56.3
Bone	8	50
Uterus	7	43.8
Skin	6	30
Blood	5	25
Cervical	4	20
Prostate	4	20
Colon	3	15
Brain	3	15
Pancreatic	2	10
Liver	1	5

The fact that more women did not mention different, specific types of cancer may indicate less understanding about cancer occurring in different forms. This notion was made evident in comments and questions women had about this task, whether they could name different types or not: "It can happen anywhere in your body." "Can you get breast cancer anywhere?" A

successive freelist followed that question, to better understand women's orientations to severity related to cancer type. The successive freelist task results are presented in the following table.

**Table 10. Frequency Distribution of Most Serious Types of Cancer Successive Freelisting Task**

<b>Serious Cancer Types Mentioned</b>	<b>Count (n=16)</b>	<b>%</b>
All of them	16	100
Lung	7	44
Breast	5	31
Prostate	1	6

Of those women distinguishing different types (n=16) each was asked, "Of all the types you mentioned, which one(s) are most serious?" Importantly, some women laughed or scoffed at this question, indicating that there are no non-serious cancers: "They are all serious!" Women did not generally think of one type of cancer as more or less serious than another, believing that all types can be fatal, and survival chances are usually slim with a diagnosis of cancer. Tellingly, all 16 women stated that all types are serious. A quote from one woman describes this sentiment best: "Kansè se kansè!" (Cancer is cancer).

Freelisting tasks about cancer were complemented by open-ended questions designed to elicit women's explanatory models of cancer and cervical cancer. Kleinman's famous eight questions, designed to elicit explanatory models (EMs) of illness from patients, are also useful in

understanding EMs from a non-patient perspective (Kleinman 1980). I adapted six of Kleinman's eight patient-oriented questions to fit my preliminary sample of non-patient women. In this adaptation, some of Kleinman's questions were best phrased in a freelist exercise format to more clearly understand cognitive domains of cancer treatment.

A broad question was first asked to elicit women's thoughts about cancer, that cover Kleinman's patient-oriented questions about fear (What do you fear most about the illness?) and what happens with the disease (What are the chief problems the illness has caused?) This question, "When you think of cancer, what comes to mind?" evoked responses centered on larger themes of fatalism and uncertainty, physical effects of cancer treatments, and war metaphors. For example, the following *in vivo* codes were applied to these text passages: end of the road; fight for survival; battle for your life; uncertainty about the future. Other inductive codes applied to recurrent themes include hair loss, weight loss, chemotherapy, disease recurrence and death/dying/terminal.

Fully 20 of the women mentioned words, phrases and sentences that conveyed fear and mortality: "Cancer? If you get it, you die! End of story!" "It is an illness that won't go away." "Li ba'm pè" (It makes me scared). Fifteen women also related that cancer made them think of the harsh physical effects of the disease and its treatments: "When I think of cancer, I think of someone who has no hair, who has lost all their weight." "You just don't know who will win and who will lose." "The drugs, the chemo, they are as bad as the disease itself! I saw what they did to my aunt. And she died

anyway.”

One woman related more personally her experience with cancer in her family. Her daughter had leukemia, and died at the age of 16, approximately 8 years before the interview took place:

“I tried to tell him [the doctor]. I didn’t want him to tell my daughter she had cancer, but he told her anyway. How could that give my daughter any hope? I was so sad, and I was sitting there in the doctor’s office, looking around, and even with all of those books, he still couldn’t help my daughter.”

Thus, women’s responses about cancer were generally resignations to the disease as one that is nearly always fatal.

In order to understand how women thought about cancer prevention, they were asked to name all the ways they’ve heard about to prevent cancer in a freelist task. The results of this exercise are presented in the following table.

**Table 11: Frequency Distribution of Ways to Prevent Cancer Freelist Task**

Items Mentioned	Count (n=20)	%
Keep a healthy diet	16	80
Pray regularly	14	70
Regular check ups with the doctor/early screenings	12	60
Don't smoke	7	35
Maybe can't prevent it	6	30
Do breast self-exam regularly	5	25
Know body well to pay attention to changes	4	20
Don't know how to prevent it	4	20
Wear SPF	1	5

This freelist task elicited a smaller number of responses, indicating that the cognitive domain for cancer prevention is relatively small. Having a healthy diet figured prominently in women's views about cancer prevention. Importantly, having a healthy diet meant not consuming processed or canned foods or water that could be contaminated with pesticides, not necessarily having a diet high in fiber and antioxidants, per the public health model for dietary cancer prevention behavior. Prayer was also very important, and noted as something to accommodate every other mode of prevention. Biomedical influences are evident in women's responses, in which check-ups at the doctor are also frequently mentioned, along with other behavioral items also common to biomedicine and public health as modes of prevention (e.g., not smoking, doing breast self-exams).

Four women expressed that they didn't know how to prevent cancer, and 6 women (30%) indicated that while there are supposed to be things one can do to prevent it, there are no guarantees. As one woman stated, "There's nothing you can really do to prevent cancer. Because people do all these things and they still get it." And, "Maybe you can only catch it early, not prevent it."

Regarding etiologic beliefs, the following question was asked of women: "What are some of the things you can think of that cause cancer?" Three women noted that they did not know what causes cancer and offered no possible suggestions. The remaining women offered multiple possible causes in their responses to this question that reflect exogenous (originating

from outside the individual/body) and endogenous (originating from within the individual/body) cognitive domains. The domains are not, however, mutually exclusive in explaining cancer causality, as women held beliefs about cancer that fell into both domains. Further, Foster's (1976) classic system of disease causality classification is useful here. This dichotomous system of illness classifications includes personalistic and naturalistic domains. Personalistic causes of illness refer to those which are deliberately put upon a person, whether it is divine retribution, supernatural spirits, sorcery, or witchcraft from human action (Foster 1976, Foster and Anderson 1978). Naturalistic causes of illness are impersonal and not supernatural; instead, they are often associated with bodily imbalance that results in disease. These distinctions are useful in the context of Haitian immigrant women's etiologic beliefs; however, they are also not mutually exclusive in explaining illness causality.

Categories of causality emerged in each domain. The exogenous domain includes environmental, personalistic, social and behavioral actions, and conspiracy. In the environmental category, more than any other cause, women believed that a cause of cancer is specifically pesticides in food (n=14, 70%). Other causes listed in the environmental category include: Processed or canned food (n=10), pollutants in water (n=8), pesticides in environment (n=7), and sun exposure (n=2). Personalistic causes included divine retribution (n=4) and through *ekspedisyon* (spell) of a houngan, most often cast at the request of a jealous enemy (n=4). In the social and behavioral category, women mentioned violence/trauma of being hit (n=7)

and conspiracy (n=4). Specifically, women gave breast and stomach cancers as examples of the result of physical violence. Other social and behavioral causes named included smoking (n=6), and alcohol consumption (n=2). Probing about conspiracy explanations produced interesting discussions about not just cancer, but HIV as well. Women who thought that these diseases might be the product of governments had strong opinions. The following exchange with one woman, Sylvie, is illustrative of these women's positions:

Sylvie: "You know they must have the cure [for cancer] out there, but they don't want *some* people to have it.

JM: What do you mean by that? Can you explain?

Sylvie: What I mean is, just like AIDS, there has to be a cure that the government has that they are keeping from people, *black* people.

JM: So you think the government doesn't want black people to have the cure? Which government?

Sylvie: The U.S. government, for sure. Why do you think so many black people are dying? I even know of a houngan in Haiti who can cure AIDS. So if he can do it, then why don't more people here have the cure?

Sylvie observed, rightly so, that the odds of surviving diseases such as cancer and AIDS were stacked against Haitians and blacks more generally. However, this sentiment was rationalized through a conspiracy model, rather than through a focus on the ultimate effects of an inadequate health care system and institutionalized racism. The other three women who had suspicions of conspiracy also related their beliefs to the U.S. government, and access to health care services. As one woman, Yvette, related:

Yvette: "They see us coming, and they do not want us here. So when we are at Krome, or wherever, we get no care."

JM: Who do you mean?

Yvette: The INS! The government...they do not like Haitians.

JM: So in places like Krome, you get no health care?

Yvette: Yes that's it. And it is a way to try to keep Haitians out of the U.S. I think.

JM: How so?

Yvette: If we are sick, they do not help and they send Haitians back to Haiti where they will die. But for Cubans, they are welcomed! Not us!

Yvette observed the differential treatment of Haitian and Cuban immigrants as it related to detention, provision of health care, and deportation as deliberate acts of the U.S. government to preclude entry of Haitians into the U.S. whenever possible. She described the structural effects, really, of the "wet foot/dry foot" U.S. immigration policy with Cuba, which states that Cubans who reach dry land will be granted residence (Zucker and Zucker 1996). In contrast, Haitians must prove that their lives are in danger in order to obtain asylum or refugee status, an often difficult task without official documentation. Yvette's beliefs are informed, then, by nearly 30 years of discriminatory immigration policy of the U.S. government. In essence, Yvette attributed cancer, as well as AIDS, to a systematic denial of health care services to Haitian immigrants. This finding is echoed in research done in Miami among Haitian adolescents and beliefs about HIV, in which the notion that a cure existed, only for the rich, was a recurrent theme (Marcelin,

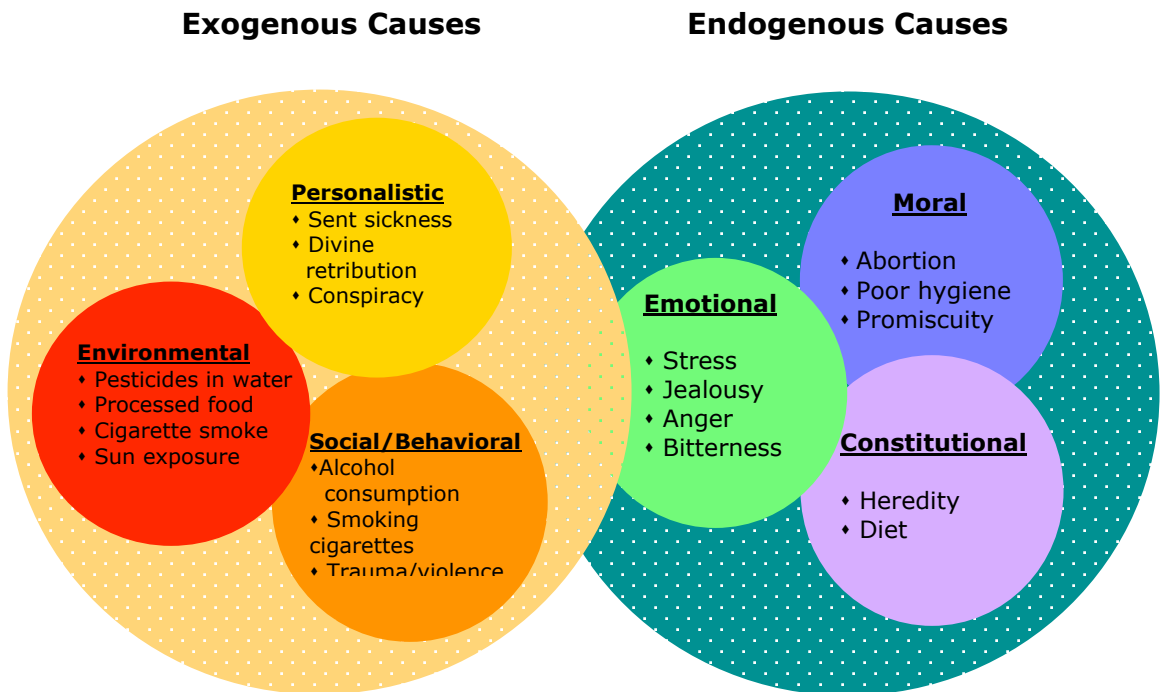


McCoy, and DiClemente 2006).

Concerning the endogenous domain, categories of cause included emotional, moral, and constitutional causes. From the emotional category, more women mentioned stress than any other cause (n=9). Also mentioned in the emotional category was a set of negative emotions involving jealousy, anger and bitterness (n=7). Women also mentioned several causes that could be assigned moral attributes: poor feminine hygiene (n=9), abortion (n=8), and promiscuity (n=7). Constitutional causes mentioned included diet/poor nutrition (n=7), and heredity (n=5).

Figure 4, below, depicts these etiologic beliefs clustering within exogenous and endogenous domains.

**Figure 4: Ethnoetiologic Beliefs about Cancer**



Concerning disease susceptibility and risk, women were asked, "Who do you think can get cancer?" Most women (n=16, 80%) indicated that anyone could get cancer. Interestingly, 10 women (50%) also associated cancer susceptibility with people living an amoral, un-Christian or "fast" lifestyle. As one woman related, "Sometimes people get it because of how they live their lives, you know, the fast life here in the U.S." And, "People who have a lot of sex partners, they can get cancer more than others."

In keeping with expressed notions of causality, a sizeable proportion of women also thought that people who ate contaminated food, or drank polluted water, could get cancer (n=9, 45%). Eight women (40%) said it is more common in older people. Eight women also believed that abortion could cause cancer. One of these women, a church pastor's wife, qualified her belief with the following statement: "That [cancer] is what happens to women who get abortions, too." This statement illustrates her understanding of a grave health consequence as due to a socially unacceptable act. Another woman grouped "getting an abortion" with other undesirable behaviors that have moral implications: "All of that – smoking, drinking alcohol, having a lot of sex partners, getting an abortion, all of that can give you cancer." Given the significant importance placed on children in Haitian culture, and that the population is predominantly Catholic, an association of morality with abortion is relevant. Lastly, four women (20%) conveyed that they thought cancer was primarily a disease of white people. Thus, ethnoetiologic beliefs guided perceived susceptibility, which was influenced by aspects from both biomedical and ethnomedical models of

cancer. Reference to promiscuity coincides with the notion of multiple sex partners as a risk factor for cervical cancer, and environmental pollution has been linked to cancer in superfund sites popularized in the media (Brown 1992, Herbert and Coffin 2008, Kearney 2008). The ideas of leading an amoral life, and, for women, neglecting personal hygiene, lead to cancer draw upon ethnomedical constructions of the disease.

Women were also asked about treatment beliefs, including how cancer can be treated, and by whom. Regarding treatment modalities, a freelisting task was used to ask, "What are all the different types of treatments you have heard about for cancer?" Table 12, below, shows women's responses.

**Table 12: Frequency Distribution of Treatments Mentioned for Cancer**

Items Mentioned	Count (n=20)	%
God/prayer	15	75
Phytotherapies/plants/ <i>remed lakay</i>	14	70
Chemotherapy	12	60
Surgery	7	35
Radiation	6	30
Noni juice	5	25
Positive attitude	3	15
Transplants	2	10

All women provided examples of treatments from both biomedical and folk sectors. Fifteen women indicated emphatically that prayer must accompany all treatments. Additionally, plant-based home remedies, or *remed lakay* figured prominently in women's stated therapy options for cancer. Women attested that they are efficacious yet *pli dous*, or gentler, than

chemotherapy. Five women also stated that the noni juice is effective for both cancer prevention and treatment. This juice is from the noni fruit (*Morinda citrifolia*), which is native to the Pacific Islands. Extracts are marketed under a variety of commercial brands and in juice and pill forms. While there are no peer-reviewed scientific data to support positive health benefits of noni extracts in any form, health claims involve both chronic and infectious disease prevention and treatment, including for cancer, hypertension, HIV, high cholesterol, and depression, to name a few (ACS 2008). Women also mentioned noni juice as a prevention strategy for other illnesses including diabetes and hypertension. Remaining items mentioned included positive attitude and transplants. Thus, these items reflect women's knowledge as drawing from biomedical and ethnomedical models of disease treatment.

Regarding women's perceptions of who can treat cancer, responses coalesced around a combination of practitioners and therapies, and prayer. Table 13, below, illustrates the results of this freelisting task.

**Table 13: Frequency Distribution of Practitioners/Healers Mentioned Who Can Treat Cancer**

Items Mentioned	Count (n=20)	%
Collective effort/combination of traditional and biomedical practitioners and prayer	17	85
God	15	75
Prayer and doctors	8	40
Doktè fey (herbalists)	7	35
Doctors	7	35
Houngans/manbos	6	30

Most women felt that the more practitioners and therapies involved, the better one's chance was of surviving cancer. Women referred to nonbiomedical practitioners who were associated with Vodou and who were not. In the case of a life threatening illness, women expressed that it was necessary to consider all possible practitioners and therapies. Primarily, women related the value of *doktè fey* and phytotherapies. Women were less critical of Vodou practitioners in the case of cancer treatment, although they emphasized that doctors and prayer needed to be part of the treatment regimen as well. As one woman related, "On dit que c'est 95% Catholique, 100% Vodou. C'est notre tradition. It is in our blood." (We say that we are 95% Catholic, 100% Vodou. It is our tradition). And, "It's Bible by day, Vodou by night."

Women who mentioned doctors reasoned that they should be able to treat cancer since they "go to school for it." Regardless of practitioner, prayer was considered an integral part of the arsenal of treatment modalities and practitioners. As one woman indicated, "Se Bondye ki kapab trete nou." (It's God who can treat us). And, "You always have to pray. Nothing works without prayer."

In sum, women expressed common responses about cancer, reflecting fear, fatalism, little separation of disease gravity by cancer type, and etiologic beliefs that encompassed personalistic, naturalistic, moral and emotional attributes in both exogenous and endogenous domains. While most women acknowledged that cancer may affect anyone, susceptibility was perceived as greater among those with poor diets, poor personal hygiene and

amoral lifestyles.

### **Eliciting Explanatory Models of Cervical Cancer**

In the freelisting task that asked the preliminary sample (n=20) of women to delineate types of cancer (in general) that they knew, nine (45%) women mentioned uterine cancer in their distinctions of cancer types, and four women (20%) specifically mentioned cervical cancer. Only one woman mentioned both of these cancers, distinguishing between the two types. Further questioning about cervical cancer revealed that few women did actually distinguish between them. This lack of distinction may reflect semantics more than a lack of understanding of anatomy: *kansè nan matris* in Kreyol and *cancer de l'utérus* in French (uterine cancer), are similar to *kansè nan kol matris* and *cancer du col de l'utérus* (cervical cancer). Thus, a shortened "kansè nan matris" was the most common phrase women used when talking about gynecological cancers and was used interchangeably with the term for cervical cancer.

A total of 35 women (preliminary, n=20, and subsequent sample, n=15) were asked questions to elicit explanatory models of cervical cancer. The questions were structured similarly to those designed to elicit explanatory models of cancer, also adapted from Kleinman's patient-oriented questions. Responses were analyzed in the same manner, using inductive coding and vivo codes when possible, to discern emergent themes in responses.

First, I asked all of the women if they had ever heard of cervical cancer. Twenty-seven of 35 women (77%) had heard of it. Among those who had heard of it, the questions designed to elicit explanatory models of cervical cancer followed. I asked, "Please tell me what you have heard about cervical cancer." Only three of these women had responses that clearly indicated a lack of knowledge of cervical cancer. These three women asked if it is a cancer in the neck, in reference to cervical vertebrae. This confusion likely reflects the significant use of chiropractors by people from the two communities studied. Chiropractors do not require insurance and often adjust their fees, making them a more accessible health care option for uninsured people. Further, chiropractic healing modalities are similar to the practice of a type of healer whose primary healing modality was the laying on of hands, which women called *manyen*. The remaining 24 women offered responses to this question that, like cancer in general, reflected fear and fatalism. Eight women also offered that cervical cancer can be treated if detected early. All 24 women felt that cervical cancer is a serious and potentially fatal illness. Sadly, a significant number of women in this group (n=14) described aspects of cervical cancer based on personal experience with the disease through relatives, friends, and in five cases, among the women themselves.

The following exchange contextualizes the experience of one woman, Marie, whose aunt died from cervical cancer. Marie is 39 years old and married with three children. She is a receptionist at a local Haitian church.

She does not have health insurance, and she has been in the U.S. for 10 years.

JM: Please tell me what you have heard about cervical cancer.

Marie: Oh... (shakes head, looks down). I watch my aunt die of this in Haiti. You walk into the room and you smell death. She suffer so much. Every night she cry. It is a terrible disease.

JM: What do you think might have caused her cancer?

Marie: It's hard to say because she was clean. I mean, she teach me, you know? She had *fibrum* before, so maybe the doctors did not get it all out with the surgery. She never go to the doctor after surgery, so who knows.

JM: So she didn't go to the doctor. Did she get any treatment at all then?

Marie: *Oui. Li te prann tè yo...*she take teas, but maybe it was not enough to clean her out inside.

JM: What do you mean, clean her out inside?

Marie: You know, when you drink teas, it help to push out the dirty blood and things inside you, *ou konprann?*

JM: Push it out from where inside you?

Marie: From your *matris, chérie*.

Marie reasoned that her aunt's cervical cancer was possibly due to uterine fibroids, potentially left in place from an unsuccessful operation. She also related the cancer to the possibility of her aunt's uterus not being clean enough, specifically referring to dirty blood, resulting in cervical cancer.

Further, the following exchange with another woman, Céleste, is based on her personal experience with cervical cancer approximately two years prior to the interview. Céleste is 43 years old, has two children, is divorced,



and has been in the U.S. for 24 years. She is a translator for the county courts system.

JM: Please tell me what you have heard about cervical cancer.

Céleste: *Ah, bon.* Let me tell you something. I went to the doctor because I was having some trouble, you know, burning when I went pee. It was a urinary tract infection. So I had to wonder where *that* came from. Then he said it was time for my annual exam, so he did the Pap test. The nurse called me a couple of weeks later and said I needed to come in to see the doctor as soon as possible. I was so scared, because I knew that something was wrong.

JM: Mm hmm, what happened then?

Céleste: The doctor told me I had cervical cancer, stage one. I just started crying. But the good thing was that it did not spread, and the Pap test caught it in time to save my life.

JM: I see, okay, so what happened next?

Céleste: I made an appointment and came back for the surgery.

JM: Where did you have the surgery? What kind of surgery was it?

Céleste: To the doctor's office. He took it out right there. I couldn't believe it. I thought I would need chemotherapy or something. But I was one of the lucky ones. The surgery gave me cramps and bleeding. And that made me worry that maybe he didn't get it all. But ever since, I have been fine and I *never* miss my doctor appointments.

JM: And how do you feel now?

Céleste: I am okay. I still have cramping sometimes. I'm not sure where they both came from, but they happened at the same time as when I learned my husband had another *fanm deyo*, you know, a side ride, as they say. I maybe got them from her.

JM: Can you explain? You got what from the fanm deyo?

Céleste: Well, I had the urinary tract infection, then the cancer in my *matris*, so maybe she was not clean, and my husband brought it to me.

JM: Not clean? How do you mean?

Céleste: Maybe she does not clean herself *inside*, you know. She maybe had dirty discharge or something that caused me to have these problems.

JM: Okay, I see.

Céleste: And after that, I got all the tests I could for every disease, because you never know. And my husband and I, we divorced. I don't need to be Mrs. So-and-So. I don't need that.

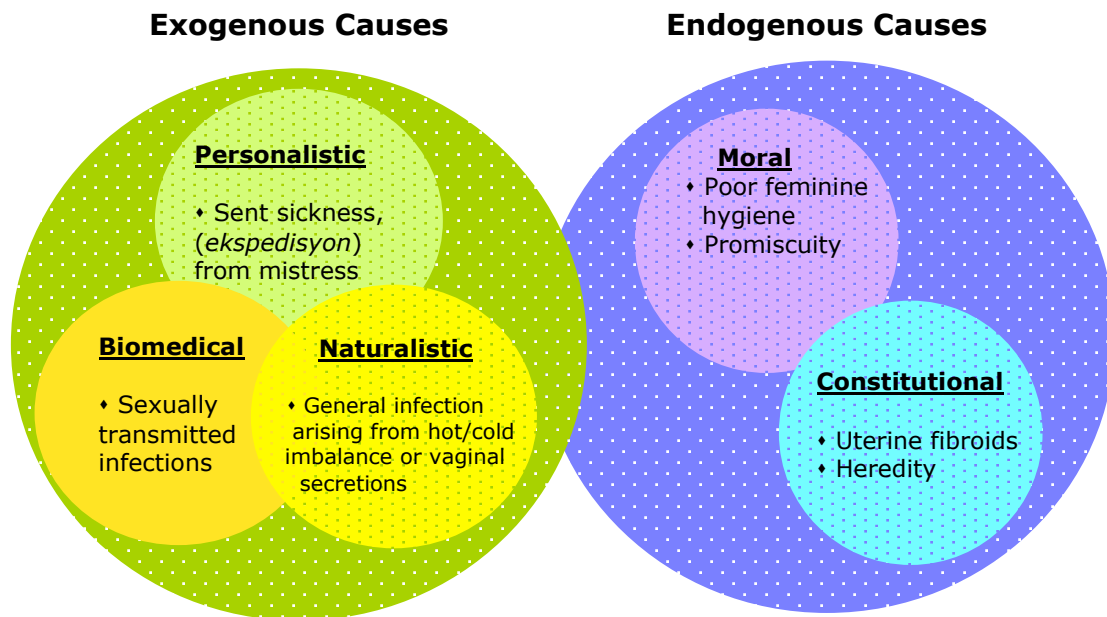
Céleste's story illustrates her knowledge about cervical cancer as drawing from biomedical and ethnomedical cognitive models of the disease. She described the standard biomedical screening for cervical cancer as a life-saving tool, and she discussed the treatment (surgery) she underwent, likely conization, in the doctor's office. Her suspicions about the cause of her cervical cancer (and urinary tract infection), however, reveal etiologic beliefs informed by an ethnomedical model that emphasizes feminine hygiene as essential to health. This exchange also illustrates her experience with historically patterned gender relations of men having multiple female partners: Her ex-husband had mistresses, whom she suspected as the source of her conditions.

In general, the 5 women who stated that they had been treated for cervical cancer tended to have a lower socioeconomic status than the women who did not state that they had cervical cancer; however, it should be noted that women were not directly asked if they had ever had cervical cancer. These 5 women chose to disclose this information in the course of the interview. It is possible that other women simply chose not to disclose information about history personal cervical cancer. One woman had private

health insurance through her husband’s employer, and four women obtained care through a free community clinic. All women had learned of their diagnoses after routine Pap screening that occurred after they emigrated to the U.S. These 5 women had been in the U.S. for a range of three to 10 years. All 5 women had total annual household incomes of less than \$30,000 and a high school education or less. Lastly, beliefs about cervical cancer causality among all 5 women included both ethnomedical and biomedical elements, as was found among women in the entire sample.

Regarding cervical cancer causality, women were asked, “What do you think can cause cervical cancer?” Patterns of belief about cervical cancer were similar to those of cancer in general; however, the domains were generally smaller, with fewer categories of causality. The following figure graphically illustrates the patterned collective domains of cervical cancer.

**Figure 5: Ethnoetiologic Beliefs about Cervical Cancer**



Exogenous causes named by women included that cervical cancer could be a sent sickness (personalistic) or be caused by getting any general gynecological infection, and sexually transmitted infections. Importantly, some women's attributions of causality and susceptibility for gynecological cancer were, on the surface, similar to the biomedical model: multiple sex partners, or having an unfaithful partner who could be the source of exposure. That is, women indicated that they could get cervical cancer from their husband's, or partner's mistress, or *fanm deyo*. However, further probing led to a more accurate understanding of how several women (n=8, 33%) understood gynecological cancer etiology, as it related to personalistic causes. The following exchange with one woman, Adèle, is characteristic of what these 8 women related as the mode of transmission of the disease. Adèle is 29 years old. She has never been legally married but is in a plasaj relationship. She has two children and has been in the U.S. for 5 years. She is a certified nursing assistant (CNA).

JM: What do you think can cause cervical cancer?

Adèle: Well, it depend on your beliefs, but in some cases, it can be because some women mess around with Vodou.

JM: Can you give me an example of what you mean?

Adèle: Women get very jealous about a man, you know? They can do things to try to hurt other women or make them sick and die.

JM: Okay, from cervical cancer? What types of things?

Adèle: *Oui*. Or any disease. If a woman is with your husband, she can make you get this. She try to kill you! *Se youn poud* [it is a powder].

JM: I see, okay. Where does she get the powder, and what is it?

Adèle: From the gangan [houngan]. I don't know what it is made from. They mess around with all kinds of things. *Zo, fey, lwa, m' pa konnen*. (Bones, leaves, spirits, I don't know).

JM: How does it work?

Adèle: She puts a powder on his penis while he [the husband] sleeps. Or maybe in his underwear. Then he goes back to the wife and has sex with her and she get it.

JM: Gets the powder?

Adèle: *Oui*. And that can kill her! It can start cancer.

JM: Okay, then what happens to the husband? Is he sick?

Adèle: No. He is okay because he got rid of it. It went inside his wife.

JM: Okay, to make sure I understand, when he has sex with his wife, it leaves his body and goes into hers?

Adèle: *Oui. Se sa*. (Yes. That's it).

Adèle further explained that the powder (or sometimes a liquid) has approximately three days to be effective. After that point it is no longer potent. She also related that the mistress must make sure that he has had sex with his wife within that time frame, or run the risk of having the spell essentially backfire.

Like the endogenous domain of cancer causality in general, responses centered on moral and constitutional causes. In the moral category, thirteen women (54%) indicated that cervical cancer was related to sexual promiscuity. Also in the moral category, 18 of the 24 women (75%) indicated that cervical cancer could arise from poor personal feminine hygiene. In the constitutional category, twelve women (50%) stated that cervical cancer can

come from uterine fibroids (*fibrum*), and eight (33%) women offered that it could be hereditary.

Continuing with elicitation of explanatory models, all 24 women were asked to name all the things they could think of to prevent cervical cancer. The following table illustrates the results of this freelisting task.

**Table 14: Frequency Distribution of Ways to Prevent Cervical Cancer**

Items Mentioned	Count (n=24)	%
Practice good feminine hygiene habits (twalet deba, lavmen)	20	83
Get check-ups at the doctor	17	71
Get Pap tests regularly	14	58
Use condoms	12	50
Know sexual history of partner	8	33
Don't know	4	17

As is evident from this table, responses fit into a small number of categories, indicating the domain for cervical cancer prevention is small, like that of cancer prevention in general. Importantly, the majority of women named feminine hygiene as a prevention method for cervical cancer. Prevention knowledge also drew from biomedical orientations to illness: Many women also stated that getting regular checkups at the doctor is a preventive measure, but Pap testing was not specifically stated. Additionally, women associated cervical cancer prevention with condom use and knowing a partner's sexual history.

Concerning susceptibility and risk, women were asked, "Who do you

think can get cervical cancer?" All women (n=24) responded that any woman could get cervical cancer. However, responses were qualified with assessments of likelihoods. For example, women who did not practice regular feminine hygiene and who were promiscuous were also seen as more likely to get cervical cancer.

Regarding treatment options, women were asked to name all the types of treatments they had heard about for cervical cancer. The following table illustrates the results of this freelisting task:

**Table 15: Frequency Distribution of Ways to Treat Cervical Cancer**

Treatments Mentioned	Count (n=24)	%
Surgery	18	75
Radiation	17	71
Home remedies (teas)	15	63
Chemotherapy	12	50
Don't know	6	25

Moreover, concerning which practitioners women thought could treat cervical cancer, all 24 women responded that physicians could treat it. Women offered that home remedies in the form of teas could be taken, but the therapies were not associated with a particular healer. Rather, women stated that if they needed to know how to prepare a tea, they would ask their mother, aunt or grandmother. Only 4 women stated that perhaps a houngan or manbo could treat it, and that was discussed only as a last resort.

## Discussion

These qualitative findings address, in part, the first research question of this study, and two specific objectives, which are as follows:

Q<sub>1</sub>: How do cultural and structural factors combine to shape knowledge, discourse, and belief systems about cancer and cervical cancer etiology, risk, prevention and treatment among Haitian immigrant women?

O<sub>1</sub>: Locate health priorities, cancer knowledge and health behaviors in cultural and structural context.

O<sub>2</sub>: Elicit and analyze explanatory models (EMs) of cancer and specifically, cervical cancer.

In order to contextualize cancer and understand its saliency in women's daily lives, it was necessary to determine where cancer fit in with regard to general health concerns. While significant fear and fatalism were evident in women's responses, other chronic illnesses were mentioned more frequently and noted as important for awareness among Haitian women: Hypertension and diabetes. The frequency with which women noted these conditions reflects their greater prevalence in the population.

While women mentioned other illnesses more frequently as important conditions to be aware of, they also stated that cancer was an important illness, which women needed to have awareness. Patterns emerged in cancer explanatory models. Women felt that cancer is a serious, potentially fatal illness that responds best to a combination of ethnomedical and biomedical treatments, and in some cases, multiple practitioners. Women did not distinguish types of cancer in terms of disease gravity or survivability. Instead, they were all viewed as equally dangerous, among the women who



delineated distinct cancer types. For ethnoetiologic beliefs, categories of causality clustered in exogenous and endogenous cause domains. That is, cancer sources were believed to originate externally (i.e., environment, food/diet, as a sent sickness, or *ekspedisyon*, and sexual transmission) and internally (poor hygiene, uterine fibroids, heredity) for naturalistic, personalistic and moral reasons.

Patterns of belief that emerged around cervical cancer were similar to those of cancer in general pertaining to the endogenous domain. That is, constitutional causes (heredity, fibroids), and moral causes (poor hygiene, promiscuity), were parallel. The fact that 8 women mentioned cervical cancer as possibly hereditary likely reflects women's relational experience with the disease, witnessing its effects on generations of Haitian women. With regard to exogenous causes identified by women, cervical cancer differed from cancer in that environmental (e.g., secondhand smoke, pesticides) and diet (e.g., non-organic food, contaminated water) reasons were not connected to development of this disease. Instead, exogenous cause categories were personalistic, as a sent sickness, and naturalistic, as arising from sexual transmission and general vaginal infections, although no women specifically mentioned HPV. Lastly, the observations that at least 6 women made about the possibility that cancer may not be preventable, but detected early, are important, as early detection is the primary method for fighting many forms of the disease. It is also especially relevant for cervical cancer, where early detection truly does save lives, through Pap screening.

The preliminary interviews revealed that culturally mediated feminine

hygiene practices, which include external and intravaginal cleansing with ethnobotanical, chemical and imported commercial products, figure prominently in women's lives, in terms of women's gynecological and overall health. The reasons for the practices are multifaceted, including hygiene and health, as well as, tightening and drying the vaginal environment. They are related to broader cultural aspects of what is expected of women, by men and by other women: to be *pròp*, or clean, with one's body, inside and out; to not have vaginal secretions, which are often construed as infectious or otherwise dirty; and to be *sere*, or tight, to increase sexual pleasure for male partners. These practices are an example of knowledge shared generation to generation, most often taught by older female relatives. The practices are also related to cancer and cervical cancer ethnoetiologic belief patterns, in which a lack of hygiene is believed to have the potential to lead to cancer. These findings have discernible implications for public health and clinical practice, including systematic research into associations of feminine hygiene practices and risk for cervical cancer, opportunities to develop women's health education materials for both men and women, and clinician education about cultural influences on patient health behaviors.

## **Summary**

This chapter presented the research setting, a demographic description of the sample, and findings related to situating cancer in the larger context of health and illness among Haitian immigrant women in the two research sites. While the majority of women in the preliminary sample had some form of

health care coverage (e.g., private insurance or public coverage through Medicaid or county health plans), women had significant concerns about using health care coverage when obtaining care. For those with employer-based insurance, women feared that their medical information might be made known to employers. Others noted that it was difficult to take time away from work to see a doctor, indicating that insurance status may not be a good proxy for trying to assess use of biomedicine in this population.

Analyses of women's responses for explanatory models of cancer and cervical cancer were presented and patterns discussed in terms of health beliefs about causality, susceptibility, therapy and practitioner options. Some causality beliefs were linked to sociopolitical sources, including accusations of systematic denial of care to Blacks and, specifically, Haitian immigrants. Information learned in the preliminary sample of women guided the formation of questions for a subsequent interview guide, administered to a secondary sample of women. These data situate cancer women's daily lives and illness conceptions. They also yielded new information about uterine fibroids and feminine hygiene that was important for women's constructions of gynecological cancers. Women's beliefs about heredity and cervical cancer may be reflective of the ways in which poverty and social inequality structure disease risk profiles and distributions to excessively impact socially marginalized women, such that women often saw family members affected. Socially structured gender relations were described, which are intricately intertwined with women's gynecological health, through increased risks of disease from partner infidelities, and, potentially, from agents used for

feminine hygiene practices. These topics were explored in greater depth in interviews with the subsequent sample of women.

The next chapter, Chapter 8, presents the findings from interviews with the subsequent sample of women, with regard to the second research question and remaining objectives. Ethnographic details of feminine hygiene practices, including the agents used, are presented in the context of gender and power relations among men and women. Findings related to women's knowledge and understanding of the Pap test and HPV are presented, alongside a discussion of observations from interviews with 5 Haitian physicians. Additionally, survey data on women's self-reports of feminine hygiene practices and cytology results are analyzed for associations. Together, these findings speak to important implications for public health and clinical practice.

## **CHAPTER 8:**

### **GYNECOLOGICAL HEALTH IN SOCIOCULTURAL AND HISTORICAL CONTEXT**

#### **Introduction**

This chapter presents the findings that address the second exploratory research question of this study and the following two objectives:

Q<sub>2</sub>: How do cultural and structural factors intersect to influence women's health behaviors associated with cervical cancer prevention, detection, and for some, therapy?

O<sub>3</sub>: Examine significance and prevalence of culturally mediated feminine hygiene practices that may impact women's risk of cervical cancer

O<sub>4</sub>: Elicit information about male-female relationships that may impact women's cervical cancer risk

Demographic characteristics are first presented to provide a snapshot of the women in the second sample. Women's access to biomedicine, including Pap tests, is examined. Knowledge and understanding of Pap tests and the HPV vaccine are assessed. Findings from interviews with physicians provide an additional perspective to the context of gynecological health of Haitian immigrant women. Detailed ethnographic data are used to synthesize a discussion of feminine hygiene practices, including descriptions of phytotherapies, commercial and chemical agents used.

This chapter also presents an analysis of cross-sectional survey data collected among women in Little Haiti. This survey represents a marriage of ethnography and epidemiology. Survey data are used to test study hypotheses that examine associations between women's self-report of feminine hygiene practices, sociodemographics, and cytology results from the use of a home Pap test self-sampling device.

Finally, historical processes, including culturally mediated gender relations, colonial medicine and gynecology, are examined for their potential roles in shaping women's concepts of female health and illness and reinforcing feminine hygiene behaviors. These findings situate women's gynecological health in multiple relevant contexts.

### **Secondary Sample Characteristics**

As in the preliminary sample of women, for the second sample of women, I deliberately recruited to create heterogeneity in the sample, in order to capture viewpoints from a diverse group of Haitian immigrant women. A quota sample of 15 women was interviewed, as this was the number at which data saturation was reached in the preliminary sample of women.

Demographic data were collected for each participant. Determining length of time in U.S. was based upon women stating that it was their primary residence. Some women returned to Haiti for a few months at a time to visit relatives. Additionally, some women left Haiti but first emigrated to Canada, then to the U.S. The majority of women did not move to Tampa or

Orlando first. Rather, seven women first went to Miami from Haiti, three women went first to Montreal, three women went first to New York, and only the remaining two women immigrated directly to Orlando from Haiti. Women who went to other cities first commonly remarked that they liked the size of Tampa or Orlando, that it wasn't too big like Miami, or too cold like New York or Montreal. The following table depicts demographic characteristics pertaining to age, residency and immigration for the 15 women.

**Table 16. Age, Residency and Immigration Characteristics of Secondary Sample of Women (N=15)**

Measure	Minimum	Maximum	Mean
Age	25.0	73.0	41.8
Age when Emigrated to US	9.0	38.0	18.4
Length of time in years lived in U.S.	4.0	45.0	16.7
Length of time in years lived in city (Tampa/Orlando)	4.0	30.0	12.3
Length of time in years lived in Haiti	9.0	65.0	24.9

The average age of women in this sample was approximately 42 years. The majority of women emigrated to the U.S. at younger ages. I observed that women in this sample who had lived in the U.S. longer tended to have a higher English proficiency, and that they lived in houses rather than apartments. I also observed that women who had lived in the U.S. for a shorter amount of time were employed in lower wage jobs, such as retail cashier, hotel housekeeping, theme park maintenance and hotel security. They also worked longer hours than women who had been in the U.S. longer.

Women worked between 0 (unemployed/retired) and 60 hours per week for pay, (mean = 45 hours/week). Women often held two or more part time jobs. The occupations of women in the sample fell in professional, skilled labor, and non-professional categories. I determined professional occupations to be those generally requiring a college degree. Examples of professional occupations included accountant, attorney and therapist (psychology). Skilled labor occupations may be defined as those requiring some training and in some cases licensure. Examples of these occupations among women in the sample included real estate sales, nurse (LPN), certified nurses assistant (CNA), and secretarial positions. Non-professional occupations were characterized by little formal training and included hotel housekeeping, hotel property security, theme park maintenance, and home babysitting. Two women in the sample were unemployed, and one woman was retired. The following table illustrates the number of women in each occupation category.

**Table 17. Occupation Categories by Number of Women in Sample (N=15)**

<b>Occupation Category</b>	<b>Frequency</b>	<b>Percent</b>
Skilled labor	5	33.3
Nonprofessional	4	26.7
Professional	3	20.0
Unemployed	2	13.3
Retired	1	6.7
TOTAL	15	100.0



With regard to annual household income, I asked key respondents for advice about how to best phrase this often sensitive question. They suggested I provide income categories from which participants could choose, in order to eliminate the need for a participant to state an exact dollar amount. Importantly, key respondents pointed out that incomes are less steady for some immigrant families, and categories would allow for income fluctuations as well. The following table illustrates the distribution of incomes of women interviewed.

**Table 18. Income Distribution among Women in Sample (N=15)**

<b>Income Range</b>	<b>Frequency</b>	<b>Percent</b>
Less than 10,000	1	6.7
10,000 - 19,999	3	20.0
20,000 - 29,999	3	20.0
30,000 - 39,999	3	20.0
40,000 - 49,999	2	13.3
50,000 - 59,999	0	0
60,000 - 69,999	2	13.3
70,000 or more	1	6.7
TOTAL	15	100

In general, annual household incomes and education levels are generally closely associated cross-culturally. This association was also observed among women in the sample. Education is extremely important in Haitian culture. I asked key respondents for the best way to ask women about their education level. They affirmed that some women could be embarrassed if they had little education. Thus, as in the question about

income, they suggested I provide categories from which women participants could choose, rather than asking for a specific grade completed. The majority of women had some high school to some college level education. Table 19 illustrates the education levels achieved by women interviewed for this sample.

**Table 19. Education Level Attained (N=15)**

<b>Grade Level</b>	<b>Frequency</b>	<b>Percent</b>
Primary school	1	6.7
Less than high school	3	20.0
High school	3	20.0
Associate degree/some college	3	20.0
College degree	4	26.7
Graduate degree	1	6.7
TOTAL	15	100

Similar to education level, language is an important social indicator in Haitian culture. The ability to speak French fluently is associated with higher education and social class (Zéphir 1997). Formal schooling in Haiti historically has used the French language. Women were asked what language they preferred to use for reading, what languages they knew how to speak fluently, and the language used most often at home. The following table illustrates the frequencies of languages used and in what ways. The category for preferred reading language is based on a total of 14 women, as one participant could not read. The category for spoken languages allows for multiple responses for each woman, since most were bilingual or multilingual. Thus, the percent category does not total 100.

**Table 20. Language Use by Women in Sample (N=15)**

	Language(s) Reading Preference		Language(s) Spoken Fluently		Language(s) Spoken Most at Home	
	Frequency	Percent	Frequency	Percent	Frequency	Percent
<b>English</b>	6	42.9	10	66.7	5	33.3
<b>Kreyol</b>	0	0	15	100	10	66.7
<b>French</b>	8	57.1	9	60	0	0
<b>Spanish</b>	0	0	5	33.3	0	0
<b>TOTAL</b>	14	100	-	-	15	100

Women's stated religious affiliations were variations of Christian denominations. Only one woman stated that she did not consider herself any particular religion. Table 21 depicts the religious denominations of women in the sample.

**Table 21. Religious Denominations of Women in Sample (N=15)**

Denomination	Frequency	Percent
Baptist	6	40.0
Catholic	6	40.0
7 <sup>th</sup> Day Adventist	2	13.3
None	1	6.7
TOTAL	15	100

Lastly, concerning family networks and households, the number of people in a household ranged from 1 to 7, with a mode of 5 people per household. The number of children women had ranged from 0 to 4, with a

mode of 3. Most often, households consisted of the woman participant, her husband and either one or both of her parents or his parents, and children. In some cases, cousins also shared the household. Table 22 illustrates the distribution of marital status categories of women in the sample.

**Table 22. Marital Status of Women (N=15)**

<b>Marital Status</b>	<b>Frequency</b>	<b>Percent</b>
Never married	2	13.3
Married	8	53.3
Separated	3	20.0
Divorced	1	6.7
Widowed	1	6.7
TOTAL	15	100

This section provided a demographic picture of women in the preliminary sample, as background to discussion of the remaining study findings. The next section examines women’s stated use of biomedical care and population characteristics related to health insurance.

### **Accessing Biomedical Healthcare**

Problematic access to biomedical healthcare, arising from structural barriers, e.g., lack of insurance, prohibitive costs, legal and linguistic reasons, is common for many immigrant groups in the U.S. (Gany and Thiel de Bocanegra 1996a). Women in the secondary sample were asked questions to assess the extent to which access to care was problematic. The

majority of them (n=12) stated that they sought biomedical care for any general illness. The question was posed, “When would you go see a medical doctor?” Responses reflected an orientation to seeing a doctor when there is a problem, not for prevention. Only 5 women specifically mentioned a “check-up” as a reason to go to a doctor. Two women mentioned that they go to the doctor for a mammogram every year.

A majority of women had health insurance in public or private forms. Public insurance included Medicaid and Medicare. Women who were enrolled in county health plans, which are income-dependent plans that facilitate access to care by making health care services affordable through sliding-scale fees, were included in this group for conceptual analysis purposes. Private insurance was obtained through their employer or that of their husband. Table 23 depicts the distribution of women by insurance types and categories.

**Table 23. Health Insurance Status by Women in Sample (N=15)**

	<b>Frequency</b>	<b>Percent</b>
<b>Yes</b>	9	60.0
Public	3	33.3
Private	6	40.0
<b>No</b>	6	40.0

Importantly, much like women in the preliminary sample, women expressed concerns about using their health insurance. These concerns centered on issues of keeping personal health information private from

employers, and on anxiety about expenses for those who had cost-sharing plans with no set co-payments. Also similar to the preliminary sample, women indicated that it was difficult to find time to go to the doctor.

Among the women without health insurance, they relied on biomedical care access through local Community Health Centers, which are Federally Qualified Health Centers that provide primary care and in some clinics more specialized care. These clinics are required to use a sliding fee scale, based on family size of patients and current poverty guidelines. Officially, as part of their federal funding stipulations, they are required to be open to any person, independent of ability to pay. Women also stated that they could rely on free, faith-based clinics when needed.

There was also a well-known, private Haitian physician at one research site who took patients pro bono or at significantly reduced rates. Women with and without insurance frequented that physician's office. A preference for private physicians, even if it meant paying out-of-pocket, was evident in women's comments about public clinics:

"Sometimes you wait, wait and wait. At [Faith-Based] clinic, you wait all day and sometime you still don't see a doctor that day. It cause all kind of problem. M' bezwen...I need to find someone to take me, and then pick me up. And I cannot work that day. I don't like that place [clinic]. In other place, you are in and out like that!" (snaps fingers)

And,

"The place [public clinic] is dirty. People leave *diapers* on the floor. Right on the floor!"

This following exchange also made evident the preference for private

physicians as related to perceived quality of care:

Colette: Oui. I can go to the doctor, but I have to pay more money (than the cost of community health center). I could have health insurance from my job, but it is too expensive.

JM: I see. Where do you go see the doctor, then?

Colette. He has his own office, so I prefer to see him.

JM: Why do you prefer to see him over the doctors at the clinic?

Colette: Doctors at that clinic are not as good. The clinic sometimes gives care for free.

JM: Why do you think doctors at the clinic aren't as good?

Colette: Because! If they were good then they would be out making more money! (laughs)

Of the six uninsured women and three with public health care coverage, six women in total indicated a preference for seeing private practice physicians for the reason described by Collette. This finding was discussed with one CBO director, who confirmed that this belief is common in the community.

Regarding biomedical models of cervical cancer prevention, women from both of the preliminary and secondary samples (n=35, total) were asked about Pap tests and about the new HPV vaccine, Gardasil®. First, women were asked if they had ever heard of the Pap test, and what the purpose of the test was. Women were also asked if they had ever had a Pap test, and when they had their last one. Dichotomous categories were created for response data about the time of women's most recent Pap test. The categories created for analysis were 'within the past 2 years' and 'not within

the past 2 years', based on current screening guidelines for women with a history of negative cytology (ACOG 2004). The following table illustrates the results of these questions.

**Table 24. Pap Test Knowledge, Understanding and Use (N=35)**

Question Item	Yes		No		Somewhat	
	Freq	%	Freq	%	Freq	%
Ever heard of Pap test	27	77.1	8	22.9	-	-
Pap test understanding (n=27)	9	33.3	3	11.1	15	55.6
Ever had a Pap test	26	74.3	9	25.7	-	-
Had Pap test in past 2 years (n=26)	18	69.3	8	30.7	-	-

In this table, a category of "somewhat" was included because in some cases, women had partial knowledge of the purpose of a Pap test. In explanation, while the majority of all women had heard of the Pap test, a significant proportion (55.6%) indicated it was a test for cancer, but *cervical* cancer was not specified. In addition, women in this group described the Pap test as a general exam that would produce findings for any abnormalities related to reproductive health organs and infections. As one woman stated, "It is a test to make sure that everything is okay with the uterus." And, "Women go to the doctor for the test to check for cancer and for sexually transmitted diseases." Thus, seeking gynecological healthcare in the biomedical sector does not imply matched cognitive models of cervical cancer etiology or preventive behavior.

In addition, of the 26 women who ever had a Pap test, 12 women



described that they disliked getting Pap tests, as part of their answers to the questions concerning Pap test knowledge and understanding. Ten of these women indicated a preference for a female physician for this particular test whenever possible. Eight women used words such as “uncomfortable,” “painful,” and “embarrassing” to describe what they knew about the Pap test. Five women specifically indicated they disliked the Pap test because of the effects of loosening the vagina, and the residual lubricant. As one woman stated, “You are open for so long during this test, and you stay that way!” And, “I don’t like it. The doctor opens you up *so much* it hurts! And then you feel wet inside afterwards from the cream [lubricant] they use.” These comments resonated with observations I had during my work for the cancer center, in which I encountered Haitian women who were concerned that the Pap test would leave them too “open,” regarding both vaginal tone and the opportunity for air to enter the body through the vagina.

Regarding knowledge about HPV and the vaccine, 10 of 35 women had heard of HPV, and subsequently the vaccine, by way of the vaccine maker’s recent advertisement campaign in print and on television, ‘One Less,’ mentioning it by name. All 10 of these women reported language proficiency in English, had been in the U.S. for 8 years or more, and had a high school or greater education level. Only two of these 10 women explained precisely that the vaccine was for a virus that causes cancer. A category of ‘Somewhat’ was also created here, as two women explained that thought it was a vaccine for cancer, but the connection to a virus was not made. The remaining 8 women were uncertain about what HPV exactly was.

**Table 25. HPV and HPV Vaccine Knowledge (N=35)**

Question Item	Yes		No		Somewhat	
	Freq	%	Freq	%	Freq	%
Ever heard of HPV	10	28.6	25	71.4	-	-
Ever heard of HPV vaccine (n=10)	10	100	0	0	-	-
HPV vaccine understanding (n=10)	2	20.0	6	60.0	2	20.0

Of the women who heard of the HPV vaccine, none expressed any association with, or concern for, the vaccine contributing to subsequent promiscuous behavior. This point is significant since opponents of the vaccine currently promote this view.

For those women who did not know of, or had an incomplete understanding of, HPV and the HPV vaccine, I provided an explanation about the connection between HPV and cervical cancer in lay terms. Although I risked compromising data if women discussed the topic with friends whom they recommended for interviews, I felt it would be unethical to withhold health information about HPV, especially given the high excess cervical cancer mortality in Haitian women. The explanation of HPV often prompted further discussion and questions from women: "Can you get it even if you haven't had sex in a long time?" And, "How can you tell if you have it?" I always encouraged women to ask their doctors for the most up-to-date information. If they did not have a physician, I referred them to a trilingual (Kreyol, French, English) female contact at CMWP, the community based nonprofit that provides health education through trained community health workers and Certified Health Education Specialists.

Questions were added in the interview guide for the second sample of women to assess opinions about intent of use of the HPV vaccine for their children, if applicable. These questions followed the lay explanation of HPV and the vaccine. The questions read, "Knowing this information, would you consider getting this vaccine for your daughter?" And, "Why, or why not?" At the time of this research, the Gardasil® vaccine is under review for eventual administration to boys. Thus, if applicable, this question was asked: "Would you consider getting the vaccine for your son, when it is available?" One woman had no children, and some women had both male and female children. The following table depicts these results:

**Table 26. HPV Vaccine Intent Opinions**

Question Item	Yes		No		Unsure	
	Freq	%	Freq	%	Freq	%
Would consider vaccine for daughter(s)? (n=9)	4	44.5	2	22.2	3	33.3
Would consider vaccine for son(s)? (n=10)	3	30.0	1	10.0	6	60.0

For those who offered that they would give the vaccine to their children, the vaccine was perceived positively. Women who indicated they would not allow their children to have the vaccine expressed concern about how recent the vaccine has been in use, that perhaps little is known about possible long term effects. Women who were unsure about the vaccine for their children expressed the same sentiment, regarding uncertainty about the vaccine's

possible long term effects. Three women who had sons expressed concern that the vaccine might negatively affect their sons' ability to reproduce.

These aspects of women's health behaviors, knowledge, understanding and opinions about prevention in the biomedical sector are important sources of information for both public health and clinical practice. They can serve to inform health education efforts and cross-cultural communication about gynecological health in the clinical encounter. The following section examines the physician perspective, as a complement to these data from the women's perspective regarding care and prevention in the in the biomedical sector.

### **The Physician Perspective**

Five Haitian physicians were interviewed for this research to gain their perspective on the topic of gynecological health and health behaviors in Haitian culture. Physicians were local to the two research sites. Three men and two women were interviewed. Three physicians were internal medicine doctors, one of whom was also a provider of immigration physicals. The other two physicians were in family practice.

Each physician was asked a series of open-ended questions about health and social issues for the Haitian immigrant community, perceptions of disease prevention, and perspectives on women's use of remedies and healers in the folk medical sector. Questions about cancer included opinions about cancer prevention in Haitian culture, the impact of cervical cancer on Haitian women patients in his/her practice, and about the impact of culture on Haitian women's beliefs about cervical cancer. They were also asked their

opinions about Gardasil®, and recommendations for how best to create culturally relevant health information about cervical cancer.

Regarding opinions about important social issues for Haitian immigrants in the U.S., all five physicians mentioned immigration status and communication problems as the most significant social issues. Immigration status was noted as a major problem that kept many from being employed in the formal economy. Communication problems referred to low literacy and low English proficiency, which also precluded higher paying employment opportunities.

The physician who provided immigration physicals also linked immigration issues to health. He explained that having certain pre-existing illnesses (i.e., tuberculosis, HIV) prevents an immigrant from entering, or staying in the country. Metaphorically, he likened the triage of diseased/not-diseased people to individual-level protection: “Well, you wouldn’t want these people in your house, would you?”

Regarding the most important health issues, response themes centered on health barriers, including access to health care, lack of prevention and health education. Four physicians indicated that health care is cost-prohibitive for many people in low wage jobs. Prevention and education concepts were linked in that all five physicians largely associated lack of preventive health behaviors with lack of education about health. Regarding opinions about perceptions of cancer prevention in the Haitian community, all five physicians again emphasized education as the distinguishing factor between “correct” and “incorrect” perceptions. As one

physician stated, "The problem is education. People need to know that they can reduce their risk of cancer by making lifestyle changes and getting regular screenings." Thus, interestingly, each physician recognized problematic issues of access (that significantly impact health behaviors), but each also placed great emphasis on the role of education to encourage preventive health behavior, including Pap tests.

Three physicians also offered that, culturally, prevention is more closely aligned with health maintenance, often through the use of phytotherapies, rather than perceived as a reason to visit a doctor, for health screenings. As one physician stated, "Haitians tend to wait until the problem, the sickness, has gotten worse, before they will seek medical treatment. They first use teas, fey (leaves), you know, home remedies." Four of the five physicians explained that unless pain is experienced, most Haitian people will not go to a doctor. Three physicians also indicated that patients may consult other practitioners in conjunction with phytotherapeutic remedies and Western doctors. Nonbiomedical practitioners mentioned included *medsin fey* (herbalist, or *doktè fey*), or a *houngan* (male Vodou practitioner). These same three physicians also mentioned several plants by name that women use for myriad health issues: *ti bonm*, *pwa kongo*, *thé mélisse*, *aloès*, *asowosi*, and *kowosol*. They also stated that they felt it was generally fine for women to use the plants as medicine, as long as using those therapies does not delay their decision to seek treatment from a physician when an illness is severe, or has the potential to become severe.

Regarding cancer, all five physicians felt that the primary problem for Haitians in their communities was late presentation, when the cancer has usually spread and treatment is less successful. Reasons for late presentation were offered, and coalesced around, cultural beliefs that first guide people to therapies in the folk medical sector and prayer, problematic access to healthcare, not feeling any pain, and fear of finding out bad news from the doctor. Two physicians also indicated that cervical cancer might be thought of by some women as sent sicknesses, or *ekspedisyon*. As expected, they spoke of such beliefs using terms such as superstition, and lack of education. As one physician put it, shaking her head, "You see, there is always a jealous person putting a *kou'd poud* (coup de poudre, or powder) on someone, sometimes women fighting over men, or a jealous neighbor. And then, *voilà, la personne tombe malade* (the person falls ill)" (laughs).

Lastly, concerning physician perspectives on the cervical cancer vaccine, two physicians spoke positively of the vaccine while three offered more cautious commentary. Those three physicians indicated that they wanted a longer surveillance period on the vaccine to decide whether or not to recommend it for patients. They expressed concerns with unknown side effects. All, however, thought it would be generally well received among Haitian women. Two doctors also advised that the vaccine must be explained in lay terms to patients, but done so delicately so that parents are not offended. Since the vaccination target age is pre-adolescence, and because it prevents a sexually transmitted virus, they explained, it may be difficult for parents to imagine their child as sexually active in the future. As one

physician offered, “It’s a tough call, I mean, I have a 9-year old daughter, and I can’t begin to even *think* about her ever having sex. You’ll see! (laughs) You’ll see what I mean when you have your baby girl!”

In sum, among physicians, education was touted as the solution to many health problems, including getting women to get Pap tests routinely. Cultural beliefs that could delay seeking care in the biomedical sector were generally discussed as in need of correction. Physicians did recognize problems of access to health care for Haitian immigrants; however, greater emphasis was placed on education for behavior change as opposed to structural constraints constricting medical treatment choice.

While this section explored physicians’ perspectives about women’s health, Haitian health and culture and cancer, the next section explores in greater depth relationships between men and women, and their impact on gynecological health. This discussion is an important segue into the following section, which examines in greater scope, sociocultural factors that influence women’s health behaviors and assesses influence of feminine hygiene practices on women’s health, using available survey data that include biological samples.

### **Gender and Power Relationship Dynamics and Women’s Health**

As described in detail in Chapter 3, the cultural practice of *plasaj*, or culturally patterned conjugal unions, has important implications for women’s health and survival. Women were first asked to describe what *plasaj* meant to them. The major response theme was that *plasaj* was a situation of a man



and woman living together, who are not married. Although, historically, different types of this union have existed, only one type, *plasaj donnet*, was mentioned among women interviewed. This union refers to a civil marriage (specifically, one that did not take place in a church). Women mentioned other types of conjugal unions, however, that they considered distinct from *plasaj*. These unions included including *byenavek* and *vivavek*, or roughly, to be with/live with. Women described these unions as virtually equivalent, in that the relationship is sexual between a man and a woman, and occasional gifts or money are exchanged, but women's economic dependence on men is much less, as compared to *plasaj*. The majority of women (n=12) also pointed out that men were more likely than women to engage in two or more sexual unions simultaneously, regardless of marital status.

Gendered dimensions of power in relationships were made evident in women's responses to questions about *plasaj* and discussions of risks for sexually transmitted infections. Women were asked how they felt about men having mistresses, and what women could do about it. The major theme in women's responses was that, naturally, women were very unhappy at the thought of partner infidelity, and they openly opposed what they recognized as a cultural tradition. Also, women explained that there is often very little that women can do about their partner's infidelities due to economic dependence on the man, especially if he is responsible for her residence in the U.S. As one woman stated, "We are unwilling participants. It is brought over from Haiti." At times, women appeared resigned to partner infidelity as a matter of immutable fact. As one women put it, "C'est leur destin, les

hommes" (It is their destiny, men, [to be unfaithful]). Five women related that if a woman has a better education, she can be more independent. The following exchange is emblematic of this sentiment:

Marcelle: Hmmmph! These men. They *prey* on you! They walk around like *le coq du village* [village rooster], going after every woman they can.

JM: So when men have *fanm deyo* [mistresses], what can women do about it?

Marcelle: Well, my father always told me that if I got an education, I would not have to put up with that. Because if I can have a good job, then I don't need a man's money and I can take care of myself.

Thus, many women (n=10) felt that there was not much that could be done to change men's behaviors; rather, women could protect themselves possibly by having a higher education and, consequently, access to occupations with higher salaries.

However, further discussion elicited examples of ways that women do, indeed, use to try to control the affairs of a husband or lover. Lively discussions ensued of examples of ways to affect either the mistress or the husband/partner, which invariably involved a manbo or houngan (Vodou practitioners). Expectedly, none of the women openly indicated that they had taken part in any such activity; rather, they provided examples of what they had witnessed, or had heard about, most often in the case of a friend. Four women described the act of obtaining a photograph of the mistress, then

beating the photo with an object or cutting it up (sympathetic magic), with the ultimate intent to bring harm to the other woman to influence her to stay away from the man. Eight women explained that an item of clothing, hair, or other personal effect is often sought for use in manipulating a situation (contagious magic). These women explained that harming a personal effect of the mistress could kill her. In the case of keeping husbands or lovers faithful, three women indicated tying a pair of his underwear in a knot would keep him from straying. Seven women also described the practice of women placing a magical agent (usually a powder), obtained from a houngan, in the husband/partner's underwear or on his penis during sleep, with the intent that he transfers this powder via intercourse to the other woman to harm or kill her.

None of the 15 women interviewed rejected the notion that such practices could actually result in harm. Rather, they cautioned that such an intent should never be taken lightly. One woman, Yolande, offered her personal story as example:

JM: So what can women do if their husband has a *fanm deyo* [mistress]?

Yolande: Let me tell you something. I was married before. I found out that my husband was with another woman. (shakes head)

JM: I see. And what happened?

Yolande: I left him. He keep seeing that woman. And I am Haitian, and I know what Haitians can do.

JM: What do you mean?

Yolande: She wanted him. I believe that she can hurt me or kill me. And I have a daughter to think about.

In sum, the dynamics of male-female relationships are linked to dimensions of power, often contested by women experiencing partner infidelity through the use of magicoreligious means. Although none of the women specifically mentioned sexual desirability, cleanliness or attractiveness as qualities essential to have to secure relationships with men, or to keep them from having affairs, it was evident from women's discourse that these qualities are indeed important for satisfying male partners and maintaining relationships. Culturally patterned sexual unions, then, may serve to reinforce the social importance of women's feminine hygiene practices.

The next section explores in greater detail the sociocultural context of gynecological health, and the relationship of women's health practices to health outcomes.

### **Sociocultural Dimensions of Gynecological Health**

Findings from the preliminary sample of women guided the design of questions to elicit more detailed ethnographic information about gynecological health. The prevalence of feminine hygiene practices was made evident in preliminary interviews, when women were asked about

phytotherapies for cervical cancer. Women also routinely referred to nonspecific *infeksyon* (infections) and *fibrum* (uterine fibroids) in discussions of cancer. Thus, these findings required that I shift my focus from primarily cervical cancer to a wider concept of gynecological health, as that is the cognitive framework from which to explore where cervical cancer fits in with other more mundane gynecological health concerns of women. Much like in the preliminary sample, women did not frequently distinguish between *uterine* and *cervical* cancers. Instead, most often, women used the phrase *kansè nan matrix* (cancer in the uterus) in discourse on cervical cancer. Again, since the terms are similar (*kansè nan kol matrix*, for cervical cancer), the difference may be semantic. However, it remains important, from a public health perspective, to note that most women did not distinguish between the two.

In shifting to a broader approach to gynecological health, detailed questions were asked of women about perceptions of uterine fibroids, including beliefs about their etiology and connection to cancer. The following section describes these findings.

### ***Fibrum (Fibroids) and Cancer***

Women were asked about the causes and treatments for fibroids, and what would happen to untreated fibroids. Responses reveal influences from ethnomedical and biomedical constructs of uterine fibroids. Etiologic beliefs were attributed to three general causes: *fredi* (cold), *pedisyon* (arrested pregnancy syndrome), and heredity. *Fredi* is best understood as excessive

cold in the body (Coreil et al. 1998). *Pedisyon*, as described earlier in Chapter 3, is a culture bound syndrome where a woman is thought to be pregnant, but the pregnancy enters a state of suspension for months or longer. The woman experiences symptoms of pregnancy during this time. This syndrome is suggested as a culturally acceptable explanation to account for infertility or subfecundity in cultural contexts where great importance is placed on a woman's ability to reproduce (Coreil et al. 1996).

Eight women suggested that fibroids could be the result of *fredi* or *pedisyon*. Four women related that fibroids were due to *fredi*, or could be inherited. The remaining three women did not know what caused fibroids. The prominence of *fredi* in attributions of causality attests to the centrality of hot/cold disease theory in Haitian ethnomedical constructs of illness. Cold was described as entering the body in primarily three ways. First, by walking barefoot on a cool tile or cement floor, cold could enter the body through the feet, and eventually settle in the womb. Second, women stated that cold can be absorbed if one becomes wet from rain. Last, cold can be gotten from abrupt changes in temperatures, when one goes from being outdoors to indoor, air conditioned buildings or houses. Cold then settles in the uterus, causes blood to pool and congeal into fibroids.

Regarding arrested pregnancy, women simply stated that sometimes a woman's pregnancy stops. When I asked why pregnancies would stop, women offered that they can stop when bleeding starts, which may be the result of a pregnant woman being overworked, or otherwise fatigued from activity. Women then stated that the *fibrum* is, in effect, an undeveloped

fetus. If the bleeding could be stopped, then perhaps the pregnancy could continue. If not, the fibrum would have to be removed surgically. These findings are consonant with both Coreil and colleagues (1996) and Singer and colleagues (1988) work in Haiti on *pedisyon*, in which a culturally sanctioned explanation for female infertility coincided with significant work and household demands of women.

Women were asked what happens if fibroids go untreated. Grave outcomes were described: infertility, cancer and death. As one woman explained, "If you have *fibrum*, you must have a doctor take them out. They can kill you! They are tumors!" Thus, perhaps the notion that fibroids are related to cancer has roots in the biomedical terminology, "fibroid tumors." Invariably, women also stated that the treatment for fibroids is surgery. This explanatory model of fibroids, then, contains both ethnomedical and biomedical components.

Thus, fibroids are a significant part of the larger cultural construct of gynecological health. Coupled with the notion of infection, these two concepts were most central in women's discussions of cervical and uterine cancer. Each condition was described having different etiologies, but lack of control of either was thought to lead to cancer. Control of these two conditions involved different behaviors. Thus, the following section examines the cultural reasons underlying feminine hygiene in the context of how women attempt to control infections through specific practices.

### ***Cultural Reasons for Feminine Hygiene Practices***

As discussed in Chapter 7, women associated gynecological cancers with poor feminine hygiene. Prevention of gynecological infections is part of a larger cultural construct of maintaining intimate hygiene health through culturally mediated feminine hygiene practices. The feminine hygiene practice of *twalet deba*, or *lavmen*, centers on maintaining women's health, and it involves the use of ethnobotanical and chemical compounds, prescription or commercial (over the counter) products applied externally to the peritoneal area and intravaginally. The practice is complemented by the use of teas (taken orally). The purpose of the practice is to clean, disinfect, tighten and, in some cases, dry the vaginal environment, to increase sexual pleasure of men and thus desirability of women.

Hygiene practices are also connected to larger cultural expectations of women to be clean, both inside and out. Indeed, five women noted that if a woman wished to insult another woman, such insults often involved derogatory comments about intimate hygiene. As one woman related, "You know, if a woman is really mad at another woman she can say, "Your vagina stinks! No man will want you!" Further, four respondents pointed out that it was critical for a woman to keep her underwear clean from discharge, which could bring on an infection. Another woman noted that it was also important that dirty underwear always be hidden out of sight in the laundry basket, never visible to any houseguest, who would think that the woman was dirty. Thus, notions of hygiene are tied to health, but also to a woman's perceived



desirability to men.

Further probing about why women must practice regular feminine hygiene revealed that cleanliness is one aspect of perceived desirability for men. The other very important aspect of the practices is the attempts of women to become *sere*, or tight, using various agents in different ways. Being tight also involved being dry, or controlling vaginal secretions, through the hygiene practices. Vaginal tightness was a concern of all 15 women interviewed, and they spoke of it directly in terms of sexual desirability for male partners. The following exchange is illustrative of the prominence of vaginal tightness to female desirability. The teenaged daughter of the woman being interviewed wished to sit in on the interview, which her mother, Angélique, invited. Angélique has been in the U.S. for five years. She works in housekeeping at a local resort hotel. The discussion surrounds the use of a particular chemical agent:

JM: You mentioned *pèmegenet* as something that women can use from time to time as part of their *twalet deba*. What does *pemegenet* do?

Angélique: *Pèmegenet* is very good to clean you out, especially after your period and after having a baby. And oooh it makes you *tight*! (holds index finger curled tightly into thumb to illustrate)

JM: Okay, so it cleans and it makes a woman tight. Why do you think women want to be tight?

Angélique: (smiles) Because! It is better for making love! Men want their women tight, my dear!

Daughter: What! Mom!

Angélique: (to daughter) How do you think I kept your father around for so long?

While Angélique pointed out that being tight was “better for making love,” she also cautioned against overuse of this particular agent: “But be careful, because it can make you burn inside if you use too much.”

The concept of vaginal infection is important to broader cultural constructions of gynecological health, as uncontrolled infections were thought by several women to give rise to *kansè nan matrix* or *kansè nan kol matrix* (uterine and cervical cancer). Nonspecific, self-diagnosed infections are generally viewed as the reason for any amount of vaginal discharge, whether actually the result of a clinically detectable infection or not. Women’s discourse on infections revealed that infections are believed to arise from four primary causes, which are not necessarily mutually exclusive, and derive from both biomedical and ethnomedical etiologic beliefs: 1) as the result of neglected feminine hygiene; 2) from sexual transmission; 3) wet or “dirty” underwear; and, 4) *chalè*, or heat.

Regarding neglected hygiene, all 15 women spoke of infection as a constant possibility, kept at bay only through regular cleansing, externally and intravaginally. Discourse about vaginal infections did not include mention of HIV, HPV or any specific sexually transmitted infection. However, sexual transmission was cited by 12 women as one method to get an infection, but the type of infection was not delineated. Eight women also related that wearing underwear that were *mwiye*, or wet (with vaginal secretions) was a sure way to get an infection: “You can’t wear wet culottes! That is dirty and you will get an infection that way.” Lastly, nine women also

related that infections can come from excessive heat entering the vagina, which could happen if a woman sat on a surface that had been heated by the sun, or sat down after someone who had left the seat warm upon leaving.

The following exchange illustrates this concept with an example.

Jacqueline has been in the U.S. for 7 years. She works as a gate security guard at a local resort hotel property.

Jacqueline: A woman must keep herself clean, you understand? I remember one time I was waiting for the bus. I sat down on the, the ...bench, to wait, and it was hot hot hot! I did not sit long, but long enough to give me an infection.

JM: I'm not sure I understand. Can you explain what you mean, how you got the infection?

Jacqueline: You see sometimes if you sit where it is hot, you know where the sun shine, or where someone else sit, you can get a *ti chalè* (little heat).

JM: A *ti chalè* where?

Jacqueline: Inside you! Then the infection start.

JM: So what did you do for the infection?

Jacqueline: I wash very good when I get home. I use the Dettol. It feels fresh, you know.

JM: What did the Dettol do?

Jacqueline: It stop my infection.

JM: How could you tell it worked?

Jacqueline: Because! You can see *des bêtes* on the cloth when you wash.

JM: *Des bêtes*? What do you mean?

Jacqueline: You know, *bêtes*. Like ants. Tou piti (very small). Bugs!  
That is the word!

These etiologic beliefs for vaginal infections, then, draw from ethnomedical disease constructs, where excessive heat is believed to induce infection. The following section examines the specific ways in which practices were done and the products women used.

### ***Reported Hygiene Methods and Agents Used***

All women were asked to describe the different methods used for intimate cleaning practices. All women explained that proper feminine hygiene included washing of the perineum followed by cleaning the vaginal canal. Washing can be done with a cloth, using hands and fingers, or a combination of these ways. Thirteen women stressed, however, that external washing was not enough, that a woman must wash inside the vagina to be clean. Nine women also mentioned vaginal douching using certain agents as another cleansing method. Cleanliness is gauged by the removal of vaginal secretions. All 15 women indicated that a woman is considered clean when the vagina no longer feels "slick," and when a finger or cloth squeaks when rubbed against the vaginal wall.

Moreover, all 15 women were asked when in life women start and stop the cleansing practices. Twelve women stated that cleaning is part of everyday hygiene from childhood forward, but that the use of feminine hygiene products and intravaginal cleaning usually begins when a girl gets

her first period, or when she becomes sexually active. The other three women associated the practices with the onset of sexual activity more generally. All 15 women indicated that older female family members (e.g., mother, aunt, sister) taught them how to use the cleansing products.

Based on information learned in the preliminary interviews, all 15 women were asked about specific agents including phytotherapies, chemicals and commercial products that were primarily liquid soaps. For each agent, all women were asked what the product is used for, how it is prepared, and where it could be purchased. Phytotherapies applied externally and in the vaginal canal were prepared primarily as decoctions, where plant parts (most often, leaves and roots) were steeped in boiling water. Some phytotherapies were prepared as infusions meant for consumption as a tea, with the purpose of cleansing and tightening the vagina. Table 27, on the following page, presents in order the most commonly recognized phytotherapies and their uses for gynecological health. It is important to note that the plant remedies presented in this table also have multiple medicinal uses in Haitian culture, apart from gynecological health. For example, *ti bonm* (yellow balsam) is well-known and used for a variety of non-serious conditions, such as colds or fevers. *Asowosi* (balsam pear) is also used as a tisane for fever and diarrhea treatment. Leaves of *sitwon* (lime) are steeped in water to make a tea to clean the intestine. Thus, all plants have multiple properties for a variety of illnesses.

**Table 27. Phytotherapies Used for Feminine Hygiene**

<b>Plant Name (Kreyol) (Scientific) (English)</b>	<b>Preparation Method(s)</b>	<b>Use(s)</b>	<b>Effect(s)</b>
<b>Ti bonm</b> <i>Croton flavens</i> Yellow balsam	Infusion & decoction of leaves	Infusion consumed as tea	Cleanse internally & externally & tighten
		Decoction for post- partum ritual ( <i>bain</i> )	
		Decoction for routine cleansing	
<b>Maskreti</b> <i>Ricinis communis</i> Castor oil plant	Infusion & decoction of leaves & stems	Infusion consumed as tea	Cleanse internally & externally
		Decoction for post- partum ritual ( <i>bain</i> )	
		Decoction for routine cleansing	
<b>Dlo sitwon</b> <i>Citrus aurantifolia</i> Lime juice	Juice extracted & diluted with water	External application	Cleanse, deodorize & tighten
<b>Asowosi</b> <i>Momordica charantia</i> Balsam pear	Infusion of leaves	Infusion consumed as tea	Cleanse and tighten internally
<b>Pwa kongo</b> <i>Cajanus cajan</i> Pigeonpea	Infusion & decoction of leaves	Infusion consumed as tea	Cleanse and tighten internally & externally
		Decoction for post- partum ritual ( <i>bain</i> )	
		Decoction for routine cleansing	
<b>Aloès</b> <i>A. barbadensis</i> Aloe vera	Decoction of leaves	Decoction for routine cleansing	Cleanse and tighten externally
<b>Kalbas kouran</b> <i>Crescentia cujete</i> Calabash tree	Decoction of leaves & poultice	Decoction for routine cleansing	Clean and tighten externally
		Direct application of leaves in poultice	

Ten of the 15 women grew their own plants for medicinal use. All women explained that if a plant was needed, women could ask local friends or family in neighboring cities or have it sent by family or friends in Haiti. I

also observed that many women rely on an informal network of sharing plant cuttings with other women to cultivate for personal use. During the course of fieldwork, I became involved in this informal sharing and acquired many medicinal plants, and in return, shared them with other women. Additionally, plant knowledge for therapeutic practice was generally passed from older to younger female family members, and among women friends. All 15 women consistently related that they would ask their mothers, aunts or grandmothers for advice about ethnobotanical remedy preparation and use when needed.

The reasons for the use of drying and tightening agents were reported as both for regular hygiene and for a post-partum practice women referred to as *bain*, or roughly, bath. A discussion of this ritual is important to include here, as virtually every woman mentioned the *bain* in explanations of intravaginal practices. Phytotherapies used for this ritual were often the same as those used for regular hygiene practices. Women stated that the purpose of the *bain* is to clean out the womb of any residual blood, to encourage the return of the organs to their original places, and to tighten the vagina. The ritual is supposed to be done within one month after childbirth.

During this ritual, a mixture of plant leaves is steeped in very hot water in a bucket. Commonly named plants used for the *bain* were, *maskreti* (Palma Christi, or *Ricinus communis*), *pwa kongo* (pigeonpea, or *Cajanus cajan*), *ti bonm* (yellow balsam, or *Croton flavens*). The leaves of the Palma Christi plant have important symbolic dimensions. First, literally meaning "hand of Christ," the leaves emerge in sets of five from plant stems, similar

to an open hand with spread fingers. Second, when the leaves are steeped in hot water, the water turns red. The use of this plant, then, to draw old blood out from the womb, appeals to the Doctrine of Signatures, or the notion that 'like cures like.'

During the *bain*, the woman sits on top of the open bucket to allow vapors from the steeped decoction to come into contact with the vagina and perineum. The healing vapors then help to draw out old, dirty blood and tighten the vaginal canal. A warm towel is placed on top of the woman's head to contain the heat within her body. The photographs of the phytotherapies below are from this ritual as done by one respondent, Margot, three weeks after she gave birth.

**Illustration 1: *Bain* Phytotherapeutic Preparation:  
*Ti Baum, Maskreti***



To complement the healing vapors provided by the steeped leaves, phytotherapies may be combined with the chemical, commercial, and



pharmaceutical remedies previously discussed. Use of other phytotherapies in the form of teas is also common post-partum, especially infusions *kanell* (cinnamon) and *jinjim* (ginger root).

In addition to phytotherapies for feminine hygiene practices, chemical compounds, a common household cleaner, and commercial cleansers and prescription pharmaceutical products were also noted by all 15 women. The following table depicts these items and their uses for feminine hygiene, in order of the most frequently named product.

**Table 28. Chemical, Commercial, Pharmaceutical and Household Products Named for Feminine Hygiene**

<b>Product Name (Kreyol) (Scientific) (English/Common)</b>	<b>Composition</b>	<b>Preparation Method(s)</b>	<b>Use(s)</b>	<b>Effect(s)</b>
<b>Pèmegenet<sup>1</sup></b> Potassium permanganate Condy's crystals	Crystals or granules	Dilute a pinch of crystals in glass of water	External and intravaginal wash	Tighten, disinfect
<b>Alum<sup>2</sup></b> Potassium aluminum sulfate Alum	Powder	Dissolve powder in water	External and intravaginal wash, douche	Tighten
<b>Borasol<sup>2</sup></b> (Brand Name)	Powder	Dissolve powder in water	Intravaginal wash & douche	Astringent, tighten
<b>Detto<sup>2</sup></b> (Brand Name)	Liquid	Dilute capful in glass of water	External and intravaginal wash	Deodorize, cleanse, antiseptic
<b>Akwomona<sup>3</sup></b> Metronizadole Acromona	Vaginal suppository	None	Suppository insert	Deodorize, tighten
<b>Vineg<sup>4</sup></b> Acetic acid Vinegar	Liquid	Dilute with water	External and intravaginal wash	Cleanse
<b>Hygisol<sup>2</sup></b> (Brand Name)	Liquid	Dilute with water	External and intravaginal wash	Antibacterial cleanser

<sup>1</sup>Commercially available chemical; <sup>2</sup>Commercially available brand product; <sup>3</sup>Prescription drug; <sup>4</sup>Common household cleaner.

Potassium permanganate, or *pèmegenet* in Kreyol, is a corrosive chemical compound that is also a strong oxidizing agent. A useful resource for understanding the potential effects of chemicals is a material safety data sheet (MSDS). These documents are designed for employers and personnel involved in industries where there may be exposure to potentially hazardous substances. They provide key information about a chemical's health hazards, reactivity, eye, skin and respiratory contact hazards, storage and disposal requirements, first aid and clean up procedures, among other information. The MSDS for potassium permanganate indicates it has a Health Rating of 3 (Severe, Life), a Contact Rating of 3 (Severe, Corrosive). The MSDS is replete with warnings calling for ventilation and protective wear when handling the substance, which naturally occurs in a dark purple crystal form (n.a. 2006). Potassium permanganate is an irritant to skin and mucous membranes (EPA 1999). It is used as a laboratory reagent in industry, a disinfectant for public water systems, aquarium fish infection control, and as a topical antiseptic for skin diseases (EPA 1999, Francis-Floyd and Klinger 2002, Programs for Appropriate Technology in Health 1988).

This chemical compound was the most commonly mentioned for use for tightening the vagina (n=13). Dilution of this agent in water creates a pink solution. These 13 women explained that this solution is applied internally in the vaginal canal, and externally to the perineum area. Regarding frequency of use, eight women noted that this product is "strong," and it should not be used more than once every week or less.

Women frequently compared potassium permanganate to the more

benign and common topical commercial antiseptic, Betadine®: "Pèmegenet? It's just like Betadine. It cleans you and pulls you all together nice and tight!" The perception that it is "just like Betadine" has very important public health implications. The misperception likely arises from the fact that each compound, when mixed with water, produces a colored solution ranging from pinkish red to pink to violet. Indeed, potassium permanganate is a compound capable of burning the skin on contact when undiluted; thus, it is quite different from the commercial Betadine® (povidone iodine) solution. Thirteen women related that they can purchase potassium permanganate from botànicas, or get it from friends or family who visit Haiti, or Miami, where it is more easily found. Potassium permanganate historically also been used in Haiti for the treatment of filariasis, as recommended by the World Health Organization (J. Coreil, personal communication, September, 25, 2008). Thus, it is possible that women's primary knowledge of this agent comes from this context. Potassium permanganate is also sold in commercial lawn and garden stores and some pet supply stores for its aquatic uses.

The next most commonly known product was alum (potassium alum sulfate) (n=11). An MSDS sheet for this chemical compound indicates a Health Rating of 2 (Moderate), and a Contact Rating of 2 (Moderate). These 11 women described this compound as a powder that is dissolved in water, and applied intravaginally using a finger or cloth, or administered through a douche. These women also discussed this agent as an astringent primarily used for vaginal tightening. Concerning frequency of use, like potassium permanganate, women cautioned against overuse since vaginal irritation

could develop. As one woman stated, "You cannot use that everyday like soap. No. That will make you burn! Maybe just before you will make love, or maybe two or three times a month that's all. It makes you pucker up tight!" (purses lips to illustrate, laughs).

Seven women showed me alum products during interviews in their homes. These products were made in the Dominican Republic and packaged in small, opaque plastic jars. These women indicated that they purchased alum at botànicas or at Haitian grocery stores. Alum powder, however, is widely available in the U.S. and has multiple applications both health and non-health related. For example, it is used as an astringent for abrasions, is the main ingredient in crystal deodorants, and is used as a preservative for foods (pickling). It is available for purchase in the spice aisle at grocery stores.

Borasol was the next most commonly known agent (n=10), and it is primarily made of boric acid, and known simply by the name borasol. Nine women described the use of this agent much the same way as alum, intravaginally and as a douche. Concerning frequency of use, these women stated that Borasol is a good product to use right after a woman's menstrual period, and that women use it as they feel the need for it. Five women who showed me their own containers, and invariably the brand was Dr. Collado Borasol Antiseptic Powder. This product, made in the Dominican Republic, is purchased in botànicas, Haitian grocery stores and is obtained in Haiti. An Internet search for the product revealed that it is available for purchase online through various online sellers of Caribbean goods and products. From

one such website (n.a. 2008), the product is thus advertised:

“Dr Collado Borasol Antiseptic Powder contains ingredients with an effective antiseptic, anti-inflammatory, antipruritic, astringent, refreshing and deodorizing action. USES: It is useful for cleansing and refreshing the internal vaginal areas, and can be used as a refreshing vaginal douche.”

Interestingly, the same Internet search yielded a recent Food and Drug Administration (FDA) document about this product (and other, similar products from that manufacturer), refusing its import as “unapproved.” The violation charge concerns the product claim as a drug, without a new drug application. This import refusal was issued June 17, 2008.

The next most commonly known product was Dettol (n=8), in liquid form. These eight women stated that a capful of the product can be diluted in a cup of water, and that solution is used for intravaginal cleansing using a cloth or finger. These women stated that this product could be used daily. Indeed, six women indicated they preferred this brand to other, similar products. For example, “I like the Dettol because it makes me feel fresh. It tingles.” A review of the products ingredients include chloroxylenol (an antibacterial) isopropanol (alcohol), and pine oil. The product has a distinctive disinfectant smell, like what can be found in some hospital settings. Women stated that they buy this product at Haitian or Caribbean grocery stores, or online. This imported product is made in the United Kingdom.

Following Dettol, the next most commonly recognized product (n=6)

was a prescription pharmaceutical vaginal suppository known as Acromona, which is its product name in its place of manufacture, the Dominican Republic. Five women indicated that use of this product should be reserved for odor control, and limited use was recommended because it causes extreme vaginal tightness. Three women who had the product in the household showed me the package, which had instructions and indications in Spanish. This drug is the generic form of the prescription brand Flagyl, or metronidazole, which is used to treat bacterial vaginosis and trichomoniasis, a sexually transmitted infection. Because it is a prescription drug, women indicated it was sometimes difficult to find at the two research sites. When needed, women stated they could ask a friend or relative to send it to them from Haiti or Miami. One other antibiotic, ampicillin, was mentioned by name by two women, taken orally for self-diagnosed vaginal infections.

The last most commonly known product among women (n=5) was Hygisol, a brand product manufactured in Haiti. The product's tag line is, "Solution bactericide pour l'hygiène" (Bactericidal solution for hygiene). These five women described that this product is used in the same way as Dettol and that choice of products was largely one of personal preference. An Internet search of Hygisol revealed that it, like Borasol, was issued FDA violations and unapproved due to no English-language labeling and no new drug application. This import refusal was issued January 9, 2008.

While this section described the agents that women use in feminine hygiene practices, the following section examines how such practices are distributed among women in Little Haiti, Miami, and the impact on

gynecological health.

### **Feminine Hygiene Practices and Cytological Outcomes**

As described in Chapter 6, ethnographic data from this research were used to help construct a 92-item survey (see Appendix F) administered to a non-probability sample of 246 Haitian women in Little Haiti, Miami. The survey was designed to assess women's hygiene practices in relation to cytology. Women who responded to the survey, then, also provided a cervical sample using a self-sampling device, which screened for HPV, gonorrhea, chlamydia and cervical abnormalities. A brief description of the sample demographic characteristics follows.

### ***Demographic Characteristics of Survey Sample***

All women in the sample are ethnically Haitian. Seven women were born in the U.S., and four women were born in the Bahamas. The remaining 235 women were born in Haiti. Kreyol is the primary language for 71% (n=174) of women. English and Kreyol are used equally by 23% (n=56) of women, and English is the primary language for 6% (n=16) of women. Age was collected as a categorical variable due to cultural norms surrounding asking women for their exact age. Instead, women chose from age categories. The distribution of age in the sample is depicted in the following table.

**Table 29. Age Categories of Women in Survey Sample, Little Haiti (N=246)**

<b>Age Category (years)</b>	<b>Frequency</b>	<b>Percent</b>
18-25	15	6.1
26-30	21	8.5
31-35	29	11.8
36-40	40	16.3
41-45	39	15.9
46-50	47	19.1
51-55	20	8.1
56-60	12	4.9
61-65	9	3.7
66-70	8	3.3
> 70	6	2.4
<b>Total</b>	<b>246</b>	<b>100.0</b>

Further, the majority of women in the sample very likely fall within federal poverty limits. Among women who responded to the question eliciting annual household income from all sources (n=183), 67% of them (n=123) indicated less than \$15,000. No women claimed household incomes higher than \$45,000 annually. Importantly, these reported annual household incomes likely do not reflect the actual amount of money available for household use, since families routinely send remittances to Haiti to support other family members (Laguerre 1998).

Regarding education, highest levels of schooling completed varied among women; however, the majority of women (70%, n=171) had a high school education or less. The following table depicts the education levels



attained by women in the sample.

**Table 30. Education Level Attained by Women in Survey Sample, Little Haiti (N=246)**

<b>Education Level Attained</b>	<b>Frequency</b>	<b>Percent</b>
Never attended school or only attended kindergarten	29	11.8
Grades 1-5	32	13.0
Grades 6-8	19	7.7
Grades 9-12	41	16.7
High School Graduate	50	20.3
Vocational school graduate	33	13.4
Some College	18	7.3
Associate degree in college	10	4.1
Bachelor's degree	13	5.3
Master's degree	1	0.4
Total	246	100.0

The majority of women in the sample were not in a cohabitating marital relationship (55%, n=135). These categories include divorced, widowed, separated, never been married and living with a partner. Approximately 45% of women (n=111) reported that they were married at the time of the survey.

### ***Healthcare, Health and Reproduction***

The vast majority of women (n=209, 89%) had no form of health care coverage. Exactly half of the women (n=123, 50%) reported that they had no regular source of biomedical health care. Concerning parity, the number of times women had been pregnant ranged from 0 to 12, mode = 3. The

number of full-term pregnancies also ranged from 0 to 12, mode = 3. Regarding Pap screening, 78% (n=193) women stated they have had a Pap test, 21% (n=51) women had never had a Pap test, and 2 women were unsure. Concerning biological samples, cytology showed 21 abnormal cases, ranging from more mild conditions to moderate dysplasia (CIN 2), which is less likely to be regressed by the immune system. HPV testing showed that approximately 21% (n=50) of women were infected with HPV; four samples were insufficient for HPV testing. Testing was also done for gonorrhea (1 case) and chlamydia (13 cases).

### ***Hypotheses***

This section presents the results of hypothesis testing using the survey data. Hypotheses were generated based on information from the literature and field observations. The hypotheses tested here are part of a larger, ongoing analysis of the survey data by an interdisciplinary team of social scientists, public health researchers and biological scientists. As such, these hypotheses focus on sociocultural factors and biological outcomes in relation to culturally mediated feminine hygiene practices. Of all women participants in the survey, approximately 31% (n=77/246) reported that they engaged in feminine hygiene practices. The first hypothesis tested is as follows:

**H<sub>1</sub>:** Women who have lived in the U.S. longer are less likely to engage in feminine hygiene practices.

This hypothesis attempts to assess the relationship between one level of acculturation (time lived in U.S. since immigration) and culturally defined feminine hygiene practices. An assumption is made that women have spent most of their time in the U.S. since their stated year of entry. Year of entry ranged from 1970 to 2007. Epidemiologic and acculturation researchers generally assess the health effects of length of time in the U.S. at 5, 10, and 15-year (or more) intervals to delineate potential health status differences by recent versus non-recent immigration (Barcenas et al. 2007, Koya and Egede 2007, Parker Frisbie, Cho, and Hummer 2001). Following that lead, two variables were created reflecting 5 and 10-year demarcations. These time markers were appropriate for this population, which is largely comprised of more recent immigrants (Zéphir 2004). A dichotomous variable was created to reflect categories of women who had entered the U.S. within the last 5 years, and those here longer than 5 years. The same structure was applied for a 10-year dichotomous variable. Hygiene practice was measured as 'yes' or 'no' based on women's self report. Among the foreign-born women in the sample (n=239), there was no statistical association between length of U.S. residency and taking part in feminine hygiene practices (for  $\leq 5$  years:  $X^2 = .330$ ,  $p = .566$ ; for  $\leq 10$  years:  $X^2 = .369$ ,  $p = .544$ ).

The second hypothesis tested is as follows:

**H<sub>2</sub>:** Women with higher education are less likely to engage in feminine hygiene practices.

Given that education level is usually related to health behaviors, and higher educational attainment is considered a protective factor in public health, I wanted to discern if women with higher educations engage less in traditional feminine hygiene practices. Education level achieved was collected in the survey as a categorical variable. Data were dichotomized into high school education and less, and more than high school for purposes of analysis. There was no association between educational level and self-report of whether or not women engaged in feminine hygiene practices ( $X^2 = .000$ ,  $p = .987$ ). Indeed, virtually the same proportions of women of lower (52/169, or 30.7%) and higher (23/75, or educational status took part in feminine hygiene practices.

The third hypothesis is as follows:

**H<sub>3</sub>:** Women who speak primarily or only Kreyol will be more likely to engage in feminine hygiene practices.

This hypothesis addresses one other area of acculturation, language, to assess its affect on whether or not women engage in feminine hygiene practices. A variable for language was created that dichotomized women into categories of those who only speak Kreyol and all others, which included women who spoke English and Kreyol in varying degrees. In this comparison, there was no significant association found between Kreyol-only speakers and feminine hygiene practices ( $X^2 = 2.35$ ,  $p = .125$ ). Another dichotomous variable was created for women who stated they spoke Kreyol more than

English, and all other speakers. This group was assessed against feminine hygiene practices. There was also no significant association ( $X^2 = .059$ ,  $p = .808$ ).

The fourth hypothesis is as follows:

**H<sub>4</sub>:** Women who have ever had a Pap test, or who have had a Pap test within the last three years, will be less likely to engage in feminine hygiene practices.

This hypothesis was tested to discern if having had contact with biomedical, gynecological health care is associated with whether or not women engage in feminine hygiene practices. Among women who had ever had a Pap test, there was no association with feminine hygiene practices ( $X^2 = .834$ ,  $p = .361$ ). No statistical association was found. Similarly, among those women who reported having had a Pap test within the last three years ( $n = 147$ ), there also was no association with feminine hygiene behaviors ( $X^2 = .384$ ,  $p = .536$ ). Again, no significant relationship was demonstrated.

The fifth hypothesis is as follows:

**H<sub>5</sub>:** Women who have STIs, including HPV, and who have cervical abnormalities, are more likely to engage in culturally mediated feminine hygiene practices.

This hypothesis tests the notion that the practices leave women more vulnerable to infection and abnormal cytology, by disrupting the cervical mucosa. Sexually transmitted infections were evaluated against feminine

hygiene practices in three separate ways: HPV infection (yes/no); gonorrhea and chlamydia only (yes/no), and all three STIs combined (yes/no). A variable measuring cervical abnormalities was created, which dichotomized cytological results into negative (no abnormalities) and positive. Positive cases included those that had precancerous conditions. Fourteen cases had cytological reports of ASCUS (Atypical Squamous Cells of Undetermined Significance), which means the results are considered mildly abnormal, but of unknown cause. Ten of these 14 cases were also HPV+; thus, those 10 were included as positive for cervical abnormality.

Regarding HPV infection only, there was no association ( $X^2 = 1.81$ ,  $p = .4$ ). Regarding cytology, there was no association between women's self-reports of feminine hygiene practices and positive or negative cervical abnormalities ( $X^2 = 1.57$ ,  $p = .2$ ). When examined with all STIs (HPV, gonorrhea, chlamydia), there also is no association ( $X^2 = .01$ ,  $p = .9$ ). However, when hygiene practices are examined with infection with chlamydia only, there is a strong association (Fisher's exact = .02). Among women infected with chlamydia ( $n=13$ ), 8 women (67%) reported engaging in feminine hygiene practices. The sixth, and final, hypothesis is as follows:

**H<sub>6</sub>:** Women with high-risk HPV infection will be more likely to engage in culturally mediated feminine hygiene practices.

This hypothesis tests whether or not there is an association between HPV infection type and feminine hygiene behaviors. A dichotomous variable

for HPV type was created, where all cases with high-risk HPV infections were grouped against cases infected with low-risk HPV types. There was no statistically significant association between HPV infection type and feminine hygiene practices ( $X^2 = 1.88, p = .17$ ).

## **Discussion**

Women's engagement in feminine hygiene practices is tied to constructs of health, in which cleanliness is a critical component. Similar feminine hygiene practices have been reported in Africa to contribute to increased risk of HIV transmission (McClelland et al. 2006). It is plausible that such a practice may also contribute to the transmission of HPV, the virus responsible for the vast majority of cervical cancer cases. Given that cervical cancer is the primary cause of cancer deaths in Haitian women, this practice warranted a more in-depth examination for a possible link to the excess cervical cancer disease burden and mortality. Part of this examination entailed obtaining detailed ethnographic information about products women used. The agents women used were commonly known, and how the cleansing practices were done were similar.

One plant, *Palma Christi (Ricinis communis)*, is reported for use in a post-partum practice intending to help remove dirty, residual blood from the womb. This plant has been found to be used to treat another blood-related culture bound syndrome in Martinique (Meyer 1998, Vilayleck 1996). In that cultural context, the plant was used for a culture bound syndrome locally called *le blès*, or roughly, injury, in which a sudden shock or fright (most

often among children and adolescents) causes blood to pool and harden in the thorax. A poultice that includes plant is used to help dissipate the pooled blood.

In addition, this chapter explored relationships between sociocultural factors and biological outcomes with culturally mediated feminine hygiene practices. Surprisingly, the majority of women (n=169, 69%) stated that they did not engage in feminine hygiene practices. Modesty about discussing this topic may have been an issue; however, to account for that possibility, the women asking the survey questions were ethnically matched and were from the same community. Additionally, given the strong cultural standards of women's hygiene, it is surprising that women in the sample would admit to not engaging in any practice. Concerning time spent in the U.S., the fact that no association was found with feminine hygiene behaviors may be a function of the women not truthfully answering the question or of how the CHWs who administered the survey posed the question. The question was literally translated into Kreyol, and asked directly about engagement in practices that aimed to preserve vaginal tightness and cleanliness: *Eske gen yon bagay ou konn fè pou vajan w toujou rete pwòp/toujou rete sere?* (Are there things you know about to use for keeping your vagina clean and tight?). This wording may have confused women, or it may have been too personal and too direct. Instead, if it were asked using the terms women themselves use, which refer to hygiene and tightening is implicit, the number of women who answered affirmatively to engaging in feminine hygiene practices would have likely been much greater. For example, posing the question this way may



have been more clear: *Eske ou fè twalet deba?* (Do you do twalet deba?) followed by, *Kouman ou fè twalet deba ou?* (How do you do your twalet deba), for verification that the question asked means the same thing to researchers and survey respondents. The same effect may have occurred, where the question was inappropriately posed, when examining associations with education level, language (Kreyol only, Kreyol more than English), and Pap test behaviors, where no association was found. Lastly, the lack of association of feminine hygiene practices with education levels, or other demographic variables, runs counter to what is observed for other health behaviors cross-culturally. The underlying reason for the practices, which is to enhance vaginal tone and dryness for the purpose of being pleasing to male partners, should be explored further in the context of a response to partner infidelity, or the possibility of partner infidelity, which was a topic frequently mentioned by women in interviews. That is, the extent to which these health behaviors may serve as efforts to control or modify sexual behavior of male partners may prove fruitful for understanding on an emic level why women engage in the practices, and why the practices do not seem to vary across social classes.

Regarding biological factors, infection with chlamydia was highly significantly associated with feminine hygiene practices, whereas infection with HPV, gonorrhea and having abnormal cervical cytology were not significantly associated with hygiene behaviors. Because the data are not prospective, it cannot be discerned that feminine hygiene practices lead to increased risk of STIs. This association was found with prevalent STIs.

Another possible explanation is that women with STIs will have more vaginal problems, which may, in part, drive the feminine hygiene practices.

Concerning infection with high-risk, oncogenic strains of HPV, there was no significant association with reported hygiene behaviors; however, more women with HR-HPV strains (n=9) than low risk strains (n=5) took part in feminine hygiene practices.

## **Summary**

This chapter presented the findings from assessments of women's understanding of Pap tests, HPV as a cause for cervical cancer, and knowledge about the Gardasil® vaccine. Findings from interviews with physicians were presented to provide their perspective on important health issues in the Haitian community, and the position of cancer in the broader picture of health concerns. Gender and power were examined in the context of culturally patterned sexual unions, and their influence on women's hygiene practices. The role of fibroids in cervical cancer ethnomedical beliefs was discussed. Additionally, the reasons for hygiene practices, and the agents women use, which include phytotherapies, chemical compounds, commercial products and prescription drugs were examined in detail. Lastly, preliminary analyses of survey data were presented to better understand relationships between demographic characteristics and hygiene practices, and the effects of practices on gynecological outcomes.

The following chapter concludes this research, providing a discussion that synthesizes the research findings and contextualizes cervical cancer in

Haitian women's lives. The implications for public health and clinical practice are examined, and recommendations are made for additional research.

## **CHAPTER 9**

### **CONCLUSION**

#### **Introduction**

This concluding chapter summarizes and synthesizes the research findings in a discussion that relates findings to the literature and situates cervical cancer in the broader social structural and cultural contexts of Haitian women's gynecological health and relationships with men. The public health implications of this research are presented. This chapter also offers recommendations for public health application, in the forms of epidemiologic study and health education, and recommendations for application to clinical practice settings. Finally, the contributions of this study to anthropological theory and applied anthropology are discussed, and recommendations for applied medical anthropologists are also offered, in the context of working with community based organizations.

#### **Findings in Relation to Historical and Contemporary Literature**

The findings in this research resonate with themes in historical and contemporary literature on Haitian health beliefs, gynecological health and health behaviors, and historically patterned male-female relationships. A review of archival literature from biomedical gynecology revealed interesting

parallels in historical and contemporary agents used intravaginally, as prevention and treatment for a variety of gynecological conditions, both real and imagined. Two commonly-used agents in historical gynecology (e.g., aluminum potassium sulfate, potassium permanganate), are also used by Haitian (and other Caribbean) women today for hygiene and tightening effects.

In addition, etiologic explanations for gynecological conditions in the archival literature drew from humoral theory, which also informs contemporary Haitian women's etiologic beliefs about cervical cancer and other illnesses. Indeed, it has been observed and documented that humoral theory has been adapted and reconstituted in various Caribbean cultural contexts as a reference for understanding general health and illness (Foster 1993, Laguerre 1987a, Payne-Jackson and Alleyne 2004, Quinlan and Quinlan 2006). The historical contexts in which cultural constructions of feminine hygiene have been adapted and reconstituted over time are also heavily steeped in gender and power relations that relegate more power to men. An awareness of historical processes, power and gender forces consideration of how these elements may become embodied as negative gynecological health outcomes.

Other findings from this research are also consonant with more recent published medical anthropological and public health literature in several ways. For example, beliefs about heat (*chalè*) and cold (*fredi*) imbalance and subsequent illness found in this study are noted in several studies of Haitian ethnomedicine and belief systems (see: Adonis-Rizzo and Jett 2007, Brodwin

1996, Coreil et al. 1998, Laguerre 1981, Minn 2001). In addition, women's beliefs about fibroids as a very serious condition, sometimes the result of an arrested pregnancy, have been documented in the literature as a culture bound syndrome called *pedisyon*, or arrested pregnancy syndrome (Coreil et al. 1996, Murray 1974, Singer, Davison, and Gerdes 1988). Women in this study shared the view that fibroids are a grave illness, adding that improper or lack of treatment of fibroid tumors may lead to cancer.

Further, the association of sent illnesses and traditional healers with morality in Haitian culture has been described at length by other researchers (Brodwin 1992, Brodwin 1996, Farmer 1988). In this association, morality is bound with perceptions of jealousies, or personal or familial wrongdoing, which may manifest as illness. Additionally, the choice of healer carries moral implications, in which consultations and treatments from Vodou practitioners (e.g., manbo, houngan, bokor), may signal to others that the illness victim (or family members) did something to bring the illness upon the victim. Consultations with such practitioners are also often perceived as actions that run counter to Christianity, as they are perceived to serve the spirits (*lwa*), who give them their healing power. Thus, morality is linked with illness not just by the type of affliction, but also by choice of healer. Findings from this study include moral dimensions of cancer and cervical cancer etiology, which are traced to poor hygiene, promiscuity, and as *ekspedisyon* (sent sickness) particularly from a husband or partner's mistress. The majority of women in this study also cautioned against consulting with Vodou practitioners, because they can heal but also harm.

In addition, the Haitian ethnomedical system in place at the two research sites in this research largely mirrors the pluralistic Haitian ethnomedical system described in the literature. Laguerre (1984), in a discussion of Haitian immigrants in New York City, describes health beliefs that fall along Foster's (1979) naturalistic/personalistic dichotomy of disease causality. Disease causes guided treatment choices and resorts to both folk and biomedical sectors. While this dichotomy exists, it is not rigid in determining health behaviors. To illustrate, my research findings of women attributing fibroid causality to *fredi* (cold) or a failed pregnancy invariably required surgery as treatment (biomedical sector) complemented with teas (ethnomedical sector) to finish cleaning the womb. Thus, women will often simultaneously seek therapies in each sector.

There are few published studies that address cancer beliefs or knowledge among Haitian immigrant women. Of those that are published none specifically detail cervical cancer (Consedine et al. 2004, David et al. 2005a); however, findings from this research still resonate with results described in those studies. To illustrate, Consedine et al. (2004) assessed breast cancer knowledge and belief differences across ethnically distinct populations, including Caribbean and African American women, Eastern European immigrant and U.S.-born white women, and Hispanics. In that study, Haitian immigrant women held the strongest beliefs that cancer could be caused by chemicals in food, or from a bruise or sore, that cancer was nearly always fatal and God determined disease outcomes. Women in that study also indicated that biomedical cancer treatments were as dangerous as

the disease itself. My findings were parallel in that cancer fatalism was a constant, women emphasized God and prayer as necessary for healing, and that chemicals (preservatives and pesticides, specifically) in food were thought to cause cancer.

In Boston, David and colleagues (2005) combined epidemiologic and ethnographic methods to contextualize breast cancer impact, experiences and cultural knowledge among Haitian immigrant women in that city. They found a cultural model of cancer that emphasizes fatalism, a general lack of understanding of mammography purpose, and significant delays in both screening and follow-up for treatment. Cancer fatalism and incomplete understanding of mammography screening are similar to my research findings about fatalism with any type of cancer, and a general lack of understanding of Pap test purpose.

Findings from my research indicate that cultural patterns of male-female relationships, including *plasaj* (co-habiting, but not legally married) and the tendency for men to have multiple female partners, exist and are common among the women interviewed for this study. Women frequently described male infidelity as an inevitable, difficult part of life that Haitian women face. Indeed, the majority of women (n=12/15; 80%) stated that male infidelity effectively crosses social class and education lines; that is, it is not limited to one social class. The anthropological literature has documented *plasaj* and its related relationship patterns for decades, and more recently, its contribution to women's health risks for HIV (Comhaire-Sylvain 1958,



Fitzgerald et al. 2000, Malow et al. 2000, Maternowska 2006, N'Zengou-Tayo 1998, Simpson 1942, Ulin, Cayemittes, and Gringle 1996).

Lastly, findings from my research are congruent with those of other researchers who recently examined feminine hygiene practices in Caribbean immigrant populations in the Bronx, New York, in efforts to reduce douching practices (Anderson et al. 2008). These researchers found that women used intravaginal agents such as potassium alum sulfate (alum), phytotherapies (aloe, peppermint) and imported commercial bactericide products for hygiene, drying and tightening purposes. Prescription antibiotics, in vaginal suppository, intravaginal gel and pill forms, were also commonly used by women to treat self-diagnosed conditions. My research also shows that Haitian women in Florida are using these same products, for the same reasons, in addition to other agents that are perhaps unique to France and Haiti (commercial products, phytotherapies). Similarly, my findings echo those described in an unpublished paper on feminine hygiene practices among women in Little Haiti (Wingerd and Page 1994). Women in that study described the hygiene practice of *twalet deba* (intimate cleaning) as involving the same variety of intravaginal agents described by women in my sample. The reasons given for the practice, which were for cleaning, drying and tightening, were also consistent with the reasons women I interviewed gave for the practice.

### **Implications for Interdisciplinary Public Health Application: Epidemiologic Study**

Epidemiologic study of women's risk of cervical cancer (and other illnesses that result from STIs) must be informed by anthropological observations of culturally sanctioned male-female relationship patterns, and women's gynecological health beliefs and behaviors. These observations situate risk in a broader context, which helps elucidate pathways of transmission, and the reasons why such pathways exist. Additionally, further study of gynecological health and culturally mediated feminine hygiene practices is warranted, given that epidemiologic evidence between the practices and cervical cancer and other gynecological health outcomes is inconsistent. For example, douching and the use of drying agents are associated with an increased risk of contracting sexually transmitted infections (Annang, Grimley, and Hook 2006, Fonck et al. 2001, Gresenguet et al. 1996, La Ruche et al. 1999, McClelland et al. 2006, Myer et al. 2005). Douching is also associated with preterm labor and low birth weight (Cottrell 2006, Misra, Trabert, and Atherly-Trim 2006). The associations are complex and not fully understood, in part due to cross-sectional study designs, which do not assess exposure and disease outcome over time, precluding causal relationships to be established.

Prospective studies allow for a temporal association to be evaluated between a potential cause and health outcome; however, these study designs are complicated by social factors that also bear upon human health, including poverty and gender inequality. The results of these studies are also inconsistent. For example, McClelland and colleagues (2006) completed a 10-

year prospective cohort study among women sex workers (n=1,270) in Kenya to evaluate the role of intravaginal practices and incident HIV-1 infection. These researchers did find an association between intravaginal washing using water and using water and soap, and incident HIV infection. Women who also used soap were at an increased risk for contracting HIV. In contrast, Myer and colleagues (2006) conducted a 2-year prospective cohort study among women in South Africa, and they found an association between intravaginal cleansing practices and *prevalent* but not incident HIV cases. These researchers suggested that HIV-positive women tend to have more vaginal infections and secretions, which may drive intravaginal hygiene practices. The remaining published study on this topic, by van de Wijgert and colleagues (2008), describes a multicenter, 2-year prospective cohort study among women in Uganda and Zimbabwe to assess relationships among intravaginal practices, bacterial vaginosis (BV), yeast infections, inflammation and HIV. In their findings, intravaginal washing was not associated with HIV acquisition. Inflammation also was not associated with incident disease. However, women who had BV or yeast infections were more likely to acquire HIV. Thus, these washing practices may indirectly contribute to HIV acquisition by upsetting vaginal flora, resulting in other infections (BV and yeast), which increase susceptibility to viral infections.

While these studies primarily examined HIV, it is plausible that the practices could contribute to increased HPV acquisition for many of the same reasons: lowered immunity due to STD co-infections, and inflamed and damaged vaginal and cervical epithelium from intravaginal agents. Unlike

HIV, HPV requires only skin-to-skin contact to be sexually transmitted. This easy transmissibility may be exacerbated by practices that further expose epithelial cells to the various virus strains. Theoretically, it is also epidemiologically plausible that such practices could, in part, account for high rates of cervical cancer in populations of women where intravaginal practices, for drying, tightening and/or hygiene purposes are reinforced by culture. This ethnographic research informed epidemiologic investigation of feminine hygiene practices, as well as, laboratory investigation of the specific effects of ethnomedical agents on cervical cell lines. Preliminary laboratory results indicate that, after application for a 24-hour period, ectocervical epithelial cells die, which may result in a more severe effect of the agents on cervical cells, when the endocervical mucosa is exposed. These results also indicate a strong inflammatory effect of the agents on cervical cells, which may act synergistically with HPV to produce carcinogenesis. While these findings are preliminary, they may have important implications for a possible link between increased risk of cervical cancer and the use of plant-based and chemical agents for feminine hygiene, drying and tightening.

In global and national perspectives, Haitian women bear a significantly disproportionate burden of mortality due to a cancer that is highly successfully treated through early detection. Prospective studies of cervical cancer in Haitian women – in the U.S. and in Haiti - are needed to better understand the reasons for the excess cervical cancer incidence and mortality in Haitian women. This type of systematic inquiry is needed to tease out potential relationships between gynecological health practices and increased

risk of developing cervical cancer, and other relationships relating to problematic access to screening and timely follow-up medical care. Such studies will serve to inform intervention development for gynecological health education, for care providers, women and their male partners, and for cervical cancer screening.

Further, epidemiologic inquiry in this area would be well served by complementary theoretical perspectives from medical anthropology, including biocultural theory, political economy and political ecology. Culturally mediated feminine hygiene practices are clearly impacted by multi-level influences, including ethnoetiologic beliefs about gynecological health and structural obstacles that impede or delay access to the formal healthcare system and to timely follow-up after screenings. It is also critical to examine the contributions of historically embedded gender and power relations to women's health, in which women have traditionally not held the same rights as men in Haiti. Included in these relations are historically patterned sexual unions where men have multiple women partners simultaneously, and unequal treatment of women in the justice system (Gardella 2006). These inequalities manifest in social interactions at the household and family levels. Applying a biocultural approach, then, widens and situates understanding of how women's hygiene practices play out in a broader social context. This approach allows for gynecological health and illness to be understood as the women, themselves, understand them, and for connections to be made to larger societal structures that help to shape women's health outcomes.

In addition to applying complementary theoretical approaches and

methodologies from medical anthropology, it is recommended that epidemiologic studies also incorporate community based participatory research (CBPR) strategies into study designs. The topic of gynecological health is a sensitive one for research in traditionally socially marginalized communities. Rapport and trust must be building blocks for any research projects investigating gynecological health. CBPR is increasingly applied in public health interventions and is even required for specific projects funded by research agenda-setting institutes and foundations. CBPR methods incorporate community perspectives, concerns and assistance across the spectrum of intervention, from conception to evaluation (Leung, Yen, and Minkler 2004, Minkler 1997). Some CBPR tenets include forming Community Advisory Boards to guide research collaborations and questions, and hiring and training people from the community to collect data and conduct outreach . This collaboration helps to foster rapport between academic and research institutions and community based groups, paving the way for additional action-oriented research projects directed at attenuating health inequities (Wallerstein and Duran 2006, Yonas et al. 2006).

Using a CBPR approach, findings from this research can inform the development of an intervention that addresses education about cervical health and cancer prevention, as well as, the potential harm of the uses of agents for feminine hygiene, drying and tightening purposes. Health-focused and women-centered CBOs should be involved as partners in the development and implementation of a women's health educational program. These CBOs can advise the best ways in which to involve Haitian men,

specifically to address culturally mediated perceptions of what constitutes female hygiene, and to provide education about the potential problems for men that occur during dry sex, including abrasions, which can increase STI risk. Importantly, all partners involved in intervention design must understand the underlying issue of women's economic dependence on men, which is often negotiated in sexual relationships.

In sum, sophisticated, interdisciplinary study designs are necessary to tease out relationships of causality. Such designs should incorporate ethnographic methods, including participant observation and in-depth interviewing. Doing so will increase content validity of survey items, including assuring that the questions that are asked mean the same thing to both researchers and survey respondents.

### **Recommendations for Public Health Practice: Health Education**

An informed understanding about feminine hygiene practices, and their place in Haitian culture, is critical for effecting meaningful public health education and intervention. Power and sociocultural dimensions of male-female relationships are central to women's health, as are syncretic beliefs about gynecological health and cancer. Education about gynecological health and cervical cancer screening must be developed with these factors in mind. For example, health education programs should address the complexities of ethnomedical beliefs about cervical cancer etiology, e.g., the sent sickness/'male-partner-as-vector' transmission dyad. Importantly, elements of sexual transmission appear to be recognized, yet dangerously, men are

thought to be free of disease once it is passed on to the woman. As a result, interventions must be multifaceted, and address the needs of both men and women.

Feminine hygiene practices may be construed as “maladaptive” health behaviors, due to demonstrated undesirable effects of engaging in feminine hygiene practices. However, keeping in mind Singer’s (1996) call for caution in using evolutionary concepts in explaining human behaviors (Singer 1996), this research recognizes that a combination of power imbalance in male-female relationships, and cultural perceptions of women’s health, guide and generate these behaviors. Whether the behaviors are thought of as maladaptive, or, essentially harmful, the social context in which they occur and are sustained is explicitly recognized and not reduced to a matter of biological adaptation. Consequently, educational interventions must specifically address culturally sanctioned feminine hygiene practices and behavior change in ways that are informed by the women themselves, and consonant with women’s values. That is, coupled with education, suggestions must be made for culturally acceptable alternatives to potentially harmful health behaviors. Any type of intravaginal practice has the potential to disrupt the balance of the vaginal environment and result in an increased risk of bacterial vaginosis and STIs. As a result, the suggestion of an alternative practice may necessarily be radically different from the current methods used by Haitian women. A suggested replacement practice should address both issues of hygiene and vaginal tightness, yet preserve the natural vaginal flora. A focus on external (perineum) washing only, combined with Kegel



exercises for tightening, might be one potential suggestion. Lastly, health education efforts to increase Pap test screenings in the Haitian community must also be informed by perceptions of effects of the Pap test on vaginal tone, and the potential of air entering the body causing *gaz* (gas), which can move throughout the body and cause pain (Laguerre 1981).

Furthermore, with regard to access to the formal health care system, it is critical to link women with timely clinical follow-up care when indicated. The issue of access to care is too frequently an afterthought in public health education interventions. Women must be able to act on the educational messages they learn about screenings. Action solutions may include developing partnerships with a variety of clinics and hospitals, which can treat patients *pro bono*, or otherwise serve as contracted partners who may receive a portion of grant funding to cover patient costs. In short, education must accompany access, when interventions are developed using a partnership framework to correct health inequities.

Moreover, health educators should be aware of moral and psychological aspects of discussing cancer, and especially, cervical cancer, as specific oncogenic strains of HPV, a sexually transmitted virus, comprise the primary etiologic factor in the disease. At the time of this writing, public health media advocacy strategies are being employed to educate women about Gardasil®, the only FDA-approved vaccine currently available in the U.S. market. An English-language media advocacy approach is limited for many immigrant communities, which may have low English proficiency, but it may serve as a springboard for further education in both public health and

clinical encounters, where women can learn about immunization options. Importantly, however, educators must be aware of the potential for stigma, while working with Haitian women in educational efforts for HPV and cervical cancer. In explanation, the word *virus* carries with it the infamous and damaging history of an entire nation of people falsely labeled as “risk factors,” and, HIV and HPV are similar-sounding abbreviations. Thus, *virus* is a loaded concept, imbued with painful meaning in the collective consciousness of Haitian people. Action solutions may include using ethnographic methods to learn from key respondents how best to talk about sensitive topics such as cancer and gynecological health, in ways that are consonant with how Haitian women discuss the topics. Health educators must also receive training that encompasses not only the health and technical components of cervical cancer, but also instruction in the social meanings and consequences of gynecological illnesses and cancer in the context of culture.

Lastly, it is critical to successful public health outreach and education to partner with local CBOs and media (e.g., radio, television), which serve the communities of interest. These organizations employ individuals who are experts at knowing how to best reach the wider community. Such organizations will also guide the creation of more effective educational materials, as organization employees and volunteers often live and work in the communities they serve. People from these organizations know the community’s communication preferences, language proficiencies and literacy

levels.

### **Recommendations for Clinical Practice**

Given that Haitian women have a high rate of cervical cancer incidence and mortality (Lewis 2004), clinical practitioners must be aware of the burden of disease in this population. Additionally, it would be useful for clinicians to be aware of the potential for patients engaging in feminine hygiene practices that may have adverse effects on gynecological health, including the post-partum *bain*, and the potentially harmful agents women may use. One limitation of this study was that physicians were not asked about their knowledge of feminine hygiene practices among their patients. Given the potential harm to cervical cells, and resultant effects on cytology, physicians need to know about the practices and how to ask their patients about the use of agents for hygiene, drying and tightening purposes. Importantly, clinicians need to understand, as well, the context from which behaviors arise and are sustained, and refrain from passing judgment on patients. Clinicians should ask women patients explicitly about the use of ethnomedical therapies, in order to more fully understand what measures women are taking to maintain health or to attempt treatment for self-diagnosed gynecological problems, including non-specific infections. This includes asking about agents that women may use for feminine hygiene.

Furthermore, it is also important that non-Haitian clinicians treating Haitian patients understand that culture is not monolithic. Culture provides a cognitive blueprint for beliefs about illness causality and health related

behaviors, but such behaviors are not rigidly predictable. For example, beliefs about illness causality may vary significantly, especially by education level and according to elements associated with acculturation, e.g., longer length of time in the U.S., English proficiency, etc. Women's actions to maintain or regain health, then, may also vary – not every woman will use home remedies, in spite of their common usage in the population as a whole. Additionally, while feminine hygiene practices may be common in the population as a whole, not all patients will engage in the practices. Cultural competency, then, must go beyond a culture trait-list approach, and recognize the influences of education, social class, history and gender relations on women's health.

Findings from my research suggest that women do not clearly understand the purpose of an annual gynecological exam. Clinicians must recognize that while women may faithfully get Pap screenings according to recommendations, women may not fully understand the purpose of the Pap test. For example, women may not know what is and is not being tested (i.e., any STI). Additionally, other aspects of a gynecological exam, including the bimanual exam, may not be understood. Other researchers have demonstrated similar findings in Latin American contexts (Calvo 2005, Gregg 2003, Hunter 2004). Consequently, prior to and during an exam, it is recommended that clinicians clearly explain, in plain language, the purpose of the entire gynecological exam, and what they can expect to happen during and after their visit. Explanations must be clear so that women do not mistake the routine gynecological exam for a comprehensive exam that tests

for all STIs and gynecological problems. Additionally, it may be reassuring to women if clinicians communicated, again in plain language, that the use of a speculum during the exam will be short in duration, and will not compromise vaginal tone, or allow air to enter the body. Again, findings from this research clearly indicate women's concern with vaginal tone, and any activity that could decrease tightness may translate to a measurable threat to their relationship with their partner or husband, and potentially as a consequence, their economic survival or immigration status. A medical interpreter may be needed, depending on language proficiency.

### **Contributions to Anthropology: Theory and Application**

This research was guided by a biocultural theoretical paradigm, which incorporates cultural and material approaches, and critically situates health and illness within a broader social context. For my research, this positioning is essential to illuminate the ways in which gynecological conditions manifest and are managed, and impact the lives of Haitian immigrant women. In effect, the concept of culture is unpacked to reveal gendered historical processes that continue to leave their mark on women's bodies. This guiding paradigm, then, allows the health consequences of the forces of social structure, and contributions of culture, to be traced to the level of the individual.

Concerning application, this research contributes to growing interdisciplinary dialogue on and attention to the importance of disaggregating data to assess intracultural variation in common U.S. ethnic categories used for social and public health research purposes. Combining

distinct populations, based on “race,” masks important variation in health behaviors, risks, and outcomes. Because cervical cancer disproportionately affects women from developing countries, this research will provide important comparative information for a more comprehensive understanding of its impact on women, families and social organization in a variety of immigrant communities in the U.S. Additionally, theory-driven, applied components of this research incorporate a community-academic collaboration with local Haitian-directed community based organizations. The community based organizations will use these research results to help in the development a cervical cancer intervention to be implemented in the communities they serve.

This research also adds to the contributions of medical anthropology to cancer disparities, in collaboration with an epidemiologic study, to learn about Haitian immigrant women’s gynecological health beliefs and behaviors on a larger scale. Ethnography was useful to assist with the development of a survey, which was administered together with a self-sampling device for cytology and STI testing.

### **Contextualizing Cervical Cancer Beliefs and Health Behaviors**

As demonstrated in this ethnographic research, cervical cancer is inextricable from the broader social context of Haitian women’s lives and health, in which a large significance is attached to personal hygiene and dimensions of personal morality. Culturally mediated feminine hygiene practices are deeply connected to maintaining a sense of desirability and

preserving relationships with men, for economic survival, emotional and possibly immigration status reasons. Cultural beliefs about illness causality are woven with social, historical and biomedical influences, resulting in ethnoetiologic models about cancer and cervical cancer that do not neatly attribute cancer to either naturalistic or personalistic causes, but instead allow for multiple reasons for causality. These reasons cluster in exogenous and endogenous domains of causality, which are also framed within humoral understandings of disease. The exogenous domain includes sexually transmitted infections (but not HPV, specifically), as a naturalistic explanation of cervical cancer causality that draws on biomedical influences. The exogenous domain also includes the personalistic cause of cervical cancer as a sent sickness, put upon a woman by her partner's mistress, most often using a powder or liquid obtained from a houngan or manbo. The endogenous domain of cervical cancer causality is comprised of moral and constitutional categories. The moral category of reasons includes poor feminine hygiene, which invariably results in self-diagnosed *infeksyon* (non-specific infection), or non-specific infections resulting from hot/cold imbalance, and promiscuity. A constitutional reason given for the development of cervical cancer is *fibrum* (uterine fibroids), which can become cancerous over time if they are not surgically removed. This perception may be due, in part, to women associating malignancy with the biomedical term, "fibroid tumors," which are actually benign. The other constitutional reason given was heredity. The perception of heredity as a cause of cervical cancer

may be the result of women witnessing suffering and death of kin who had cervical cancer, or seeing other families impacted by this disease.

## **Summary**

This research contributes to a growing body of interdisciplinary health research, including research that aims to unpack social causes of disease that result in population health disparities. This research also contributes to medical anthropological inquiry into the ways that historically embedded gender relations create unequal power dynamics in male-female relationships, and have a marked impact on women's health. In the context of Haitian immigrant women in Florida, gynecological health and illness, including cervical cancer, are inextricably bound to relationships with men. Men's expectations of women to be *prop* (clean) and *sere* (tight), and women's dependence on men for economic and immigration reasons, encourage feminine hygiene practices that ultimately compromise women's gynecological health. The intersections of social structure and culture, which include unequal gender relations and history, were examined for their contributions to Haitian immigrant women's cultural constructions of gynecological health and illness, and for their collective impact on women's health and lives.



## REFERENCES CITED

- (ACCP), A. f. C. C. P. 2004. *The Case for investing in cervical cancer prevention*. ACCP.
- (ACS), A. C. S. 2004. "Detailed Guide: Cervical Cancer," vol. 2005, pp. General website with specific information about cervical cancer risk, etiology and treatment.
- (ARHP), A. o. R. H. P. 2005. Cervical Cancer Prevention and HPV DNA Testing: Targeting High Risk Virus Types. *Health & Sexuality* 10:Special Issue.
- ACOG. 2004. "Revised Cervical Cancer Screening Guidelines Require Reeducation of Women and Physicians: All Women Should Have an Annual Pelvic Exam But Not All Women Need Annual Pap Tests," vol. 2007, pp. Press release of guideline change.  
[http://www.acog.org/from\\_home/publications/press\\_releases/nr05-04-04-1.cfm](http://www.acog.org/from_home/publications/press_releases/nr05-04-04-1.cfm): American College of Obstetricians & Gynecologists.
- ACS. 2008. "Noni Plant," vol. 2008, pp.  
[http://www.cancer.org/docroot/ETO/content/ETO\\_5\\_3X\\_Noni\\_Plant.aspx](http://www.cancer.org/docroot/ETO/content/ETO_5_3X_Noni_Plant.aspx): American Cancer Society.
- Adler, S. 1999. Complementary and alternative medicine use among women with breast cancer. *Medical Anthropology Quarterly* 13:214-222.
- Adonis-Rizzo, M. T., and K. F. Jett. 2007. Health Beliefs of Haitian Elders Related to Influenza Prevention. *Public Health Nursing* 24:18-25.
- Al-Hendy, A., and S. A. Salama. 2006. Ethnic distribution of estrogen receptor-alpha polymorphism is associated with a higher prevalence of uterine leiomyomas in black Americans. *Fertility and Sterility* 86:686-693.
- Allman, J., and S. N. Allman. 1987. Women's status and family planning in Haiti. *International Journal of Sociology of the Family* 17:109-20.
- Anderson, M. R., D. McKee, J. Yukes, A. Alvarez, and A. Karasz. 2008. An investigation of douching practices in the botánicas of the Bronx. *Culture, Health & Sexuality* 10:1-11.
- Annang, L., D. M. Grimley, and E. W. Hook. 2006. Vaginal Douche Practices Among Black Women at Risk: Exploring Douching Prevalence, Reasons for Douching, and Sexually Transmitted Disease Infection. *Sexually Transmitted Diseases* 33:215-219.
- Arrossi, S., R. Sankaranarayanan, and D. M. Parkin. 2003. Incidence and mortality of cervical cancer in Latin America. *Salud Publica Mex* 45 Suppl 3:S306-14.

- Averill, G. 1997. *A Day for the Hunter, A Day for the Prey: Popular Music and Power in Haiti. Chicago Studies in Ethnomusicology*. Chicago: The University of Chicago Press.
- Baer, R. D., L. Clark, and C. Peterson. 1998. "Folk Illnesses," in *Handbook of Immigrant Health*. Edited by S. Loue, pp. 183-202. New York: Springer.
- Balshem, M. 1993. *Cancer in the Community: Class and Medical Authority. Smithsonian Series in Ethnographic Inquiry*. Washington, D.C.: Smithsonian Books.
- . 1999. "Negotiating Medical Authority: Contradictions in Oncology Practice," in *Preventing and Controlling Cancer in North America: A Cross-Cultural Perspective*. Edited by D. Weiner. Westport, CT: Praeger.
- Barcenas, C. H., A. V. Wilkinson, S. S. Strom, Y. Cao, K. C. Saunders, S. Mahabir, M. A. Hernández-Valero, M. R. Forman, M. R. Spitz, and M. L. Bondy. 2007. Birthplace, years of residence in the United States, and obesity among Mexican-American adults. *Obesity (Silver Spring)* 15:1043-52.
- Barnes-Josiah, D., C. Myntti, and A. Augustin. 1998. The "three delays" as a framework for examining maternal mortality in Haiti. *Social Science & Medicine* 46:981-93.
- Barnett, D. B. 1996. Cervical cancer screening programs: technical cooperation in the Caribbean. *Bull Pan Am Health Organ* 30:409-12.
- Barnett, E., T. Anderson, J. Blosnich, J. Halverson, and J. Novak. 2005. Promoting Cardiovascular Health: From Individual Goals to Social Environmental Change. *American Journal of Preventive Medicine* 29:107-112.
- Barnett, E., and M. Casper. 2001. A definition of "social environment." *American Journal of Public Health* 91:465.
- Basen-Engquist, K., E. D. Paskett, J. Buzaglo, S. M. Miller, L. Schover, L. B. Wenzel, and D. C. Bodurka. 2003. Cervical Cancer: Behavioral Factors Related to Screening, Diagnosis, and Survivors' Quality of Life *Cancer* 98:2009-2014.
- Beksinska, M., H. Rees, I. Kleinschmidt, and J. McIntyre. 1999. The practice and prevalence of dry sex among men and women in South Africa: A risk factor for sexually transmitted infections? *Sexually Transmitted Infections* 75:178-.
- Bell, B. 2001. *Walking on Fire: Haitian Women's Stories of Survival and Resistance*: Cornell University Press.
- Bernard, H. R. 2006. *Research Methods in Anthropology: Qualitative and Quantitative Approaches*, 4th edition. Lanham: Altamira Press.
- Blumenthal, P., M. Lauterbach, J. Sellors, and R. Sankaranarayanan. 2005. Training for cervical cancer prevention programs in low-resource settings: Focus on visual inspection with acetic acid and cryotherapy. *International Journal of Gynecology and Obstetrics* 89:S30-S37.

- Blumhagen, D. 1982. "The Meaning of Hypertension," in *Clinically Applied Anthropology*. Edited by N. Chrisman and T. Maretzki. Dordrecht, Holland: D. Reidel Publishing Company.
- Boyer, L. E., M. Williams, L. Clark Callister, and E. S. Marshall. 2001. Hispanic women's perceptions regarding cervical cancer screening. *JOGNN* 30:240-245.
- Brabin, L., S. A. Roberts, F. Farzaneh, and H. C. Kitchener. 2006. Future acceptance of adolescent human papillomavirus vaccination: A survey of parental attitudes. *Vaccine* 24:3087-3094.
- Bradley, J., M. Barone, C. Mahe, R. Lewis, and S. Luciani. 2005. Delivering cervical cancer prevention services in low-resource settings. *International Journal of Gynecology and Obstetrics* 89:S21-S29.
- Brodwin, P. E. 1992. "Guardian Angels and Dirty Spirits: The Moral Basis of Health Power in Rural Haiti," in *Anthropological Approaches to the Study of Ethnomedicine*. Edited by M. Nichter, pp. 57-74. New York: Gordon and Breach, Science Publishers.
- . 1996. *Medicine and Morality in Haiti: The contest for healing power*. *Cambridge Studies in Medical Anthropology*. Cambridge: Cambridge University Press.
- Brown, J. E., O. B. Ayowa, and R. C. Brown. 1993. Dry and tight: sexual practices and potential AIDS risk in Zaire. *Social Science & Medicine* 37:989-994.
- Brown, J. E., and R. C. Brown. 2000. Traditional intravaginal practices and the heterosexual transmission of disease: a review. *Sexually Transmitted Infections* 27:183-187.
- Brown, P. 1992. Popular epidemiology and toxic waste contamination: lay and professional ways of knowing. *Journal of Health & Social Behavior* 33:267-81.
- Buvé, A., K. Bishikwabo-Nsarhaza, and G. Mutangadura. 2002. The spread and effect of HIV-1 infection in sub-Saharan Africa. *The Lancet* 359:2011-2017.
- Calvo, A. 2005. Social Construction of Cervical Cancer Screening Among Women in Panama City, Panama, University of South Florida.
- Castle, P. E., A. Aftab, G. Saint-Jean, and L. Mendez. 2006. Detection of Carcinogenic Human Papillomavirus in Specimens Collected with a Novel Self-Sampling Device *Journal of Clinical Microbiology* 44:2158-2159.
- CDC. 2008. "Programs & Tools: Vaccines for Children Program (VFC)," vol. 2008, pp. Web page. Atlanta, GA: Centers for Disease Control & Prevention.
- Chaffee, S. 1994. The Survival Strategies of Haitian Immigrant Women, Florida International University.
- Charles, J. 2001. "Haitians fearing census numbers: Undercount could cause funds shortfall," in *The Miami Herald*. Miami.
- Chavez, L. R., F. A. Hubbell, J. M. McMullin, R. G. Martinez, and S. I. Mishra. 1995. Structure and meaning in models of breast and cervical cancer

- risk factors: a comparison of perceptions among Latinas, Anglo women, and physicians. *Med Anthropol Q* 9:40-74.
- Chavez, L. R., F. A. Hubbell, S. I. Mishra, and R. B. Valdez. 1997. The Influence of Fatalism on Self-Reported use of Papanicolaou smears. *Am J Prev Med* 13:418-24.
- Chavez, L. R., J. M. McMullin, S. I. Mishra, and F. A. Hubbell. 2001. Beliefs matter: Cultural beliefs and the use of cervical cancer screening tests. *American Anthropologist* 103:114-29.
- Chrisman, N. J., C. J. Strickland, K. Powell, M. D. Squeochs, and M. Yallup. 1999. Community Partnership Research with the Yakama Indian Nation. *Human Organization* 58:134-141.
- Clarke, A. E., and M. J. Casper. 1996. From Simple Technology to Complex Arena: Classification of Pap Smears 1917-1990. *Medical Anthropology Quarterly* 10:601-623.
- Comhaire-Sylvain, S. 1958. Courtship, Marriage and Plasaj at Kenscoff, Haiti. *Social and Economic Studies* 7:211-233.
- Consedine, N. S., C. Magai, R. Spiller, A. I. Neugut, and F. Conway. 2004. Breast cancer knowledge and beliefs in subpopulations of African American and Caribbean women. *American Journal of Health Behavior* 28:260-71.
- Coreil, J. 1983a. Allocation of Family Resources For Health Care in Rural Haiti. *Social Science & Medicine* 17:709-19.
- . 1983b. Parallel structures in professional and folk health care: a model applied to rural Hati. *Cult Med Psychiatry* 7:131-51.
- . 1983c. Parallel structures in professional and folk health care: a model applied to rural Hati. *Culture, Medicine & Psychiatry* 7:131-51.
- . 1988. Innovation among Haitian healers: the adoption of oral rehydration therapy. *Human Organization* 47:48-57.
- Coreil, J., D. L. Barnes-Josiah, A. Augustin, and M. Cayemittes. 1996. Arrested pregnancy syndrome in Haiti: findings from a national survey. *Medical Anthropology Quarterly* 10:424-36.
- Coreil, J., G. Mayard, J. Louis-Charles, and D. Addiss. 1998. Filarial elephantiasis among Haitian women: social context and behavioural factors in treatment. *Tropical Medicine & International Health* 3:467-73.
- Coreil, J., J. Wilke, and I. Pintado. 2004. Cultural Models of Illness and Recovery in breast cancer support groups. *Qualitative Health Research* 14:905-923.
- Cottrell, B. H. 2002. Vaginal douching. *Journal of Obstetric, Gynecologic and Neonatal Nursing* 32:12-18.
- . 2006. Vaginal Douching Practices of Women in Eight Florida Panhandle Counties. *Journal of Obstetric, Gynecologic and Neonatal Nursing* 35:24-33.
- Courlander, H. 1960. *The Drum and the Hoe: Life and Lore of the Haitian People*: University of California Press.

- Cronjé, H. S. 2004. Screening for cervical cancer in developing countries. *International Journal of Gynecology & Obstetrics* 84:101-108.
- Crosby, R. A., D. Newman, M. L. Kamb, J. Zenilman, J. M. Douglas, and M. Iatesta. 2000. Misconceptions about STD-protective behavior. Project RESPECT Study Group. *American Journal of Preventive Medicine* 19:167-173.
- Damasus-Awatai, G., and T. Freeman-Wang. 2003. Human papilloma virus and cervical screening. *Curr Opin Obstet Gynecol* 15:473-7.
- David, M. M., L. Ko, N. Prudent, E. H. Green, M. M. Posner, and K. M. Freund. 2005a. Mammography use. *Journal of the National Medical Association* 97:253-61.
- . 2005b. Mammography use. *J Natl Med Assoc* 97:253-61.
- de Alba, I., F. A. Hubbell, J. M. McMullin, J. M. Weningson, and R. Saitz. 2005. Impact of U.S. citizenship status on cancer screening among immigrant women. *J Gen Internal Med* 20:290-296.
- de Melo-Martin, I. 2006. The promise of the human papillomavirus vaccine does not confer immunity against ethical reflection. *The Oncologist* 11:393-396.
- Dein, S. 2004. Explanatory models of and attitudes towards cancer in different cultures. *Lancet Oncol* 5:119-24.
- Deren, M. 1953. *Divine Horsemen: Living Gods of Haiti*. New York: Thames and Hudson.
- DeSantis, L. 1989a. Health care orientations of Cuban and Haitian immigrant mothers: implications for health care professionals. *Med Anthropol* 12:69-89.
- . 1989b. Health care orientations of Cuban and Haitian immigrant mothers: implications for health care professionals. *Medical Anthropology* 12:69-89.
- . 1993. Haitian Immigrant Concepts of Health. *Health Values* 17:3-16.
- DeSantis, L., and R. Halberstein. 1992. The Effects of Immigration on the Health Care System of South Florida. *Human Organization* 51:223-234.
- DeSantis, L., and R. M. Tappen. 1990. Preventive Health Practices of Haitian Immigrants.
- DeSantis, L., and J. T. Thomas. 1990. The immigrant Haitian mother: transcultural nursing perspective on preventive health care for children. *Journal of Transcultural Nursing* 2:2-15.
- . 1992. Health education and the immigrant Haitian mother: cultural insights for community health nurses. *Public Health Nurs* 9:87-96.
- Descourtilz, M.-É. 1809. *Voyage d'un naturaliste et ses observations faites sur les trois règnes de la Nature, dans plusieurs ports de mer français, en Espagne, au continent de l'Amérique septentrionale, à Sant-Yago de Cuba et à Saint-Domingue, ou l'auteur, devenu le prisonnier de 40.000 Noirs révoltés, et par suite mis en liberté par une colonne de l'armée française, donne les détails circonstanciés sur l'expédition du général Leclerc*. Paris: Defart.

- Desmangles, L. 1994. *The Faces of the Gods: Vodou and Roman Catholicism in Haiti*. Chapel Hill: University of North Carolina Press.
- DeWees, K. D. 1995. Dechouke: A study of Haitians nad Haitian-Americans living in the United States, Smith College.
- DiGiacomo, S. 1987. "Biomedicine as a cultural system: An Anthropologist in the kingdom of the sick," in *Encounters with Biomedicine: Case Studies in Medical Anthropology*. Edited by H. A. Baer, pp. 315-347. New York: Gordon and Breach.
- Dignan, M., R. Michielutte, H. Bradley wells, P. Sharp, K. Blinson, L. D. Case, R. Bell, J. Konen, S. Davis, and R. P. McQuellon. 1998. Helath education to increase screening for cervical cancer among Lumbee Indian women in North Carolina. *Health Education Research* 13:545-556.
- Dorsainvil, J.-C. 1934. *Manuel d'histoire d'Haiti*. Port-au-Prince, Haiti: Procure des Frères de l'Instruction Chrétienne
- Doyal, L., and I. Pennell. 1991. *The Political Economy of Health*. London: Pluto Press.
- Dressler, W. 1982. *Hypertension and Culture Change: Acculturation and Disease in the West Indies*. South Salem, NY: Redgrave Publishing Company.
- Dressler, W., and K. Oths. 1997. "Cultural Determinants of Health," in *Handbook of Health Behavior Research I: Personal and Social Determinants*, vol. 1. Edited by D. Gochman: Springer.
- Dressler, W. W. 2001. Medical Anthropology: Toward a Third Moment in Social Science? . *Medical Anthropology Quarterly* 15:455-465.
- Duany, J. 1998. Reconstructing Racial Identity: Ethnicity, Color, and Class among Dominicans in the United States and Puerto Rico. *Latin American Perspectives* 25:147-172.
- Dubois, L. 2001. Vodou and History. *Comparative Studies in Society and History* 43:92-100.
- Dunham, K. 1969. *Island Possessed*. Garden City, NY: Doubleday & Company, Inc.
- Dunn, F. L., and C. Janes. 1986. "Introduction: Anthropology and Epidemiology," in *Anthropology and Epidemiology: Interdisciplinary approaches to the study of health and disease*. Edited by C. Janes, R. Stall, and S. M. Gifford, pp. 3-34. Norwell, MA: Kluwer Academic Publishers.
- Eluf-Neto, J., and C. M. Nascimento. 2001. Cervical cancer in Latin America. *Semin Oncol* 28:188-97.
- EPA, E. P. A. 1999. *EPA Guidance Manual. Alternative Disinfectants and Oxidants. Chapter 5: Potassium Permanganate*. U.S. Environmental Protection Agency.
- Epstein, R. J. 2005. Primary prevention of human papillomavirus-dependent neoplasia: no condom, no sex. *European Journal of Cancer* 41:2595-2600.

- Erwin, D., T. S. Spatz, and C. L. Turturro. 1992. Development of an African-American role model intervention to increase breast self-examination and mammography. *J Cancer Educ* 7:311-9.
- Erwin, D. O. 2002. Cancer education takes on a spiritual focus for the African American faith community. *Journal of Cancer Education* 17:46-9.
- Erwin, D. O., T. S. Spatz, R. C. Stotts, and J. A. Hollenberg. 1999. Increasing mammography practice by African American women. *Cancer Pract* 7:78-85.
- Erwin, D. O., T. S. Spatz, R. C. Stotts, J. A. Hollenberg, and L. A. Deloney. 1996. Increasing mammography and breast self-examination in African American women using the Witness Project model. *J Cancer Educ* 11:210-5.
- Farmer, P. 1988. Bad Blood, Spoiled Milk: Bodily Fluids as Moral Barometers in Rural Haiti. *American Ethnologist* 15:62-83.
- . 1990. Sending Sickness: Sorcery, Politics, and Changing Concepts of AIDS in Rural Haiti. *Medical Anthropology Quarterly* 4:6-27.
- . 1992. *AIDS and Accusation: Haiti and the Geography of Blame*. Berkeley: University of California Press.
- . 1999a. *Infections and Inequalities: The Modern Plagues*. Berkeley: University of California Press.
- . 1999b. Pathologies of power: rethinking health and human rights. *American Journal of Public Health* 89:1486-96.
- . 2003. *The Uses of Haiti*, 2nd edition. Monroe, ME: Common Courage Press.
- Fitzgerald, D. W., F. Behets, A. Caliendo, D. Roberfroid, C. Lucet, J. W. Fitzgerald, and L. Kuykens. 2000. Economic Hardship and Sexually Transmitted Diseases in Haiti's Rural Artibonite Valley *American Journal of Tropical Medicine and Hygiene* 62:496-501.
- Fonck, K., R. Kaul, F. Keli, and e. al. 2001. Sexually transmitted infections and vaginal douching in a population of female sex workers in Nairobi, Kenya. *Sexually Transmitted Infections* 77:271-.
- Foster, G. 1976. Disease Etiologies in Non-Western Medical Systems. *American Anthropologist* 78:773-82.
- Foster, G. M. 1993. *Hippocrates' Latin American Legacy: Humoral Medicine in the New World*: Gordon and Breach.
- Foster, G. M., and B. G. Anderson. 1978. *Medical Anthropology*. New York: John Wiley K. Sons.
- Francis-Floyd, R., and R. Klinger. 2002. *Use of Potassium Permanganate to Control External Infections of Ornamental Fish* Fisheries and Aquatic Sciences Department, Florida Cooperative Extension Service, Institute of Food and Agricultural Sciences, University of Florida FA37.
- Franco, E., D.-F. E, and F. A. 2003. Prospects for controlling cervical cancer at the turn of the century. *Salud publica Mex* 45:S367-S375.
- Freeman, H. 2004. Poverty, Culture, and Social Injustice: Determinants of Cancer Disparities. *CA A Cancer Journal for Clinicians* 54:72-77.

- Freeman, H., and B. Wingrove. 2005. "Excess Cervical Cancer Mortality: A Marker for Low Access to Health Care in Poor Communities." Edited by U. S. DHHS: National Cancer Institute.
- Fruchter, R. G., J. C. Remy, W. S. Burnett, and J. G. Boyce. 1986. Cervical cancer in immigrant Caribbean women. *Am J Public Health* 76:797-9.
- Gage, A. 1998. "Moving the Big Apple: Tabou Combo's Diasporic Dreams," in *Island Sounds in the Global City: Caribbean Popular Music and Identity in New York*. Edited by R. Allen and L. Wilcken, pp. 138-161. New York: The New York Folklore Society, Institute for Studies in American Music, Brooklyn College.
- Gage, A. J., and P. L. Hutchinson. 2006. Power, control, and intimate partner sexual violence in Haiti. *Archives of Sexual Behavior* 35:11-24.
- Gammage, S. 2004. Exercising Exit, Voice and Loyalty: A Gender Perspective on Transnationalism in Haiti. *Development and Change* 35:743-771.
- Gany, F., and H. Thiel de Bocanegra. 1996a. Overcoming barriers to improving the health of immigrant women. *Journal of the American Medical Women's Association* 51:155-60.
- . 1996b. Overcoming barriers to improving the health of immigrant women. *J Am Med Womens Assoc* 51:155-60.
- Gardella, A. 2006. *Gender Assessment/USAID Haiti*. USAID, United States Agency for International Development.
- Garro, L. C. 1990. Culture, pain and cancer. *J Palliat Care* 6:34-44.
- Garro, L. C., and C. Mattingly. 2000. "Narrative as Construct and Construction," in *Narrative and the Cultural Construction of Illness and Healing*. Edited by C. Mattingly and L. C. Garro, pp. 1-49. Berkeley: University of California Press.
- Gazmararian, J. A., F. C. Bruce, J. S. Kendrick, C. C. Grace, and S. Wynn. 2001. Why Do Women Douche? Results from a Qualitative Study. *Maternal and Child Health Journal* 5:153-160.
- Glick-Schiller, N., and G. E. Fouron. 2001. *Georges Woke Up Laughing: Long Distance Nationalism and the Search for Home*. Durham: Duke University Press.
- Glick-Schiller, N., and G. Fouron. 1990. Everywhere We Go, We Are in Danger!: Ti Manno and the Emergence of a Haitian Transnational Identity. *American Ethnologist* 17:329-347.
- Goldie, S., L. Kuhn, L. Denny, A. Pollack, and T. C. Wright. 2001. Policy analysis of cervical cancer screening strategies in low-resource settings: Clinical benefits and cost-effectiveness. *Journal of the American Medical Association* 285:3107-3115.
- Goldman, R. E., and P. M. Risica. 2004. Perceptions of breast and cervical cancer risk and screening among Dominicans and Puerto Ricans in Rhode Island. *Ethn Dis* 14:32-42.
- Good, B. J. 1994. *Medicine, Rationality and Experience: An anthropological perspective*. Cambridge: Cambridge University Press.
- Gornick, M., P. Eggers, and G. Riley. 2004. Associations of race, education, and patterns of preventive service use with stage of cancer at time of diagnosis. *Health Serv Res* 39:1403-28.



- Green, E. C. 1999. "Engaging Indigenous African Healers in the Prevention of AIDS and STDs," in *Anthropology in Public Health*. Edited by R. A. Hahn, pp. 63-83. New York: Oxford University Press.
- Green, E. H., K. M. Freund, M. M. Posner, and M. M. David. 2005. Pap Smear Rates Among Haitian Immigrant Women in Eastern Massachusetts. *Public Health Reports* 120:133-139.
- Gregg, J. 2003. *Virtually Virgins: Sexual Strategies and Cervical Cancer in Recife, Brazil*. Stanford: Stanford University Press.
- Gresenguet, G., J. K. Kreiss, M. K. Chapko, S. L. Hillier, and N. S. Weiss. 1996. HIV Infection and vaginal douching in Central Africa. *AIDS* 11:101-106.
- Grimley, D. M., L. Annang, H. R. Foushee, F. C. Bruce, and J. S. Kendrick. 2006. Vaginal douches and other feminine hygiene products: Women's practices and perceptions of product safety. *Maternal and Child Health Journal* 10:303-310.
- Hahn, R. A. 1998. "The State of Federal Health Statistics on Racial and Ethnic Groups," in *Understanding and Applying Medical Anthropology*. Edited by P. J. Brown, pp. 261-267. Mountain View, CA: Mayfield Publishing Company.
- Hakim, A. A., P. S. Lin, S. Wilczynski, K. Nguyen, B. Lynes, and M. T. Wakabayashi. 2007. Indications and efficacy of the human papillomavirus vaccine. *Current Treatment Options in Oncology* 8:393-401.
- Halperin, D. 1999. Dry sex practices and HIV infection in the Dominican Republic and Haiti. *Sexually Transmitted Infections* 75:445-446.
- Hemmerling, A., M. Potts, J. Walsh, B. Young-Holt, K. Whaley, and D. A. Stefanski. 2007. Lime Juice as a Candidate Microbicide? An Open-Label Safety Trial of 10% and 20% Lime Juice Used Vaginally. *Journal of Women's Health* 16:1041-1051.
- Herbert, J., and J. Coffin. 2008. Reducing patient risk for human papillomavirus infection and cervical cancer. *Journal of the American Osteopathic Association* 108:65-70.
- Herskovits, M. 1937. *Life in a Haitian Valley*, 1st edition. New York: Alfred A. Knopf.
- Hess, D. 1996. Technology and alternative cancer therapies: An analysis of heterodoxy and Constructivism. *Medical Anthropology Quarterly* 10:657-674.
- . 1999. "Patients, Science, and Alternative Cancer Therapies," in *Preventing and Controlling Cancer in North America: A Cross-Cultural Perspective*. Edited by D. Weiner, pp. 15-23. Westport, CT: Praeger.
- Heurtin-Roberts, S. 1993. High-Pertension: The Uses of a Chronic Folk Illness for Personal Adaptation. *Soc Sci Med* 37:285-94.
- Hewitt, G. 1880. "Disorders of Uterine Functions," in *A System of Medicine*, vol. 3: Diseases of the Digestive, Blood-Glandular, Urinary, Reproductive and Cutaneous Systems. Edited by J. R. Reynolds, pp. 765-774. Philadelphia: Henry O. Lea's Son & Co.

- Hoffman-Goetz, L., N. Breen, and H. Meissner. 1998. The impact of social class on the use of cancer screening within three racial/ethnic groups in the United States. *Ethn Dis* 8:43-51.
- Holcomb, L. O., L. C. Parsons, J. N. Giger, and R. Davidhizar. 1996. Haitian Americans: implications for nursing care. *Journal of Community Health Nursing* 13:249-60.
- Holmes, K. K., R. Levine, and M. Weaver. 2004. Effectiveness of condoms in preventing sexually transmitted infections. *Bulletin of the World Health Organization* 82:454-461.
- Holschneider, C. H., J. C. Felix, W. Satmary, M. T. Johnson, L. M. Sandweiss, and F. J. Montz. 1999. A single-visit cervical carcinoma prevention program offered at an inner city church: A pilot project. *Cancer* 15:2659-2667.
- Holzman, C., J. M. Leventhal, H. Qiu, N. M. Jones, J. Wang, and B. S. Group. 2001. Factors Linked to Bacterial Vaginosis in Nonpregnant Women. *American Journal of Public Health* 91:1664-1670.
- Hoyo, C., W. C. Miller, B. M. Newman, and J. A. Fortney. 2000. Selective screening for cervical neoplasia: an approach for resource-poor settings. *Int J Epidemiol* 29:807-12.
- Hunt, L. M. 1998. Moral reasoning and the meaning of cancer: causal explanations of oncologists and patients in southern Mexico. *Med Anthropol Q* 12:298-318.
- Hunter, J. L. 2004. Cervical cancer in Iquitos, Peru: local realities to guide prevention planning. *Cadernos Saúde Pública* 20:160-71.
- Hurston, Z. N. 1938. *Tell My Horse: Voodoo and Life in Haiti and Jamaica*. Philadelphia: JB Lippincott Company.
- Imade, G., A. Sagay, D. Egah, V. Onwulin, M. Grigg, C. Egbodo, T. Thacher, M. Potts, and R. V. Short. 2008. Prevalence of HIV and other sexually transmissible infections in relation to lemon or lime juice douching among female sex workers in Jos, Nigeria. *Sexual Health* 5:55-60.
- Imade, G., A. Sagay, V. Onwuliri, D. Egah, M. Potts, and R. Short. 2005. Use of lemon or lime juice douches in women in Jos, Nigeria. *Sexual Health* 2:237-239.
- Jackson, C. 1998. "Medical Interpretation: An Essential Clinical Service for Non-English Speaking Immigrants," in *Handbook of Immigrant Health*. Edited by S. Loue, pp. 61-79. New York: Springer.
- Jackson, C. J., V. M. Taylor, K. Chitnarong, J. Mahloch, M. Fischer, R. Sam, and P. Seng. 2000. Development of a cervical cancer control intervention program for cambodian american women. *Journal of Community Health* 25:359-375.
- Jacob, M., F. F. Broekhuizen, W. Castro, and J. Sellors. 2005. Experience using cryotherapy for treatment of cervical precancerous lesions in low resource settings. *Int J Gynec Obst* 89:S13-S20.
- Jeronimo, J., O. Morales, J. Horna, J. Pariona, J. Manrique, J. Rubiños, and R. Takahashi. 2005. Visual inspection with acetic acid for cervical cancer screening outside of low-resource settings. *Pan American Journal of Public Health* 17:1-5.

- Kaiser Commission. 2003. *Kaiser Commission on Key Facts: Immigrants' Health Care Coverage and Access*. Kaiser Family Foundation.
- Kaur, I., and I. P. Singh. 1992. Risk Factors in Cancer of Cervix Uteri. *Journal of Human Ecology* 3:225-228.
- Kearney, G. 2008. A procedure for detecting childhood cancer clusters near hazardous waste sites in Florida. *Journal of Environmental Health* 70:29-34.
- Kemp, C., and L. A. Rasbridge. 1994. *Refugee and Immigrant Health: A Handbook for Health Professionals*, 1 edition. Cambridge: Cambridge University Press.
- Kershaw, T. S., M. Small, G. Joseph, M. Theodore, and R. Bateau. 2006. The influence of power on HIV risk among pregnant women in rural Haiti. *AIDS and Behavior* 10:309-318.
- Kleinman, A. 1980. *Patients and Healers in the Context of Culture: An Exploration of the Borderland between Anthropology, Medicine, and Psychiatry. Comparative Studies of Health Systems and Medical Care*. Berkeley: University of California Press.
- Koya, D. L., and L. E. Egede. 2007. Association between length of residence and cardiovascular disease risk factors among an ethnically diverse group of United States immigrants. *Journal of General Internal Medicine* 22:841-6.
- Kramer, E. J., S. L. Ivey, and Y. Ying. Editors. 1999. *Immigrant Women's Health: Problems and Solutions*. San Francisco: Jossey-Bass
- Kramer, E. J., L. C. Tracy, and S. L. Ivey. 1999. "Demographics, Definitions, and Data Limitations," in *Immigrant Women's Health: Problems and Solutions*. Edited by E. J. Kramer, S. L. Ivey, and Y.-W. Ying, pp. 3-18. San Francisco: Jossey-Bass Publishers.
- Krieger, N. 2001a. Theories for social epidemiology in the 21st century: an ecosocial perspective. . *International Journal of Epidemiology* 30:668-677.
- . 2001b. Theories for social epidemiology in the 21st century: an ecosocial perspective. . *Int J Epidemiol* 30:668-677.
- . 2002. Is Breast Cancer a disease of Affluence, Poverty, or Both? The Case of African American Women. *American Journal of Public Health* 92:611-613.
- Kun, K. E. 1998. Vaginal drying agents and HIV transmission. *International Family Planning Perspectives* 24:93-94.
- La Ruche, G., N. Messou, L. Ali-Napo, and e. al. 1999. Vaginal douching: Association with lower genital tract infections in African pregnant women. *Sex Transm Dis* 26.
- Laguerre, M. 1998. *Diasporic Citizenship: Haitian Americans in Transnational America*, first edition. New York: St. Martin's Press.
- Laguerre, M. S. 1981. "Haitian Americans," in *Ethnicity and Medical Care*. Edited by A. Harwood, pp. 172-210. Cambridge, MA: Harvard Univ Press.
- . 1987a. *Afro-Caribbean Folk Medicine*. South Hadley, MA: Bergin & Garvey Publishers, Inc.

- . 1987b. Migration and urbanization in Haiti. *Sociologus* 37:118-39.
- . 1989. *Voodoo and Politics in Haiti*. New York: St. Martin's Press.
- Leatherman, T. 1998. Changing Biocultural Perspectives on Health in the Andes. *Soc Sci Med* 47:1031-1041.
- . 2005. A Space of Vulnerability in Poverty and Health: Political-Ecology and Biocultural Analysis. *Ethos* 33:46-70.
- Leti, G. 2000. *L'univers magico-religieux antillais: ABC des croyances et superstitions d'hier et d'aujourd'hui*. Paris: L'Harmattan.
- Leung, M. W., I. H. Yen, and M. Minkler. 2004. Community based participatory research: a promising approach for increasing epidemiology's relevance in the 21st century. *International Journal of Epidemiology* 33:499-506.
- Lewis, M. J. 2004. *A Situational Analysis of Cervical Cancer in Latin America and the Caribbean*. Noncommunicable Diseases Unit, Pan American Health Organization.
- Leyburn, J. G. 1941. *The Haitian People*, 2nd edition. New Haven: Yale University Press.
- Lichtenstein, B., and T. R. Nansel. 2000. Women's douching practices and related attitudes: Findings from four focus groups. *Women & Health* 31:117-131.
- Lieberman, L. S., E. P. Stoller, and M. A. Burg. 1997. Women's health care: cross-cultural encounters within the medical system. *J Fla Med Assoc* 84:364-73.
- Lindau, S. T., C. Tomori, T. Lyons, L. Langseth, C. L. Bennett, and P. Garcia. 2002. The association of health literacy with cervical cancer prevention knowledge and health behaviors in a multiethnic cohort of women. *Am J Obstet Gynecol* 186:938-43.
- Loederer, R. A. 1935. *Voodoo Fire in Haiti*. Garden City, NY: Country Life Press.
- Lorincz, A. 2003. Screening for cervical cancer: New alternatives and research. *Salud publica Mex* 45:S376-387.
- Luke, K. 1996. Cervical cancer screening: meeting the needs of minority ethnic women. *Br J Cancer Suppl* 29:S47-50.
- Lunec, A. 2005. Issues raised by prophylactic vaccine for cervical cancer. *The Lancet* 6:923-924.
- Magloire, E., and K. Yelvington. 2005. Haiti and the Anthropological Imagination. *Gradhiva* 1:127-152.
- Magloire, G. 2003. "Dossier Jean Price-Mars," <http://www.lehman.cuny.edu/ile.en.ile/paroles/price-mars.htm>.
- Malow, R. M., T. Cassagnol, R. McMahon, T. E. Jennings, and V. G. Roatta. 2000. Relationship of psychosocial factors to HIV risk among Haitian women. *AIDS Education & Prevention* 12:79-92.
- Mandelblatt, J. S., W. F. Lawrence, L. Gaffikin, K. Lyimpahayom Kobchitt, P. Lumbiganon, S. Warakamin, J. King, B. Yi, P. Ringers, and P. D. Blumenthal. 2002. Costs and benefits of different strategies to screen for cervical cancer in less-developed countries. *Journal of the National Cancer Institute* 94:1469-1483.

- Manderson, L. 1999. Editorial. New perspectives in anthropology on cancer control, disease and palliative care. *Anthropology and Medicine* 6:317-321.
- Manderson, L., and L. M. Whiteford. 2000. "Introduction: Health, Globalization, and the Fallacy of the Level Playing Field," in *Global Health Policy, Local Realities: The Fallacy of the Level Playing Field*. Edited by L. M. Whiteford and L. Manderson, pp. 1-22. Boulder: Lynne Rienner Publishers, Inc.
- Marcelin, L. H., H. V. McCoy, and R. J. DiClemente. 2006. HIV/AIDS Knowledge and Beliefs Among Haitian Adolescents in Miami-Dade County, Florida. *Journal of HIV AIDS Prevention in Children & Youth* 7:121-38.
- Markel, H., and A. Minna Stern. 2002. The Foreignness of Germs: The Persistent Association of Immigrants and Disease in American Society. *The Milbank Quarterly* 80:757-788.
- Martinez, R. G., L. R. Chavez, and F. A. Hubbell. 1997. Purity and Passion: Risk and Morality in Latina Immigrants' and physicians' Beliefs about Cervical Cancer. *Medical Anthropology* 17:337-362.
- Martino, J. L., and S. H. Vermund. 2002. Vaginal douching: Evidence for risks or benefits to women's health. *Epidemiol Rev* 24:109-124.
- Maternowska, M. C. 2006. *Reproducing Inequities: Poverty and the Politics of Population in Haiti*. *Studies in Medical Anthropology*. New Brunswick: Rutgers University Press.
- Mathews, H., D. R. Lannin, and J. P. Mitchell. 1994. Coming to terms with advanced breast cancer: Black women's narratives from Eastern North Carolina. *Soc Sci Med* 38:789-800.
- Mathews, H. F. 2000. Negotiating cultural consensus in a breast cancer self-help group. *Med Anthropol Q* 14:394-413.
- Maynard-Tucker, G. 1996. Haiti: unions, fertility and the quest for survival. *Social Science & Medicine* 43:1379-887.
- McAlister, E. 2002. *Rara! Vodou, Power, and Performance in Haiti and its Diaspora*. Berkeley: University of California Press.
- McCarthy Brown, K. 1991. *Mama Lola: A Vodou Priestess in Brooklyn*. Berkeley: University of California Press.
- McClelland, R. S., L. Lavreys, W. M. Hassan, K. Mandaliya, J. O. Ndinya-Achola, and J. M. Baeten. 2006. Vaginal washing and increased risk of HIV-1 acquisition among African women: A 10-year prospective study. *AIDS* 20:269-273.
- McElroy, A., and M. A. Jezewski. 2000. "Cultural variation in the experience of health and illness," in *Handbook of Social Studies in Health and Medicine*. Edited by G. L. Albrecht, R. Fitzpatrick, and S. C. Scrimshaw, pp. 191-209. London: Sage Publications.
- McElroy, A., and P. K. Townsend. 2004. *Medical Anthropology in Ecological Perspective*, 4th edition. Boulder: Westview Press.
- McKee, M. D., M. Baquero, M. R. Anderson, A. Alvarez, and A. Karasz. 2008. Vaginal douching among Latinas: Practices and Meaning. *Maternal and Child Health Journal* [Epub ahead of print].

- McMullin, J. M., L. R. Chavez, and F. A. Hubbell. 1996. Knowledge, power and experience: variation in physicians' perceptions of breast cancer risk factors. *Med Anthropol* 16:295-317.
- Metraux, A. 1972. *Voodoo in Haiti*. New York: Schocken Books.
- Meyer, J. 1998. Health Conditions and Therapy Choice in the French West Indies. M.A., The University of Alabama.
- Miller, N. L. 2000. Haitian ethnomedical systems and biomedical practitioners: directions for clinicians. *Journal of Transcultural Nursing* 11:204-11.
- Minkler, M. 1997. *Community organizing and community building for health*. New Brunswick: Rutgers University Press.
- Minn, P. 2001. Water in their eyes, dust on their land: Heat and Illness in a Haitian town. *Journal of Haitian Studies* 7:4-25.
- Misra, D. P., B. Trabert, and S. Atherly-Trim. 2006. Variation and predictors of vaginal douching behavior. *Women's Health Issues* 16:275-282.
- Moberg, M. 2002. Erin Brockovich Doesn't Live Here: Environmental Politics and "Responsible Care" in Mobile County, Alabama. *Human Organization* 61:377-389.
- Moreau de Saint-Méry, M.-L.-É. 1958 [1796-1797]. *Description topographique, physique, civile, politique et historique de la partie Française de l'isle Saint-Domingue*. Paris: Société de l'histoire des Colonies Françaises et Librairie Larose.
- Moscicki, A. B. 2005. Impact of HPV infection in adolescent populations. *The Journal of Adolescent Health* 37:Suppl: S3-9.
- Murray, G. F. 1974. "Women in Perdition: Ritual Fertility Control in Haiti. ," in *Culture, Natality and Family Planning*, vol. 21. Edited by J. F. Marshall and S. Polgar, pp. 59-78. Chapel Hill, NC: UNC Carolina Population Center Monograph.
- Myer, L., L. Denny, M. De Souza, M. A. Barone, T. C. Wright, and L. Kuhn. 2004. Intravaginal practices, HIV and other sexually transmitted diseases among South African women. *Sexually Transmitted Diseases* 31:174-179.
- Myer, L., L. Kuhn, Z. Stein, T. J. Wright, and L. Denny. 2005. Intravaginal practices, bacterial vaginosis, and women's susceptibility to HIV infection: Epidemiological evidence and biological mechanisms. *Lancet Infectious Diseases* 5:786-794.
- N.A. 2006. "Haitian Immigration: Eighteenth and Nineteenth Centuries," in *In Motion: The African American Migration Experience, Haitian Immigration*, vol. 2006: The Schomburg Center for Research in Black Culture.
- n.a. 2006. *Material Safety Data Sheet: Potassium permanganate*. Mallinckrodt Baker, Inc. P6005.
- . 2008. vol. 2008, pp. Caribbean goods website.
- N'Zengou-Tayo, M. J. 1998. "Fanm se poto mitan": Haitian woman, the pillar of society. *Feminist Review* 59:118-142.

- Navarro, A. M., K. L. Senn, L. J. McNicholas, R. M. Kaplan, B. Roppé, and M. Campo. 1998. *Por la Vida* model intervention enhances use of cancer screening tests among Latinas. *Am J Prev Med* 15:32-41.
- Newmann, S. J., and E. O. Garner. 2005. Social inequities along the cervical cancer continuum: a structured review. *Cancer Causes and Control* 16:63-70.
- Nicholls, D. 1985. *Haiti in Caribbean Context: Ethnicity, Economy and Revolt*. London: The Macmillan Press Ltd.
- . 1996. *From Dessalines to Duvalier: Race, Colour and National Independence in Haiti*, 3rd edition. New Brunswick, NJ: Rutgers University Press.
- NLM-NIH. 2004. "Cervical Cancer," in *Medline Plus: Trusted Health Information for You*, vol. 2004: NIH.
- O'Malley, A. S., J. Mandelblatt, K. Gold, K. A. Cagney, and J. Kerner. 1997. Continuity of care and the use of breast and cervical cancer screening services in a multiethnic community. *Arch Intern Med* 157:1462-70.
- Oswald, L. R. 1999. Culture Swapping: Consumption and the Ethnogenesis of Middle-Class Haitian Immigrants. *The Journal of Consumer Research* 25:303-318.
- Oths, K. S. 1999. Debilidad: a biocultural assessment of an embodied Andean illness. *Medical Anthropology Quarterly* 13:286-315.
- PAHO. 2001. "Cervical Cancer in Latin America and the Caribbean: Fact Sheet 2001," vol. 2004: Pan American Health Organization.
- . 2003. "PAHO Prepared to Help Caribbean Reduce High Cervical Cancer Rate," vol. 2004, pp. Press Release. Washington D.C.: PAHO.
- . 2008. *Burden of Human Papillomavirus (HPV) Infection and HPV-Related Disease in Latin America and the Caribbean, and Health and Economic Outcomes of HPV Vaccination in Selected Countries in Latin America*. The Albert B. Sabine Vaccine Institute, Pan American Health Organization, Centers for Disease Control & Prevention, Harvard School of Public Health, Institut Catala d'Oncologia.
- Palacio-Mejia, L. S., G. Rangel-Gomez, M. Hernandez-Avila, and E. Lazcano-Ponce. 2003. Cervical cancer, a disease of poverty: Mortality differences between urban and rural areas in Mexico. *Salud publica Mex* 45:S315-S325.
- Parker Frisbie, W., Y. Cho, and R. A. Hummer. 2001. Immigration and the Health of Asian and Pacific Islander Adults in the United States. *American Journal of Epidemiology* 153:372-380.
- Payne-Jackson, A., and M. C. Alleyne. 2004. *Jamaican Folk Medicine: A Source of Healing*. Mona, Jamaica: University of the West Indies Press.
- Peek, M. E., and J. H. Han. 2004. Disparities in screening mammography. Current status, interventions and implications. *JGIM* 19:184-94.
- Pelto, P. J., and G. H. Pelto. 1997. Studying Knowledge, Culture, and Behavior in Applied Medical Anthropology. *Medical Anthropology Quarterly* 11:147-163.

- Pérez Y Mena, A. 1998. Cuban Santería, Haitian Vodun, Puerto Rican Spiritualism: A Multiculturalist Inquiry into Syncretism. *Journal for the Scientific Study of Religion* 37:15-27.
- Peronnette, H. 1982. *9 Histoires de Quimbois: faits vécus de sorcellerie*. Fort-de-France, Martinique: Desormeaux.
- Pollack, A., and V. Tsu. 2005. Preventing Cervical Cancer in low-resource settings: Building a case for the possible. *International Journal of Gynecology and Obstetrics* 89:S1-S3.
- Price-Mars, J. 1928. *Ainsi Parla l'Oncle*. Port-au-Prince, Haiti: Imprimerie de Compiègne.
- . 1959. *De Saint-Domingue à Haiti: Essai sur la Culture, les Arts et la Littérature*. Paris: Présence Africaine.
- Priestley, W. O. 1880. "Inflammation of the Uterus," in *A System of Medicine*, vol. 3: Diseases of the Digestive, Blood-Glandular, Urinary, Reproductive and Cutaneous Systems. Edited by J. R. Reynolds, pp. 774-798. Philadelphia: Henry O. Lea's Son & Co.
- Programs for Appropriate Technology in Health, P. 1988. Skin Diseases. *Health Technology Directions* 8:1-10.
- Quinlan, M. B., and R. J. Quinlan. 2006. "Balancing the System: Humoral Medicine and Food in the Commonwealth of Dominica," in *Eating and healing : traditional food as medicine* Edited by A. Pieroni, pp. 197-212. New York: Food Products Press.
- Quinlan, S. 2005. "Colonial Bodies, Hygiene, and Abolitionist Politics in Eighteenth-Century France," in *Bodies in Contact: Rethinking Colonial Encounters in World History*. Edited by T. Ballantyne and A. M. Burton, pp. 106-120. Durham: Duke University Press.
- Rajamanoharan, S., N. Low, S. B. Jones, and A. Pozniak. 1999. Bacterial vaginosis, ethnicity and the use of genital cleansing agents: A case-control study. *Sexually Transmitted Diseases* 26:404-409.
- Reed, B. D., K. Ford, and D. N. Wirawan. 2001. The Bali STD/AIDS study: Association between vaginal hygiene practices and STDs among sex workers. *Sexually Transmitted Infections* 77:46-.
- Reynier, M. 1999. "L'oeuvre et la pensée de Melville Herskovits," vol. 2005: <http://www.reynier.com/Anthro/Amerique/Herskovits.html>.
- Robles, S. C., F. White, and A. Peruga. 1996. Trends in cervical cancer mortality in the Americas. *Bull Pan Am Health Organ* 30:290-301.
- Rosenberg, M. J., R. S. Phillips, and M. D. Holmes. 1991. Vaginal douching: Who and why? *The Journal of Reproductive Medicine* 36:753-758.
- Roushdy-Hammady, I. 2004. Contested Etiology and Fragile Castles: An Ethnography of Cancer Risk and Cancer Research in Two Parts. *Culture, Medicine & Psychiatry* 28:311-314.
- Runganga, A., M. Pitts, and J. McMaster. 1992. The use of herbal and other agents to enhance sexual experience. *Social Science & Medicine* 35:1037-1042.
- Saint-Jean, G., and L. A. Crandall. 2004. Sources and Barriers to Health Care Coverage for Haitian Immigrants in Miami-Dade County, Florida. *Journal of Health Care for the Poor and Underserved* 16:29-41.



- . 2005a. Sources and Barriers to Health Care Coverage for Haitian Immigrants in Miami-Dade County, Florida. *Journal of Health Care for the Poor and Underserved* 16:29-41.
- . 2005b. Utilization of Preventive Care by Haitian Immigrants in Miami, Florida. *Journal of Immigrant Health* 7:283-292.
- Sanghavi Goel, M., C. C. Wee, E. P. McCarthy, R. B. Davis, Q. Ngo-Metzger, and R. S. Phillips. 2003. Racial and Ethnic Disparities in Cancer Screening: The Importance of Foreign Birth as a Barrier to Care. *JGIM* 18:1028-1035.
- Sankaranarayanan, R., R. Rajkumar, P. O. Esmey, J. M. Fayette, S. Shanthakumary, L. S. Frappart, S. Thara, and J. Cherian. 2007. Effectiveness, safety and acceptability of 'see and treat' with cryotherapy by nurses in a cervical screening study in India. *British Journal of Cancer* 96:738-43.
- Scarcini, I. C., B. M. Beech, K. W. Kovach, and T. L. Bailey. 2003. An examination of sociocultural factors associated with cervical cancer screening among low income Latina Immigrants of reproductive age. *Journal of Immigrant Health* 5:119-128.
- Schiller, N. G., M. L. Brutus, C. Charles, A. Dewind, G. Fouron, and L. Thomas. 1987. Exile, ethnic, refugee: the changing organizational identities of Haitian immigrants. *Migr World Mag* 15:7-11.
- Seeff, L. C., and M. T. McKenna. 2003. Cervical Cancer Mortality Among Foreign-Born Women Living in the United States, 1985 to 1996. *Cancer Detection and Prevention* 27:203-208.
- Sered, S., and E. Tabory. 1999. You are a number, not a human being. *Medical Anthropology Quarterly* 13:223-252.
- Sharp, L. K., J. M. Zurawski, P. Y. Roland, C. O'Toole, and J. Hines. 2002. Health literacy, cervical cancer risk factors, and distress in low-income African American women seeking colposcopy. *Ethn Dis* 12:541-545.
- Simpson, G. E. 1942. Sexual and familial institutions in Northern Haiti. *American Anthropologist* 44:655-674.
- Singer, M. 1996. Farewell to adaptationism: Unnatural selection and the politics of biology. *Medical Anthropology Quarterly* 10:496-515.
- Singer, M., L. Davison, and G. Gerdes. 1988. Culture, Critical Theory, and Reproductive Illness Behavior in Haiti. *Medical Anthropology Quarterly* 2:370-385.
- Smith Fawzi, M. C., W. Lambert, J. M. Singler, S. P. Koenig, F. Leandre, P. Nevil, D. Bertrand, M. S. Claude, J. Bertrand, J. J. Salazar, M. Louissaint, L. Joanis, and P. E. Farmer. 2003. Prevalence and risk factors of STDs in rural Haiti: implications for policy and programming in resource-poor settings. *International Journal of STD and AIDS* 14:848-53.
- Sontag, S. 1978. *Illness as Metaphor*. New York: Farrar, Strauss and Giroux.
- Stepick, A. 1991. Haitian Informal sector in Miami. *City and Society* 5:10-22.
- . 1998. *Pride Against Prejudice: Haitians in the United States*. New Immigrants Series. Boston: Allyn & Bacon.

- Stepick, A., and C. Dutton Stepick. 1992a. *Ethnographic Evaluation of the 1990 Decennial Census Report Series: Alternative Enumeration of Haitians in Maima*. Center for Survey Methods Research 8.
- . 1992b. *Ethnographic Evaluation of the 1990 Decennial Census Report Series: Alternative Enumeration of Haitians in Miami*. Center for Survey Methods Research 8.
- Stepick, A., and A. Portes. 1986. Flight into Despair: A Profile of Recent Haitian Refugees in South Florida. *International Migration Review* 20:329-350.
- Stepick, A., and C. Stepick. 1990. People in the shadows: Survey Research among Haitians in Miami. *Human Organization* 49:64-77.
- Stepick, A., C. D. Stepick, and P. Kretsedemas. 2001. *Civic Engagment of Haitian immigrants and Haitian Americans in Miami-Dade County*. Cetner for Labor Research & Studies, Florida International University, Immigration and Ethnicity Institute.
- Stewart, B., and P. Kleihues. 2003. *World Cancer Report*. World Health Organization.
- Stoller, P. 2004. *Stranger in the Village of the Sick: A Memoir of Cancer, Sorcery, and Healing*. Boston: Beacon Press.
- Strickland, C. J., M. D. Squeoch, and N. J. Chrisman. 1999. Health promotion in cervical cancer prevention among the Yakama Indian women of the Wa'Shat Longhouse. *J Transcult Nurs* 10:190-6.
- Strickland, J., N. Chrisman, M. Yallup, K. Powell, and M. D. Squeoch. 1996. Walking the Journey of Womanhood: Yakama Indian Women and Papanicolaou (Pap) Test Screening. *Public Health Nursing* 13:141-150.
- Trefzer, A. 2000. Possessing the Self: Caribbean Identities in Zora Neale Hurston's Tell My Horse. *African American Review* 34:299-312.
- Trostle, J. A. 2005. *Epidemiology and Culture*, 1st edition. *Cambridge Studies in Medical Anthropology*. Cambridge: Cambridge University Press.
- Trostle, J. A., and J. Sommerfeld. 1996. Medical Anthropology and Epidemiology. *Annual Reviews of Anthropology* 25:253-274.
- Trottier, H., and E. L. Franco. 2006. The epidemiology of genital human papilloma virus infection. *Vaccine* 24:S1-S15.
- U.S. Census Bureau. 2000a. "American Fact Finder, Summary File 3," vol. 2006: U.S. Bureau of the Census.
- 2000b. "American Fact Finder, Summary File 3."
- Ulin, P. R., M. Cayemittes, and R. Gringle. 1996. "Bargaining for life: women and the AIDS epidemic in Haiti," in *Women's experiences with HIV / AIDS: An International Perspective*. Edited by L. D. Long and E. M. Ankrah, pp. 91-111. New York: Columbia University Press.
- Vetter, K. M., and S. E. Geller. 2007. Moving forward: human papillomavirus vaccination and the prevention of cervical cancer. *J Womens Health (Larchmt)* 16:1258-1268.
- Vilayleck, E. 1996. Le Bles, maladie Creole Antillaise. *Bulletin de la Societe de Pathologie Exotique* 89:57-67.

- Wallerstein, N., and B. Duran. 2006. Using community-based participatory research to address health disparities. . *Health Promotion & Practice* 7:312-323.
- Walsh, V., and J. Goodman. 2002. From Taxol to Taxol(R): The Changing Identities and Ownership of an Anti-Cancer Drug. *Medical Anthropology* 21:307-336.
- Ward, E., A. Jemal, V. Cokkinides, G. K. Singh, C. Cardinez, A. Ghafoor, and M. J. Thun. 2004. Cancer disparities by Race/Ethnicity and Socioeconomic Status. *CA A Cancer Journal for Clinicians* 54:78-93.
- Wardlow, H., and R. H. Curry. 1996. "Sympathy for my body": breast cancer and mammography at two Atlanta clinics. *Med Anthropol* 16:319-40.
- Watts, D. 1987. *The West Indies: Patterns of Development, Culture and Environmental Change since 1492*. Cambridge: Cambridge University Press.
- Weidman, H. H. 1978. *Miami Health Ecology Project Report: A Statement on Ethnicity and Health*. University of Miami, Department of Psychiatry Vol. 1.
- Weiner, D. 1999. "American Indian Cancer Discourse and the Prevention of Illness," in *Preventing and Controlling Cancer in North America: A Cross-Cultural Perspective*. Edited by D. Weiner, pp. 55-70. Westport: Praeger.
- Weiss, M. 1997. Signifying the Pandemics: Metaphors of AIDS, Cancer, and Heart Disesae. *Medical Anthropology Quarterly* 11:456-476.
- Weiss, M. G. 2001. Cultural epidemiology: an introduction and overview. *Anthropology & Medicine* 8:5-29.
- Weissman, J. S., and E. C. Schneider. 2005. Social disparities in cancer: lessons from a multidisciplinary workshop. *Cancer Causes and Control* 16:71-74.
- Weller, S., and A. K. Romney. 1988. *Systematic Data Collection. Qualitative Research Methods Series*. Newbury Park, CA: Sage Publications, Inc.
- Wilson, P. J. 1969. Reputation and Respectability: A Suggestion for Caribbean Ethnology. *Man* 4:70-84.
- Wingerd, J., and J. B. Page. 1994. "Bucket Bidet," University of Miami.
- Wood, K., R. Jewkes, and N. Abrahams. 1997. Cleaning the womb: Constructions of cervical screening and womb cancer among rural Black women in South Africa. *Soc Sci med* 45:283-294.
- World Health Organization. 2002. *Cervical cancer screening in developing countries : report of a WHO consultation*. World Health Organization, Programme on Cancer Control, Department of Reproductive Health and Research WP 480.
- Wright, T. C., W. K. Huh, B. J. Monk, J. S. Smith, K. Ault, and T. J. Herzog. 2008. Age considerations when vaccinating against HPV. *Gynecologic Oncology* 109:S40-S47.
- Yang, B. H., F. I. Bray, D. M. Parkin, J. W. Sellors, and Z. F. Zhang. 2004. Cervical cancer as a priority for prevention in different world regions: an evaluation using years of life lost. *Int J Cancer* 109:418-24.

- Yoder, P. S. 1997. Negotiating Relevance: Belief, Knowledge, and Practice in International Health Projects. *Medical Anthropology Quarterly* 11:131-146.
- Yonas, M. A., N. Jones, E. Eng, A. I. Vines, R. Aronson, D. M. Griffith, B. White, and M. DuBose. 2006. The Art and Science of Integrating Undoing Racism with CBPR: Challenges of Pursuing NIH Funding to Investigate Cancer Care and Racial Equity. *Journal of Urban Health: Bulletin of the New York Academy of Medicine* 83:1004-1012.
- Young, A. 1983. The Relevance of Traditional Medical Cultures to Modern Primary Health Care. *Social Science & Medicine* 17:1205-1211.
- Zangwill, M. 2004. The hidden risk of HPV. *CURE Cancer Updates, Research & Education* 3:29-35.
- Zéphir, F. 1997. The Social Value of French for Bilingual Haitian Immigrants. *The French Review* 70:395-406.
- . 2004. *The Haitian Americans. The New Americans*. Westport, CT: Greenwood Press.
- Zhang, J., G. Thomas, and E. Leybovich. 1997. Vaginal douching and adverse health effects: A meta-analysis. *AJPH* 87:1207-1211.
- Zucker, N. F., and N. L. Zucker. 1996. *Desperate Crossings: Seeking Refuge in America*. Armonk, NY: M.E. Sharpe.

## APPENDICES

## APPENDIX A

### Institutional Review Board Approval, USF



December 3, 2007

Janelle Menard, M.A., MPH  
11867 Batello Lane  
Orlando, FL 32827

RE: **Expedited Approval** for Continuing Review  
IRB#: 105201  
Title: *The Social Context of Cervical Cancer Knowledge and Prevention among Haitian Immigrant Women*  
Study Approval Period: 11/29/2007 to 11/27/2008

Dear Ms. Menard:

On November 29, 2007, Institutional Review Board (IRB) reviewed and **APPROVED** the above protocol for the period indicated above. It was the determination of the IRB that your study qualified for expedited review based on the federal expedited category number six (6): Collection of data from voice, video, digital, or image recordings made for research purposes and seven (7): Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note, if applicable, the enclosed informed consent/assent documents are valid during the period indicated by the official, IRB-Approval stamp located on page one of the form. Valid consent must be documented on a copy of the most recently IRB-approved consent form. Make copies from the enclosed original.

Please reference the above IRB protocol number in all correspondence regarding this protocol with the IRB or the Division of Research Integrity and Compliance. In addition, we have enclosed an Institutional Review Board (IRB) Quick Reference Guide providing guidelines and resources to assist you in meeting your responsibilities in the conduction of human participant research. Please read this guide carefully. It is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB.

OFFICE OF RESEARCH • DIVISION OF RESEARCH INTEGRITY & COMPLIANCE  
INSTITUTIONAL REVIEW BOARDS, FWA No. 00001669  
University of South Florida • 12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799  
(813) 974-5638 • Fax (813) 974-5618

## Appendix A (continued)

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-9343.

Sincerely,



Paul G. Stiles, J.D., Ph.D., Chairperson  
USF Institutional Review Board

Enclosures: (If applicable) IRB-Approved, Stamped Informed Consent/Assent Document(s)  
IRB Quick Reference Guide

Cc: Henry Zych, USF IRB Professional Staff  
Roberta Baer, Ph.D.

SB-IRB-Approval-EXPEDITED-0601

## APPENDIX B

### Key Respondent Interview Guide

#### ***Informed Consent Statement:***

***Study involves Research:*** As we have discussed, I am doing research on the context and meaning of cervical cancer in the lives of Haitian immigrant women in Tampa and Orlando. Your insight, perspectives and opinions are valuable to me. My study is called "The Social Context of Cervical Cancer Knowledge and Prevention among Haitian Immigrant Women." ***Study Purpose:*** I am interested in learning more about the social context of the Haitian community, its challenges and strengths, as well as how Haitian cultural beliefs contribute to how Haitian people think about health in general, and cancer more specifically. This knowledge will be used to create cervical cancer educational materials that will be culturally and linguistically meaningful to Haitian women. ***Study Procedures/Nº. of Participants/Duration:*** If you are interested in taking part in this research study, I will interview you for about one hour at this time, and I will ask to consult with you from time to time as the research continues so I can get your feedback and opinions about things I have learned. This may involve a telephone call or an in-person conversation. I will talk with a total of 6 to 10 individuals like you who have special insight into your community during the course of this research. ***No experimental procedures:*** This research project does not involve any type of experiment, only interviews. ***Foreseeable Risks:*** There are no foreseeable risks to taking part in this research study. ***Benefits:*** There are no known direct benefits to you for taking part in this study; however, your participation would contribute to the general knowledge about Haitian women's health and culture that this study aims to describe and that will be used to create health education materials for Haitian women. ***Compensation:*** There is no compensation for taking part in this study. ***Alternatives:*** Right now, this is the only study going on among Haitian women in our community about these topics. There are no other known studies being conducted. ***Voluntary Participation:*** You don't have to take part in this study if you don't want to. Your participation is completely voluntary. If you do not wish to take part, you will not lose any benefits. You may also stop taking part any time, and there are no penalties. ***Confidentiality:*** *If you choose to take part, your identity will be protected and your name will not be attached to this paper or any other document. The people who will be allowed to have access to this information are myself and officials who ensure that this study is being done in an ethical way, and this includes the University of South Florida's Office of Research Integrity, the Florida Department of Health, the Food and Drug Administration and the Department of Health and Human Services. I will give you my contact information and that of the University in case you have questions or concerns about this study or anything else at a later time. [provide study contact information sheet].*



**APPENDIX B (continued)**

*This interview will not be tape recorded. Because what you have to say is so important, I will take notes as we talk. You may choose to not answer any question, or stop the interview at any time. Are you interested in taking part? \_\_\_\_ Do you have any questions before we start?* \_\_\_\_\_

1. What do you think are the biggest problems that Haitian people in the Tampa Bay area face?

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1. a. What are the strengths of the local Haitian community?

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2. What health issues do you think are the most important for Haitians here?

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3. How do you think cancer affects Haitian immigrants?

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4. What do you think causes cancer?

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**APPENDIX B (continued)**

5. Besides doctors or nurses, who can Haitian people go to when they have an illness here?

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6. What kinds of Haitian traditional healers are found in Tampa/Orlando?

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7. When would someone consult with a traditional healer?

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8. What are some of the beliefs in Haitian culture about cancer?

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9. How do you think Haitian women perceive cancer? Cervical cancer?

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10. What are some of the terms Haitians use to talk about cancer? Cervical cancer?

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## APPENDIX B (continued)

11. What else do you think I should think about as this study moves forward?

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These are all the questions I have for you right now. Thank you very much for sharing your insight with me. I appreciate very much your time. Do you have any questions now that we've finished?

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## APPENDIX C

### Semistructured Interview Guide: Preliminary Sample of Women

**VERBAL INFORMED CONSENT STATEMENT:** *Hello, my name is Janelle Menard. I am a student at the University of South Florida and I'm working on a study about culture and women's health among Haitian women who were born in Haiti or elsewhere in the Caribbean and live here now. Would you be willing to answer some questions about this topic?*

NO: I'm sorry you won't be taking part in this study. Thank you for your time.

YES: Thanks. Before we begin, I'd like to make sure that you understand what we are going to do. Here's an information sheet with details about the study [provide info sheet]. I'd like to talk with you for about an hour about these very important women's health issues for the Haitian community. Everything you say will be kept confidential and you don't need to answer any questions you don't want to. Because what you have to say is very important to me, I will take notes during our conversation. I will not tape record this interview. Please take a minute to look at the information sheet and I can answer any questions you might have.

[...Pause...]

Do you have any questions? [Address any questions or concerns.]

Are you still interested in taking part? \_\_\_\_\_

NO: I'm sorry you won't be taking part in this study. Thank you for your time.

YES: OK – let's begin...

**DEMOGRAPHICS:** *To begin, I would like to know a little bit about you and your thoughts about living in this city in Florida. Please take a moment to fill out some basic questions about you and your household. Please feel free to ask me any questions if you're not sure about a question. GIVE DEMO FILLOUT SHEET\*\*\*PROVIDE TIME FOR ANSWERS*

### APPENDIX C (continued)

Thanks for taking part in this study. Please take a moment to answer these questions about you and your household. There are no right or wrong answers. You don't have to write an answer down if you don't want to. Remember, your identity is protected, so please don't write your name on this form.

**Mesi anpil!**

1. Please tell me where you were born in Haiti.											
1.a. How long did you live in Haiti?											
1.b. How old were you when you came to live in the U.S.?											
2. What year were you born?											
3. How long have you lived in the U.S.?											
4. What is the highest grade of school or degree you finished?	(for example, primary school, high school, college, or more than college)										
5. How many children do you have?											
5.a. How many people live in your household?											
6. Thinking about your total household income, which category would you say you fit into? (Please circle one) <table style="width: 100%; border: none;"> <tr> <td style="width: 50%;">1) \$10,000 per year or less</td> <td style="width: 50%;">5) \$40,500 – 50,000 per year</td> </tr> <tr> <td>2) \$10,500 – 20,000 per year</td> <td>6) \$50,500 – 60,000 per year</td> </tr> <tr> <td>3) \$20,500 – 30,000 per year</td> <td>7) \$60,500 – 70,000 per year</td> </tr> <tr> <td>4) \$30,500 – 40,000 per year</td> <td>8) \$70,500 or more per year</td> </tr> <tr> <td></td> <td>9) Prefer not to say</td> </tr> </table>		1) \$10,000 per year or less	5) \$40,500 – 50,000 per year	2) \$10,500 – 20,000 per year	6) \$50,500 – 60,000 per year	3) \$20,500 – 30,000 per year	7) \$60,500 – 70,000 per year	4) \$30,500 – 40,000 per year	8) \$70,500 or more per year		9) Prefer not to say
1) \$10,000 per year or less	5) \$40,500 – 50,000 per year										
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3) \$20,500 – 30,000 per year	7) \$60,500 – 70,000 per year										
4) \$30,500 – 40,000 per year	8) \$70,500 or more per year										
	9) Prefer not to say										
7. What is your religion? (such as Baptist, Catholic, 7 <sup>th</sup> Day Adventist, etc.)											
8. What is your marital status? (please mark one)	<input type="checkbox"/> Married <input type="checkbox"/> Separated <input type="checkbox"/> Divorced <input type="checkbox"/> Never married <input type="checkbox"/> Widow										

### APPENDIX C (continued)

*Thanks very much. I'll continue now with a few other questions to learn a little more about you.*

9. What are the languages that you speak fluently?	
9.a. What language do you speak most at home?	
9.b. Do you have a language or languages that you prefer to read in?	No Yes: Which one(s)? _____
10. What do you do for a living? Or are you now retired?	
10.a. Is that full or part time? About how many hours per week do you work?	
10.b. What is that like?	
11. Do you have health insurance?	No Yes: What kind? _____ (prompts: private, Medicaid, County Health plan, etc).

**APPENDIX C (continued)**

12. Do you have a regular doctor or clinic you can go to when you need to?	
13. How long have you lived in Tampa/Orlando?	
13.a. How do you like it here?	
13.b. How often to you get to go back to Haiti?	

**NOTES:**

## APPENDIX C (continued)

**HEALTH BELIEFS, OPINIONS, KNOWLEDGE** Thank you very much. In these next few questions, I'd like to learn your opinions about important health topics, including women's health issues. Your thoughts about these issues are important to me, and there are no right or wrong answers.

(Suggested prompt to use as needed to build lists: Is there anything else you can think of?)

14. In your opinion, what are all the things a woman can do to stay healthy?

1	16
2	17
3	18
4	19
5	20
6	21
7	22
8	23
9	24
10	25
11	26
12	27
13	28
14	29
15	30

15. What are all the illnesses that you think are important for Haitian women to know about?

1	11
2	12
3	13
4	14
5	15
6	16
7	17
8	18
9	19
10	20



**APPENDIX C (continued)**

15.a. Of all these illnesses you mentioned, which ones do you feel are the most serious?

1	6
2	7
3	8
4	9
5	10

16. What other health issues do you think are important to Haitian women here?

1
2
3
4
5
6
7
8
9
10

*One of the health topics I study is women’s cancers, and how we can try to prevent it or catch it early. I would like to get your opinions in the next few questions about cancer.*

17. When you hear the word “cancer,” what comes to mind?

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18. Who do you think can get cancer?

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### APPENDIX C (continued)

19. What are some things you can think of that can cause cancer? (prompt: is there anything else you want to add?)

1	16
2	17
3	18
4	19
5	20
6	21
7	22
8	23
9	24
10	25
11	26
12	27
13	28
14	28
15	30

20. What are all the different types of cancer you've heard of? (prompt: *for example, for women vs. men's types of cancer*)

1	6
2	7
3	8
4	9
5	10

20.a. Of all the kinds of cancer you mentioned, which ones do you think are the most serious?

1	6
2	7
3	8
4	9
5	10

## APPENDIX C (continued)

21. What are all the different ways you think or that you have heard about to prevent cancer?

1	6
2	7
3	8
4	9
5	10

21.a. Of all these ways you mentioned, which ones do you think are the most effective?

1	6
2	7
3	8
4	9
5	10

22. What are all the different types of treatments that you have heard about for cancer?

1	6
2	7
3	8
4	9
5	10

22.a. Of all these treatments you mentioned, which ones do you think are the best?

1	6
2	7
3	8
4	9
5	10

### APPENDIX C (continued)

23. Who are the types of people who can treat cancer? (prompts: doctors, nurses, traditional healers, clergy)

1	6
2	7
3	8
4	9
5	10

23.a. Of all the types of people you mentioned who can treat cancer, who do you think are the most effective?

1	6
2	7
3	8
4	9
5	10

*Thanks for sharing your opinions with me about cancer. The next few questions deal with important health topics that specifically apply to women, and another topic that I study, which is women's gynecological health.*

24. There are many different types of feminine hygiene products that women sometimes use, like soaps and douches. For example, Lemosol, or Borasol. What are the types of products that you know about?

Name/type	What is this product used for?
1	
2	
3	
4	
5	
6	
7	
8	
9	
10	

### APPENDIX C (continued)

25. In your opinion, what are all the things that women can do to maintain their gynecological health?

1	6
2	7
3	8
4	9
5	10

*The next few questions are about cervical cancer. I would like to know your opinions about this topic.*

26. Please tell me all the things you have heard about cervical cancer. (If hasn't heard of it, skip to Q.33).

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27. Who do you think can get cervical cancer? (prompt: any woman?)

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28. What do you think are all the things that can cause cervical cancer?

1	6
2	7
3	8
4	9
5	10

### APPENDIX C (continued)

29. What do you think women can do to prevent cervical cancer?

1	6
2	7
3	8
4	9
5	10

(If provided more than one answer above):

29.a. Of all the things that you mentioned that women can do to prevent cervical cancer, which ones are most important?

1	6
2	7
3	8
4	9
5	10

30. What are the ways that you think cervical cancer can be treated?

1	6
2	7
3	8
4	9
5	10

(If provided more than one answer above):

30.a. Of all these ways you mentioned, which ones do you think are most effective?

1	6
2	7
3	8
4	9
5	10

**APPENDIX C (continued)**

31. Who are the types of people who can treat cervical cancer?

1	6
2	7
3	8
4	9
5	10

(If provided more than one answer above):

31.a. Of these people, who do you think would be the most effective?

1	6
2	7
3	8
4	9
5	10

32. What do you think are some symptoms of cervical cancer?

1	6
2	7
3	8
4	9
5	10

33. Have you ever heard of the Pap test? \_\_\_\_\_

IF NO: Skip to Q. 34.

IF YES: 33.a. Please tell me what you've heard or know about it. What do you think it is a test for?

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34. Have you ever heard of the human papillomavirus, sometimes called HPV? \_\_\_\_\_

**APPENDIX C (continued)**

IF NO: Skip to Q. 35.

IF YES: 34.a. Please tell me what you've heard or know about it.

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35. Have you ever heard of a vaccine for cervical cancer?

IF NO: Skip to Information, then Q. 36.

IF YES: 35.a. Please tell me what you've heard or know about it.

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*Okay. I'll share with you some information about "HPV" and cervical cancer. The human papillomavirus, also called "HPV," is now known as a major cause of cervical cancer. This is a virus that most people are exposed to if they've ever had sex. Most people never even know they have it, and they don't have any problems. But for some women, if it isn't caught early, it can cause cervical cancer if it goes untreated. There is a new vaccine that prevents women from getting HPV, which then lowers their risk of getting cervical cancer. Because vaccines work best when they are given early, before a person has ever been exposed to an illness, this vaccine is recommended for young girl adolescents and women aged 9 - 26 years.*

36. Are there any other women's reproductive health topics that you think are important to know about?

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**APPENDIX C (continued)**

36.a. I've heard about a lot of plants and teas and tisanes that can be used to treat different types of illnesses, or just to help a person feel better. Are there any home remedies like these that Haitian women use for reproductive health?

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36.b. When thinking about women's reproductive health, relationships with men are important topics. Can you tell me a little about the different kinds of relationships that exist between men and women in the Haitian community?

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36.c. I've heard that men sometimes have relationships with women outside of their main relationship or marriage. Please tell me more or what you've heard about this practice. Is there a name for this practice?

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36.d. How do women feel about this? What can they do?

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*These are almost all the questions I have for you. The last couple of questions ask your opinions about the best ways you think women should get important health information.*



## APPENDIX D

### Semistructured Interview Guide: Secondary Sample of Women

**Verbal Informed Consent statement:** *Hello, my name is Janelle Menard. I am a student at the University of South Florida and I'm working on a study about culture and women's health among Haitian women who were born in Haiti or elsewhere in the Caribbean and live here now. In exchange for your valuable time, you will receive a gift card worth \$20 to Wal-Mart. Would you be willing to answer some questions about this topic?*

NO: *I'm sorry you won't be taking part in this study. Thank you for your time.*

YES: *Thanks. Before we begin, I'd like to make sure that you understand what we are going to do. Here's an information sheet with details about the study [provide info sheet]. I'd like to talk with you for about two hours about these very important women's health issues for the Haitian community. Everything you say will be kept confidential and you don't need to answer any questions you don't want to. Because what you have to say is very important to me, I will take notes during our conversation. I will not tape record this interview. Please take a minute to look at the information sheet and I can answer any questions you might have.*

[...Pause...]

*Do you have any questions? [Address any questions or concerns.]*

*Are you still interested in taking part?\_\_\_\_\_*

NO: *I'm sorry you won't be taking part in this study. Thank you for your time.*

YES: *OK - let's begin...*

**PART 1: DEMOGRAPHICS:** *TO BEGIN, I WOULD LIKE TO LEARN SOME BASIC INFORMATION ABOUT YOUR HOUSEHOLD. PLEASE TAKE A MOMENT TO FILL OUT SOME BASIC QUESTIONS ABOUT YOU AND YOUR HOUSEHOLD. PLEASE FEEL FREE TO ASK ME ANY QUESTIONS IF YOU'RE NOT SURE ABOUT A QUESTION. GIVE DEMOGRAPHIC FORM \*\*\*PROVIDE TIME FOR ANSWERS \*\*\* **IF INFORMANT HAS LOW LITERACY, ASK THE DEMOGRAPHIC QUESTIONS INSTEAD.***

## APPENDIX D (continued)

Thanks for taking part in this study. Please take a moment to answer these questions about you and your household. There are no right or wrong answers. You don't have to write an answer down if you don't want to. Remember, your identity is protected, so please don't write your name on this form.

**Mesi anpil!**

1. Please tell me where you were born in Haiti.	
1.a. How long did you live in Haiti?	
1.b. How old were you when you came to live in the U.S.?	
2. What year were you born?	
3. How long have you lived in the U.S.?	
4. What is the highest grade of school or degree you finished?	(for example, primary school, high school, college, or more than college)
5. How many children do you have?	
5.a. How many people live in your household?	
<p>6. Thinking about your total household income, which category would you say you fit into? (Please circle one)</p> <div style="display: flex; justify-content: space-between;"> <div style="width: 45%;"> <p>5) \$10,000 per year or less</p> <p>6) \$10,500 – 20,000 per year</p> <p>7) \$20,500 – 30,000 per year</p> <p>8) \$30,500 – 40,000 per year</p> </div> <div style="width: 45%;"> <p>5) \$40,500 – 50,000 per year</p> <p>6) \$50,500 – 60,000 per year</p> <p>7) \$60,500 – 70,000 per year</p> <p>8) \$70,500 or more per year</p> <p>9) Prefer not to say</p> </div> </div>	
7. What is your religion? (such as Baptist, Catholic, 7 <sup>th</sup> Day Adventist, etc.)	
8. What is your marital status? (please mark one)	<input type="checkbox"/> Married <input type="checkbox"/> Separated <input type="checkbox"/> Divorced <input type="checkbox"/> Never married <input type="checkbox"/> Widow

**APPENDIX D (continued)**

*Thanks very much for your answers. I'll keep going now with a few other questions to learn a little more about you.*

9. What are the languages that you speak fluently?

\_\_\_\_\_

9.a. What language do you speak most at home?

\_\_\_\_\_

9.b. Do you have a language or languages that you prefer to read in? \_

No \_\_\_\_\_

Yes: Which one(s)? \_\_\_\_\_

10. What do you do for a living? Or are you now retired?

\_\_\_\_\_

If Retired or unemployed, skip to Question 11.

10.a. Is that full or part time? \_\_\_\_\_

10.b. About how many hours per week do you work? \_\_\_\_\_

11. Do you have health insurance? \_\_\_\_\_

if No- Probe: Medicaid, County Health Plan? \_\_\_\_\_

if Yes: What type is it? \_\_\_\_\_

12. How long have you lived in the US?

\_\_\_\_\_

12.a. How long have you lived in Tampa/Orlando? \_\_\_\_\_

12. How often do you get to go back to Haiti?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

*Thanks so much for sharing with me so that I can learn a little more about you. Do you have any questions for me at this point?*

**APPENDIX D (continued)**

**Part 2: HEALTH BELIEFS, OPINIONS, KNOWLEDGE** *In these next few questions, I'd like to learn your opinions about important women's health issues that I study, including women's gynecological health and hygiene. Your thoughts and opinions are important to me, and there are no right or wrong answers.*

15. What health issues are most important to you as woman?

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16. In general, when would you go see a medical doctor?

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16.a. If you need to see a doctor for any reason, is that easy for you to do? (probes: Does it take a lot of time? Why is it hard?)

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15. I've heard that fibroids are a problem for a lot of women. Can you tell me more about fibroids? (Probe: serious illness?)

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15.a. What are some causes of fibroids?

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15.b. What treatments are out there for fibroids? (Probe for biomedical and traditional treatments)

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15.c. What happens if fibroids aren't treated?

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**APPENDIX D (continued)**

16. Thinking about women’s intimate health and hygiene in general, what do you think women can do to take care of themselves? (Probe: For their *sante pati intim?*)

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17. I’ve learned about several different types of commercial products that women can use for intimate hygiene and health. Some of the products come from Haiti and other countries. I’m going to name the ones I’ve heard about, and I’d like to get your opinions about each one. If you don’t know one of them, that’s okay.

**[STATE PRODUCT NAME AND ASK LIST OF QUESTIONS WITH EACH PRODUCT]**

<b>Product Name</b>	<b>Question</b>
Borasol	What is _____ used for?
	How do you prepare it?
	How is _____ taken/applied?
	When is _____ used? (probe: how often?)
	How do you know when it is working?
	What does _____ do?
	Why use _____ over other products?
	Where can you get _____ ?
	How do you learn how to use _____ ? (Probe: who teaches you?)

**APPENDIX D (continued)**

Hygisol	What is _____ used for?
	How do you prepare it?
	How is _____ taken/applied?
	When is _____ used? (probe: how often?)
	How do you know when it is working?
	What does _____ do?
	Why use _____ over other products?
	Where can you get _____ ?
	How do you learn how to use _____ ? (Probe: who teaches you?)
Lemisol	What is _____ used for?
	How do you prepare it?
	How is _____ taken/applied?
	When is _____ used? (probe: how often?)
	How do you know when it is working?
	What does _____ do?
	Why use _____ over other products?
	Where can you get _____ ?
	How do you learn how to use _____ ? (Probe: who teaches you?)



**APPENDIX D (continued)**

Pemegenet (Potassium permanganate)	What is _____ used for?
	How do you prepare it?
	How is _____ taken/applied?
	When is _____ used? (probe: how often?)
	How do you know when it is working?
	What does _____ do?
	Why use _____ over other products?
	Where can you get _____ ?
	How do you learn how to use _____ ? (Probe: who teaches you?)
Alum	What is _____ used for?
	How do you prepare it?
	How is _____ taken/applied?
	When is _____ used? (probe: how often?)
	How do you know when it is working?
	What does _____ do?
	Why use _____ over other products?
	Where can you get _____ ?
	How do you learn how to use _____ ? (Probe: who teaches you?)

**APPENDIX D (continued)**

Gwo savon or savon lavé	What is _____ used for?
	How do you prepare it?
	How is _____ taken/applied?
	When is _____ used? (probe: how often?)
	How do you know when it is working?
	What does _____ do?
	Why use _____ over other products?
	Where can you get _____ ?
	How do you learn how to use _____ ? (Probe: who teaches you?)
Vinaigre	What is _____ used for?
	How do you prepare it?
	How is _____ taken/applied?
	When is _____ used? (probe: how often?)
	How do you know when it is working?
	What does _____ do?
	Why use _____ over other products?
	Where can you get _____ ?
	How do you learn how to use _____ ? (Probe: who teaches you?)

**APPENDIX D (continued)**

Ogynol	What is _____ used for?
	How do you prepare it?
	How is _____ taken/applied?
	When is _____ used? (probe: how often?)
	How do you know when it is working?
	What does _____ do?
	Why use _____ over other products?
	Where can you get _____ ?
	How do you learn how to use _____ ? (Probe: who teaches you?)

Protectyl	What is _____ used for?
	How do you prepare it?
	How is _____ taken/applied?
	When is _____ used? (probe: how often?)
	How do you know when it is working?
	What does _____ do?
	Why use _____ over other products?
	Where can you get _____ ?
	How do you learn how to use _____ ? (Probe: who teaches you?)

**APPENDIX D (continued)**

Intimiss	What is _____ used for?
	How do you prepare it?
	How is _____ taken/applied?
	When is _____ used? (probe: how often?)
	How do you know when it is working?
	What does _____ do?
	Why use _____ over other products?
	Where can you get _____ ?
	How do you learn how to use _____ ? (Probe: who teaches you?)
Neoprosone (savon bleu)	What is _____ used for?
	How do you prepare it?
	How is _____ taken/applied?
	When is _____ used? (probe: how often?)
	How do you know when it is working?
	What does _____ do?
	Why use _____ over other products?
	Where can you get _____ ?
	How do you learn how to use _____ ? (Probe: who teaches you?)

**APPENDIX D (continued)**

*Thank you very much for helping me learn more about these products. In addition to the ones we talked about, are there any others that you know of that we didn't mention yet?*

*LIST AND ASK PER PATTERN ABOVE*

A.

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B.

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C.

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*Thank you for helping me to learn more about these products.*

## APPENDIX D (continued)

18. *I'm also interested in how women use home remedies from Haitian culture for their health. Specifically, I'd like to know a little more about how women use some plants for health and intimate hygiene reasons. I've learned about several plants that I'd like to get your opinions about, so I can understand them better. If you don't know some of them, that's OK.*

[STATE PLANT NAME AND ASK LIST OF QUESTIONS WITH EACH PLANT]

Plant Name(s)	Question
Ti bonm	What is _____ used for?
	How do you prepare it? (Probe: What parts are used? Is it boiled/steeped? How long?)
	How is _____ taken/applied?
	When is _____ used? (probe: About how often?)
	How do you know when it is working?
	What does _____ do?
	Why use _____ over other plant remedies?
	Where can you get _____?
	How do you learn how to use _____ ? (Probe: who teaches you?)

**APPENDIX D (continued)**

Palma christi  (or)  Maskreti	What is _____ used for?
	How do you prepare it? (Probe: what parts are used?)
	How is _____ taken/applied?
	When is _____ used? (probe: how often?)
	How do you know when it is working?
	What does _____ do?
	Why use _____ over other plant remedies?
	Where can you get _____ ?
	How do you learn how to use _____ ? (Probe: who teaches you?)

Citron  or  Dlo sitwon	What is _____ used for?
	How do you prepare it? (Probe: what parts are used?)
	How is _____ taken/applied?
	When is _____ used? (probe: how often?)
	How do you know when it is working?
	What does _____ do?
	Why use _____ over other plant remedies?
	Where can you get _____ ?
	How do you learn how to use _____ ?

### APPENDIX D (continued)

Pois congo or Pwa kongo	What is _____ used for?
	How do you prepare it? (Probe: what parts are used?)
	How is _____ taken/applied?
	When is _____ used? (probe: how often?)
	How do you know when it is working?
	What does _____ do?
	Why use _____ over other plant remedies?
	Where can you get _____ ?
	How do you learn how to use _____ ? (Probe: who teaches you?)
Kalbas kouran	What is _____ used for?
	How do you prepare it? (Probe: what parts are used?)
	How is _____ taken/applied?
	When is _____ used? (probe: how often?)
	How do you know when it is working?
	What does _____ do?
	Why use _____ over other plant remedies?
	Where can you get _____ ?
	How do you learn how to use _____ ? (Probe: who teaches you?)



**APPENDIX D (continued)**

Asosi or Asowosi	What is _____ used for?
	How do you prepare it? (Probe: what parts are used?)
	How is _____ taken/applied?
	How do you know when it is working?
	What does _____ do?
	Why use _____ over other plant remedies?
	Where can you get _____ ?
	How do you learn how to use _____ ? (Probe: who teaches you?)

*I appreciate your help with teaching me about these plants and their uses. In addition to these that we've talked about, are there any others that you know about that women can use for intimate health and hygiene?*

**LIST AND ASK PER PATTERN ABOVE**

A.

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**APPENDIX D (continued)**

B.

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C.

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19. If you ever need to know about a certain plant to use for health purposes, who do you ask?

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20. In general, when in life do women start doing their twalet with plants or products?

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21. When in life do women stop doing their twalet with plants or products?

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**APPENDIX D (continued)**

22. How often do women use plants and products for their twalet?

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23. What would happen if a woman decided she didn't want to use any products like Borasol or Hygisol or any remed lakay for her twalet?

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*Thank you for your opinions about these women's hygiene topics. I appreciate your time.*

*The next few questions have to do with an important area of women's health that includes women's cancers.*

24. When you think of the word "cancer," what comes to mind?

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25. Have you ever heard of cervical cancer, sometimes called kanse nan kol matris or kanse nan matris?

If YES: Please tell me what you have heard about it.

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*If NO: SKIP TO QUESTION 26.*

**NOTES:**

**APPENDIX D (continued)**

25.a.

(CERVICAL CANCER)	Who do you think can get cervical cancer?
	What are some things that can cause cervical cancer?
	How do you think you can prevent cervical cancer?
	Who can people go to for treatment if they have cervical cancer?
	What are some of the treatments you've heard of cervical cancer?

26. Have you ever heard of the Pap test, sometimes called a Pap smear?

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**IF NO: Skip to Question 27.**

IF YES: Please tell me what you have heard about it (Probe: What is it a test for?)

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26.a. Have you had a Pap test before? \_\_\_\_\_

IF NO or DK: Skip to Question 27.

IF YES: Please tell me about that. (Probes: Can you describe the experience? Where did you have it done? Was the provider a man or a woman?)

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**APPENDIX D (continued)**

26.b. How often do you get a Pap test?

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27. Have you ever heard of something called the human papillomavirus, sometimes called HPV? \_\_\_\_\_

**IF NO: Skip to Question 28.**

IF YES: Please tell me what you have heard about it.

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28. Have you ever heard of a vaccine for cervical cancer? \_\_\_\_\_

**IF NO: Read passage & skip to Question 29.**

IF YES: Please tell me what you have heard about it.

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[READ PASSAGE]

*Okay. I'll share with you some information about "HPV" and cervical cancer. The human papillomavirus, also called "HPV," is now known as a major cause of cervical cancer. This is a virus that most people are exposed to if they've ever had sex. Most people never even know they have it, and they don't have any problems. But for some women, if it isn't caught early, it can cause cervical cancer if it goes untreated. There is a new vaccine that prevents women from getting HPV, which then lowers their risk of getting cervical cancer. Because vaccines work best when they are given early, before a person has ever been exposed to an illness, this vaccine is recommended for young girl adolescents and women aged 9 – 26 years.*

29. Knowing this information, would you consider getting the vaccine for your daughter?

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**APPENDIX D (continued)**

29.a. Why/why not?

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29.b. Knowing this information, would you consider getting the vaccine for your son, once it becomes available?

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29.c. Why/why not?

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30. In general, how do you like to get information about women's intimate health topics? (Probes: hear it, read it, see it)

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*Thanks very much for sharing your thoughts and opinions with me. Do you have any questions for me so far? (Answer & continue).*

**NOTES:**

**APPENDIX D (continued)**

**PART 3: Traditional Healers & Home Remedies Knowledge & Beliefs**

*I've learned that, in addition to medical doctors, there are several different types of people who have healing abilities from Haitian culture. I'd like to learn your opinions about the types of healer's I have heard about, in these next few questions.*

31. First of all, in general, when might a woman want to go see a:

<b>Healer type</b>	<b>Condition(s) stated</b>
Dokte fey	
Saj fanm	
Manbo	
Houngan	

31.a. Besides these healers, who are other people from Haitian culture that a woman might go to for women's health reasons?

<b>Healer type named</b>	<b>Condition(s) stated</b>
A.	
B.	
C.	
D.	
E.	

32. In your opinion, in what cases would a woman go to healers like these, instead of a doctor or a clinic?

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**APPENDIX D (continued)**

32.a. When might a woman go to both a doctor, and a traditional healer at the same time?

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33. I've heard about how illnesses can sometimes be "sent," or put on someone, as opposed to illnesses that just happen naturally. In Creole, I've heard them called "maladi mò, or ekspedisyon" compared to "maladi Bondye." Can you help me understand the difference between these types of illnesses?

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33.a. What types of illnesses might be thought of as "maladi majik" or "maladi mò?"

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33.b. What types of illnesses might be thought of as "maladi Bondye?"

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33.c. Thinking about how we just talked about cancer, how would cancer be thought of, as maladi majik or as a maladi Bondye?

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**APPENDIX D (continued)**

33.d. What type of illness would cervical cancer be thought of as?

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*Thanks for helping me to understand the differences in these types of illnesses. The last couple of questions are about relationships with men, since relationships can affect women's health. I'd like to get your feedback on some things I've heard about, and make sure I understand them correctly.*

34. First, I've heard about "plasaj." Can you tell me what this means exactly?

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34.a. Is plasaj something that is more common in older men or younger men?

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35. When men have "fanm deyo" or outside women, how do men's wives or partners feel about this?

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**APPENDIX D (continued)**

35.a. What can women do about it?

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36. When do women accept that their husbands or partners have fanm deyo?

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36.a. When would women not tolerate it if their husbands or partners have fanm deyo?

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37. Some women have explained that the fanm deyo will put illnesses on the women whose husbands or partners they are with; can you help me understand what that means?

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*Thank you very much for your answers. I really appreciate your time and the opinions and knowledge you shared with me. These are all the questions I have.*

*Do you have any questions for me? (If YES, answer).*

*If NO: Thank you again. I really enjoyed talking with you.*

## APPENDIX D (continued)

[GIVE PARTICIPANT COMPENSATION INCENTIVE]

**NOTES:**

## APPENDIX E

### Physician Interview Guide

#### Verbal Informed Consent Statement:

Hello, my name is Janelle Menard. I am a doctoral candidate in Anthropology at the University of South Florida. Study involves Research: I'm conducting dissertation research about Haitian culture and immigrant women's health. Study Purpose: The results of this research will be applied to the creation of culturally and linguistically competent cervical cancer health education materials. Study Procedures/Nº. of Participants/Duration: I am talking with Haitian women and Haitian physicians to get insight into what health issues are important in the community, and specifically, perspectives about cancer and cervical cancer. I will interview a total of 5-10 Haitian physicians in both Tampa and Orlando about these topics and I would like to get your opinion. If you are interested, I will interview you one time at a time & place convenient for you, and the interview will take about 30 – 45 minutes. No experimental procedures: This research project does not involve any type of experiment, only interviews. Foreseeable Risks: There are no foreseeable risks to taking part in this research study. Benefits: There are no known direct benefits to you for taking part in this study; however, your participation would contribute to the general knowledge about Haitian women's health that this study aims to describe and that will be used to create health education materials for Haitian women. Compensation: There is no compensation for taking part in this study. Alternatives: You can decline to take part in this interview or otherwise stop the interview at any time. Right now, to my knowledge, there is no other ongoing local research about these topics for this population. Voluntary Participation: You don't have to take part in this study. Your participation is completely voluntary. If you do not wish to take part, you will not lose any benefits. You may also stop taking part any time, and there are no penalties. Confidentiality: If you choose to participate, your identity will be protected and your name will not be attached to this paper or any other document or future project reports. The people who will be allowed to have access to this study information are myself and my assistant. The other people who will have access to this study information are officials who ensure that this study is conducted ethically and in accordance with human subjects protections, and this includes the University of South Florida's Office of Research Integrity, the Florida Department of Health, the Food and Drug Administration and the Department of Health and Human Services. I will give you my contact information and that of the University in case you have questions or concerns about this

**APPENDIX E (continued)**

study or anything else at a later time. *[provide study contact information sheet].*

Because what you have to say is very important to me, I will take notes during our conversation. I will not tape record this interview. Are you interested in taking part?\_\_\_\_\_

*No:* I'm sorry you won't be taking part in this study. Thank you for your time.

*Yes:* Thank you for agreeing to take part. Do you have any questions before we start?

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*To begin, I would like to know a little bit about you.*

1. Please tell me where you were born.

\_\_\_\_\_

2. How long have you lived in the U.S.? \_\_\_\_\_

3. What type of medicine do you practice? \_\_\_\_\_  
What is that like?

\_\_\_\_\_

4. What do you think are some of the most important social issues for Haitians who emigrate to the US?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

5. What do you think are the most important health issues for Haitian women who have emigrated to the US?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

6. How do you think cancer impacts Haitian women here in Florida?

\_\_\_\_\_  
\_\_\_\_\_

**APPENDIX E (continued)**

7. What would you estimate is the rate of cervical abnormalities or cervical cancer that you have found among Haitian women here in your practice?

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8. How do you think Haitian women perceive the Pap test?

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9. What do you think are some of the barriers to health care for Haitian women here?

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10. Besides doctors or nurses, where else, or to whom else, can Haitian women go for treatment when they are ill?

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11. What are some home remedies you know of, if any, that Haitian women use for women's health purposes?

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12. Please tell me your opinions about how disease prevention is perceived in the Haitian community.

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**APPENDIX E (continued)**

13. How do you think cancer prevention is perceived in the Haitian community?

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14. Please tell me about how you think culture may impact Haitian women's beliefs about cancer and specifically, cervical cancer.

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15. Based on your clinical observations, what recommendations would you have for creating effective cervical cancer health education materials for Haitian immigrant women?

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16. What do you think about the new HPV vaccine?

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17. Given your clinical experience, how do you think this vaccine would be perceived among Haitian immigrant women?

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18. What suggestions would you have for health educators who want to convey information about the cervical cancer vaccine to Haitian immigrant women?

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## APPENDIX E (continued)

These are all the questions I have for you. Thank you very much for your time. Now that the interview questions are finished, do you have any questions for me?

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*Notes:*



## APPENDIX F

### Survey Instrument for *Pap Tès Lakay* Project, Little Haiti

ID# \_\_\_\_\_

Date \_\_\_\_\_

CHW Name \_\_\_\_\_

#### **INTRODUCTION:**

BEFORE WE GET STARTED, I AM GOING TO ASK YOU SOME QUESTIONS TO MAKE SURE THAT YOU ARE ELIGIBLE TO PARTICIPATE AND TO GATHER SOME INFORMATION ABOUT YOUR HEALTH. SOME OF THE QUESTIONS ARE PERSONAL AND IF AT ANY TIME YOU FEEL UNCOMFORTABLE ANSWERING THEM, WE WILL STOP THE INTERVIEW UNTIL YOU ARE READY TO CONTINUE. ALL OF THIS INFORMATION WILL BE KEPT CONFIDENTIAL AND CAN NEVER BE LINKED BACK TO YOU. DO YOU HAVE ANY QUESTIONS BEFORE WE BEGIN?

I AM GOING TO START BY ASKING YOU SOME QUESTIONS ABOUT CANCER AND YOUR REPRODUCTIVE HEALTH.

01. Is your age between...

- |              |   |
|--------------|---|
| 18 -25 ..... | 1 |
| 26-30 .....  | 2 |
| 31-35 .....  | 3 |
| 36-40 .....  | 4 |
| 41-45 .....  | 5 |
| 46-50 .....  | 6 |
| 51-55 .....  | 7 |
| 56-60 .....  | 8 |

**APPENDIX F (continued)**

61-65.....	9
66-70.....	10
OVER 70 YEARS OLD.....	11
 02. Have you ever been told by a health care provider that you had cancer?	
YES.....	1
NO.....	2
<b>(SKIP TO 04.)</b>	
YES, BUT IT WAS A MIS-DIAGNOSIS .....	3
<b>(SKIP TO 04.)</b>	
DON'T KNOW .....	4
 03. What type of cancer was it, or in what part of the body did the cancer start?	
[CODE ALL THAT APPLY.]	
BLADDER CANCER.....	1
BONE CANCER.....	2
BREAST CANCER .....	3
<b>CERVICAL CANCER (CANCER OF THE CERVIX)...</b>	<b>4</b>
<b>(INELIGIBLE CLOSING)</b>	
COLON CANCER.....	5
ENDOMETRIAL CANCER (CANCER OF THE UTERUS)..	6
HEAD AND NECK CANCER.....	7
HODGKIN'S LYMPHOMA.....	8
LEUKEMIA/BLOOD CANCER.....	9
LIVER CANCER .....	10
LUNG CANCER.....	11
MELANOMA .....	12
NON-HODGKIN'S LYMPHOMA .....	13
OTHER SKIN CANCER.....	14
ORAL CANCER .....	15
<b>OVARIAN CANCER.....</b>	<b>16</b>
<b>(INELIGIBLE CLOSING)</b>	
PANCREATIC CANCER .....	17
PHARYNGEAL (THROAT) CANCER .....	18
RECTAL CANCER.....	19
RENAL (KIDNEY) CANCER.....	20

**APPENDIX E (continued)**

STOMACH CANCER ..... 21  
**UTERINE CANCER ..... 22**  
**(INELIGIBLE CLOSING)**  
OTHER (SPECIFY) \_\_\_\_\_ 23

04. How old were you when you had your first menstrual period? |\_\_\_\_\_|  
YEARS OLD

05. Have your menstrual periods stopped permanently?  
YES ..... 1  
NOT SURE, PERIODS LESS FREQUENT ..... 2 **(SKIP**  
**TO 07.)**  
NO ..... 3 **(SKIP**  
**TO 08.)**

06. How old were you when your menstrual periods stopped permanently?  
|\_\_\_\_\_| YEARS OLD

07. Did your menstrual periods stop because you had surgery to remove  
your uterus and /or ovaries?  
YES ..... 1  
**(INELIGIBLE CLOSING)**  
NO ..... 2

**INELIGIBLE CLOSING:**  
**THANK YOU FOR YOUR TIME TODAY, BUT YOU ARE NOT ELIGIBLE TO**  
**PARTICIPATE IN THIS STUDY. IF YOU HAVE ANY QUESTIONS, HERE**  
**IS MY CONTACT INFORMATION AND I WOULD BE HAPPY TO ANSWER**  
**THEM FOR YOU NOW OR IN THE FUTURE.**

08. What was the first day of your last menstrual period? |\_\_\_||\_\_\_|  
MONTH/DATE

**NOTE: IF THE FIRST DAY OF LAST MENSTRUAL PERIOD IS WITHIN 7**  
**DAYS OF TODAY'S DATE, PARTICIPANT MUST BE RESCHEDULED FOR**  
**A TIME WHEN SHE IS NOT ACTIVELY MENSTRUATING.**

**"THANK YOU FOR YOUR TIME TODAY, BUT WE WILL HAVE TO**  
**RESCHEDULE FOR A TIME THAT YOU ARE NOT ACTIVELY**  
**MENSTRUATING. LET'S LOOK AT THE CALENDAR AND SELECT A DATE**  
**WHEN I CAN COME BACK AND CONTINUE."**

09. How many times have you been pregnant? |\_\_\_\_\_| **(NONE**  
**SKIP TO 12.)**

**APPENDIX E (continued)**

10. How many of these pregnancies did you carry to full term? |\_\_\_\_\_|  
**(FULL TERM = 37 weeks or greater)**

11. Approximately how old were you during your first pregnancy? |\_\_\_\_\_|  
YEARS OLD

**THE NEXT FEW QUESTIONS ARE ABOUT CERVICAL CANCER.**

12. Have you ever had a Pap smear?  
YES ..... 1  
NO ..... 2  
**(SKIP TO 18.)**  
DON'T KNOW ..... 3

13. Have you had at least one Pap smear in the last 3 years?  
YES ..... 1  
NO ..... 2  
DON'T KNOW ..... 3

14. Approximately when was your last Pap smear? |\_\_\_\_\_| |\_\_\_\_\_|  
MONTH/YEAR

15. What was the main reason you had this Pap smear? **(DO NOT READ RESPONSES)**  
ROUTINE ANNUAL PAP SMEAR OR PART OF  
ROUTINE PHYSICAL EXAM ..... 1  
LAST PAP SMEAR WAS NOT NORMAL ..... 2  
A SPECIFIC PROBLEM..... 3  
SOMETHING SHE HEARD / SAW / READ ..... 4  
SHE HAD NEVER HAD ONE AND THOUGHT SHE SHOULD  
.....5  
PREGNANCY / FOLLOW-UP TO BIRTH ..... 6  
OTHER  
(SPECIFY) \_\_\_\_\_  
..... 7

16. Have you ever been told by a healthcare provider that your Pap smear was abnormal?  
YES ..... 1  
NO ..... 2 **(SKIP TO 18.)**  
DON'T KNOW ..... 3

17. What did you do about it? **(DO NOT READ RESPONSES)**  
NOTHING ..... 1

## APPENDIX E (continued)

- |     |   |                |
|-----|---|----------------|
|     | REPEAT PAP SMEAR, THEN NORMAL .....   | 2              |
|     | TREATED FOR CERVICAL DYSPLASIA USING FREEZING ...   | 3              |
|     | UNDERWENT COLPOSCOPY & BIOPSY, THEN NORMAL .....  | 4              |
|     | OTHER (SPECIFY)_____  | 5              |
|     | DON'T KNOW .....  | 6              |
| 18. | How often do you think a woman your age should have a Pap smear?  |                |
|     | MORE THAN TWICE A YEAR .....  | 1              |
|     | TWICE A YEAR / EVERY SIX MONTHS.....  | 2              |
|     | ONCE A YEAR .....   | 3              |
|     | EVERY TWO YEARS .....   | 4              |
|     | EVERY THREE YEARS.....  | 5              |
|     | MORE THAN EVERY THREE YEARS .....   | 6              |
|     | NEVER.....  | 7              |
| 19. | Do you think that women should receive yearly Pap smears once they are 18 or have become sexually active? |                |
|     | YES .....   | 1              |
|     | NO .....  | 2              |
|     | DON'T KNOW .....  | 3              |
| 20. | Do you think that when you stop having children you no longer need to have Pap smears?                    |                |
|     | YES .....   | 1              |
|     | NO .....  | 2              |
|     | DON'T KNOW .....  | 3              |
| 21. | Have you ever been treated for genital warts?   |                |
|     | YES .....   | 1              |
|     | NO .....  | 2              |
|     | DON'T KNOW .....  | 3              |
| 22. | Have you ever heard of HPV? HPV stands for Human Papillomavirus.  |                |
|     | YES .....   | 1              |
|     | NO .....  | 2 <b>(SKIP</b> |
|     | <b>TO 30.)</b>  |                |
|     | DON'T KNOW .....  | 3              |
| 23. | Have you ever been told by a healthcare provider that you had an HPV infection?                           |                |
|     | YES .....   | 1              |
|     | NO .....  | 2              |
|     | DON'T KNOW .....  | 3              |

## APPENDIX E (continued)

24. Do you think that HPV causes cervical cancer?  
YES ..... 1  
NO ..... 2  
DON'T KNOW ..... 3
25. Do you think that HPV is a sexually transmitted disease?  
YES ..... 1  
NO ..... 2  
DON'T KNOW ..... 3
26. Do you think that HPV infection is rare?  
YES ..... 1  
NO ..... 2  
DON'T KNOW ..... 3
27. Do you think that HPV infection will often go away on it's own without treatment?  
YES ..... 1  
NO ..... 2  
DON'T KNOW ..... 3
28. Do you think HPV can cause abnormal Pap smears?  
YES ..... 1  
NO ..... 2  
DON'T KNOW ..... 3
29. Do you think that HPV can affect a woman's ability to get pregnant?  
YES ..... 1  
NO ..... 2  
DON'T KNOW ..... 3
30. Do you think that being hit in your lower abdomen can cause cervical cancer?  
YES ..... 1  
NO ..... 2  
DON'T KNOW ..... 3
31. Do you think that most women diagnosed with cervical cancer die from the disease?  
YES ..... 1  
NO ..... 2  
DON'T KNOW ..... 3

**APPENDIX E (continued)**

32. Do you think that cervical pre-cancers and early cancers show symptoms or signs?  
YES ..... 1  
NO ..... 2  
DON'T KNOW ..... 3
33. Do you think that multiple abortions can cause cervical cancer?  
YES ..... 1  
NO ..... 2  
DON'T KNOW ..... 3
34. Do you think that having a high number of sexual partners increases your risk for cervical cancer?  
YES ..... 1  
NO ..... 2  
DON'T KNOW ..... 3
35. Do you think that women who smoke are more likely to develop cervical cancer than non-smokers?  
YES ..... 1  
NO ..... 2  
DON'T KNOW ..... 3
36. Do you think that Black women develop cervical cancer more often than White women?  
YES ..... 1  
NO ..... 2  
DON'T KNOW ..... 3

**NEXT ARE SOME QUESTIONS ABOUT SMOKING AND YOUR USE OF TOBACCO.**

37. Have you ever smoked?  
YES ..... 1  
NO ..... 2 **(SKIP TO 42.)**
38. Do you now smoke cigarettes . . . **(READ RESPONSES)**  
EVERY DAY ..... 1  
SOME DAYS ..... 2  
NOT AT ALL ..... 3  
..... **(SKIP TO 40.)**
39. On average, how many cigarettes do you smoke a day?  
| \_\_\_\_\_ | CIGARETTES

**APPENDIX E (continued)**

40. Around this time 12 months ago, were you smoking cigarettes.....  
EVERY DAY ..... 1  
SOME DAYS ..... 2  
NOT AT ALL..... 3
41. About how long has it been since you completely quit smoking cigarettes?  
**(ENTER UNIT.)**  
\_\_\_\_\_ DAYS..... 1  
\_\_\_\_\_ WEEKS ..... 2  
\_\_\_\_\_ MONTHS ..... 3  
\_\_\_\_\_ YEARS ..... 4
42. Are you exposed to tobacco smoke at your place of work?  
YES ..... 1  
NO ..... 2  
DON'T WORK OUTSIDE THE HOME ..... 3
43. Are you exposed to tobacco smoke at your home?  
YES ..... 1  
NO ..... 2

**THESE NEXT QUESTIONS ARE ABOUT EATING, EXERCISE AND YOUR HEALTH IN GENERAL.**

44. During the past month, on how many days did you drink 100% fruit juice such as orange, apple and grape juices? This doesn't include fruit drinks such as Kool-Aid or Hi-C.  
| \_\_\_\_\_ | DAYS **(IF ZERO, SKIP TO 46)**
45. How often do you drink fruit juice per day? | \_\_\_\_\_ |  
TIMES PER DAY
46. During the past month, on how many days did you eat fruit?  
| \_\_\_\_\_ | DAYS **(IF ZERO, SKIP TO 48)**
47. How often do you eat fruit per day? | \_\_\_\_\_ | TIMES  
PER DAY
48. During the past month, on how many days did you eat potatoes? This doesn't include things like fried potatoes, potato chips, French fries or rice. | \_\_\_\_\_ |  
DAYS **(IF ZERO, SKIP TO 50)**



**APPENDIX E (continued)**

49. How often do you eat potatoes per day? |\_\_\_\_\_|  
TIMES PER DAY

50. During the past month, on how many days did you eat vegetables other than potatoes? Include things like salad, cooked beans, corn and broccoli. |\_\_\_\_\_| DAYS  
**(IF ZERO, SKIP TO 52)**

51. How often do you eat vegetables per day (excluding potatoes)? |\_\_\_\_\_| TIMES PER DAY

52. In a typical week, on how many days do you do any moderate-intensity physical activity or exercise comparable to walking as if you were in a hurry? |\_\_\_\_\_| DAYS **(IF ZERO, SKIP TO 54)**

53. On the days that you do any moderate physical activity or exercise, how long are you typically doing these activities? |\_\_\_\_\_| MINUTES

54. As far as you know, does physical activity or exercise... **(READ RESPONSES)**

- INCREASE CHANCES OF CANCER ..... 1
- DECREASE CHANCES OF CANCER..... 2
- MAKES NO DIFFERENCE ..... 3
- DON'T KNOW ..... 4

55. In general, would you say your health is... **(READ RESPONSES)**

- EXCELLENT ..... 1
- GOOD..... 2
- FAIR..... 3
- POOR ..... 4

56. Have you ever been told by a health care provider that you have any of the following? **(READ RESPONSES)**

- TB..... 1
- HEART DISEASE ..... 2
- HYPERTENSION ..... 3
- DIABETES ..... 4
- HIV/AIDS..... 5
- OTHER (SPECIFY)\_\_\_\_\_ 6
- DON'T KNOW ..... 7

**APPENDIX E (continued)**

**THE NEXT FEW QUESTIONS ARE ABOUT HEALTH CARE COVERAGE.**

57. Do you have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicare?
- YES ..... 1
  - NO ..... 2
  - DON'T KNOW ..... 3
58. During the past 12 months, not counting times you went to an emergency room, how many times did you go to a doctor, nurse or other health care provider to get care for yourself?
- 1 TIME..... 1
  - 2 TIMES..... 2
  - 3 TIMES..... 3
  - 4 TIMES..... 4
  - 5-9 TIMES..... 5
  - 10 OR MORE TIMES ..... 6
  - NONE ..... 7
59. Do you have a regular place that you go for medical care?
- YES ..... 1
  - NO ..... 2
  - ..... **(SKIP TO 61.)**
60. Can you describe this place? Is it a....
- DOCTOR'S OFFICE ..... 1
  - HEALTH DEPARTMENT ..... 2
  - EMERGENCY ROOM ..... 3
  - COMMUNITY CLINIC  
(SPECIFY)\_\_\_\_\_ .. 4
  - OTHER (SPECIFY)\_\_\_\_\_ .. 5
  - ..... 5
61. Do you take steps to prevent illness or stay healthy?
- YES ..... 1
  - NO ..... 2
  - ..... **(SKIP TO 63.)**

**APPENDIX E (continued)**

62. What do you do to prevent illness or stay healthy? **(DO NOT READ RESPONSES)**

**[CHECK ALL THAT APPLY.]**

	<b>YES</b>	<b>NO</b>
DAILY VITAMINS		
EAT HEALTHY		
HAVE REGULAR CHECK-UPS		
GET SCREENED FOR CANCER / GET TESTED FOR CANCER		
HERBS		
EXERCISE		
DRINK TEA		
PRAY		
HOT BATHS		
OTHER (SPECIFY)		

63. Do you do anything to preserve vaginal cleanliness and/or vaginal tightness?

YES ..... 1

NO ..... 2

**(SKIP TO 70.)**

64. What products do you use? **(DO NOT READ RESPONSES)**

**[CHECK ALL THAT APPLY.]**

	<b>YES</b>	<b>NO</b>
TI BAUME		
PALMA CHRISTI		
PEMAGANATE		
ALUM/ALUMINUM CRYSTALS		
DETTOL		
LEMISOL		
HYGISOL		
PROTECTYL		
OTHER (SPECIFY)		

**APPENDIX E (continued)**

65. How often do you use these products? <b>[CHECK ALL THAT APPLY.]</b>									
	EA. DAY	2-3 TIMES A WEEK	ONCE PER WEEK	EVERY OTHER WEEK	ONCE PER MO.	EVERY 2-3 MOS.	EVERY 6 MOS.	ONCE PER YEAR	OTHER (SPECIFY)
TI BAUME									
PALMA CHRISTI									
PEMAGANATE									
ALUM/ ALUMINUM CRYSTALS									
DETTOL									
LEMISOL									
HYGISOL									
PROTECTYL									
OTHER (SPECIFY)									

66. How long have you been using these products? <b>(CHECK ALL THAT APPLY)</b>					
	ALWAYS OR SINCE CHILDHOOD	SINCE PUBERTY OR ADOLESCENCE	SINCE BECOMING SEXUALLY ACTIVE	SINCE GETTING MARRIED	OTHER (SPECIFY)
TI BAUME					
PALMA CHRISTI					
PEMAGANATE					
ALUM/ ALUMINUM CRYSTALS					
DETTOL					
LEMISOL					
HYGISOL					
PROTECTYL					
OTHER (SPECIFY)					

**APPENDIX E (continued)**

67. What reason(s) do you use these products? (DO NOT READ RESPONSES [CHECK ALL THAT APPLY.]		
	<b>YES</b>	<b>NO</b>
TIGHTEN AND DRY THE VAGINA		
INCREASE PLEASURE DURING SEX		
CLEANSE THE VAGINA		
PREVENT/MASK ODOR		
TREAT ITCHING/BURNING SYMPTOMS		
LESSEN/TREAT VAGINAL DISCHARGE		
PREVENT PREGNANCY		
PREVENT TRANSMISSION OF SEXUALLY TRANSMITTED DISEASES		
OTHER (SPECIFY)		

68. How do you use these products? (CHECK ALL THAT APPLY)			
	<b>APPLY EXTERNALLY</b>	<b>USE INTRAVAGINALLY (INTERNALLY)</b>	<b>ADD PRODUCT TO BATH AND SOAK</b>
TI BAUME			
PALMA CHRISTI			
PEMAGANATE			
ALUM/ ALUMINUM CRYSTALS			
DETTOL			
LEMISOL			
HYGISOL			
PROTECTYL			
OTHER (SPECIFY)			

**APPENDIX E (continued)**

69. Where do you buy these products? <b>(CHECK ALL THAT APPLY)</b>					
	BOTANICA	FROM A FRIEND OR CO-WORKER	HAITI	MAIL ORDER OR ONLINE	OTHER (SPECIFY)
TI BONM					
PALMA CHRISTI					
PEMAGANA TE					
ALUM/ ALUMINUM CRYSTALS					
DETTOL					
LEMISOL					
HYGISOL					
PROTECTYL					
OTHER (SPECIFY)					

70. Where does most of your health related information come from?
- BROCHURES/BOOKS ..... 1
  - RADIO ..... 2
  - CHURCH ACTIVITIES..... 3
  - TELEVISION ..... 4
  - TALKING WITH OTHER COMMUNITY MEMBERS ..... 5
  - HEALTH FAIRS..... 6
  - OTHER (SPECIFY) \_\_\_\_\_ 7

**IT'S GETTING CLOSE TO THE END OF THIS PART OF THE SURVEY. THERE ARE JUST A FEW MORE QUESTIONS.**

71. Are you currently . . .
- EMPLOYED FOR WAGES..... 1
  - SELF-EMPLOYED ..... 2
  - OUT OF WORK FOR MORE THAN ONE YEAR ..... 3
  - OUT OF WORK FOR LESS THAN ONE YEAR ..... 4
  - HOMEMAKER..... 5
  - STUDENT, ..... 6
  - RETIRED ..... 7
  - UNABLE TO WORK ..... 8

**APPENDIX E (continued)**

72. Are you . . .
- MARRIED ..... 1
  - DIVORCED ..... 2
  - WIDOWED ..... 3
  - SEPARATED, ..... 4
  - NEVER BEEN MARRIED ..... 5
  - LIVING WITH A PARTNER ..... 6
73. What is the highest level of school you completed?
- NEVER ATTENDED SCHOOL OR ONLY ATTENDED  
NUSERY SCHOOL/KINDERGARTEN..... 1
  - GRADES 1 THROUGH 5 (ELEMENTARY) ..... 2
  - GRADES 6 THROUGH 8 (MIDDLE)..... 3
  - GRADES 9 THROUGH 12 (SOME HIGH SCHOOL BUT NO  
DIPLOMA) ..... 4
  - HIGH SCHOOL GRADUATE (HIGH SCHOOL DIPLOMA OR  
EQUIVALENT, E.G., GED, FOREIGN EQUIVALENT) .... 5
  - VOCATIONAL OR TRADE SCHOOL GRADUATE ..... 6
  - SOME COLLEGE, BUT NO DEGREE ..... 7
  - ASSOCIATE DEGREE IN COLLEGE ..... 8
  - BACHELOR’S DEGREE..... 9
  - MASTER’S DEGREE ..... 10
  - PROFESSIONAL SCHOOL OR DOCTORATE DEGREE (MD, DDS,  
JD, DVM, Ph.D., Ed.D, etc)..... 11
74. Were you born in the United States?
- YES ..... 1
  - (SKIP TO 77.)**
  - NO ..... 2
75. In what country were you born?  
|\_|\_|\_|\_|\_|\_|\_|\_|\_| COUNTRY
76. In what year did you come to live in the United States?  
|\_|\_|\_|\_| YEAR
77. What is your mother’s national origin or ancestry?  
|\_|\_|\_|\_|\_|\_|\_|\_|\_| COUNTRY
78. What is your father’s national origin or ancestry?  
|\_|\_|\_|\_|\_|\_|\_|\_|\_| COUNTRY

**APPENDIX E (continued)**

79. What language do you usually speak or read in? **(READ RESPONSES)**
- |                                |   |
|--------------------------------|---|
| CREOLE ONLY .....              | 1 |
| CREOLE MORE THAN ENGLISH ..... | 2 |
| BOTH EQUALLY.....              | 3 |
| ENGLISH MORE THAN CREOLE ..... | 4 |
| ENGLISH ONLY .....             | 5 |
80. What language do you usually speak at home? **(READ RESPONSES)**
- |                                |   |
|--------------------------------|---|
| CREOLE ONLY .....              | 1 |
| CREOLE MORE THAN ENGLISH ..... | 2 |
| BOTH EQUALLY.....              | 3 |
| ENGLISH MORE THAN CREOLE ..... | 4 |
| ENGLISH ONLY .....             | 5 |
81. What language do you usually think in? **(READ RESPONSES)**
- |                                |   |
|--------------------------------|---|
| CREOLE ONLY .....              | 1 |
| CREOLE MORE THAN ENGLISH ..... | 2 |
| BOTH EQUALLY.....              | 3 |
| ENGLISH MORE THAN CREOLE ..... | 4 |
| ENGLISH ONLY .....             | 5 |
82. What language do you usually speak with your friends? **(READ RESPONSES)**
- |                                |   |
|--------------------------------|---|
| CREOLE ONLY .....              | 1 |
| CREOLE MORE THAN ENGLISH ..... | 2 |
| BOTH EQUALLY.....              | 3 |
| ENGLISH MORE THAN CREOLE ..... | 4 |
| ENGLISH ONLY .....             | 5 |
83. What language do you usually speak with doctors or other health care providers? **(READ RESPONSES)**
- |                                |   |
|--------------------------------|---|
| CREOLE ONLY .....              | 1 |
| CREOLE MORE THAN ENGLISH ..... | 2 |
| BOTH EQUALLY.....              | 3 |
| ENGLISH MORE THAN CREOLE ..... | 4 |
| ENGLISH ONLY .....             | 5 |
84. Is your annual household income from all sources...**(READ RESPONSES)**
- |                           |   |
|---------------------------|---|
| LESS THAN \$15,000.....   | 1 |
| \$15,000 – \$25,000 ..... | 2 |
| \$25,000 – \$35,000 ..... | 3 |
| \$35,000 - \$45,000.....  | 4 |
| OVER \$45,000.....        | 5 |



APPENDIX E (continued)

**THANK YOU FOR YOUR TIME IN ANSWERING THESE IMPORTANT QUESTIONS. WE WILL NOW GO OVER THE VISUAL INSTRUCTIONS FOR THE SELF-SAMPLER TOGETHER AND AFTERWARDS, PLEASE GO INTO THE BATHROOM OR ANOTHER PRIVATE ROOM, AND FOLLOW THE INSTRUCTIONS. I WILL BE RIGHT OUTSIDE THE DOOR IF YOU HAVE ANY QUESTIONS.**

**NOTE: GO OVER THE VISUAL INSTRUCTIONS FOR THE SELF-SAMPLER WITH THE PARTICIPANT. AFTERWARDS, HAND THE INSTRUCTION BOOKLET AND THE SELF-SAMPLER KIT TO THE PARTICIPANT AND ASK HER TO GO INTO THE BATHROOM AND FOLLOW THE INSTRUCTIONS. WAIT NEARBY FOR HER TO COMPLETE THE EXAM IN CASE ANY QUESTIONS SHOULD ARISE. AFTER SHE IS FINISHED, PLACE THE SAMPLE IN YOUR BAG.**

**BEFORE WE FINISH UP TODAY, I HAVE JUST A FEW MORE QUESTIONS TO ASK YOU ABOUT YOUR EXPERIENCE USING THE SELF-SAMPLER.**

85. Did you find the self-sampler easy or hard to use?
- |              |   |
|--------------|---|
| EASY .....   | 1 |
| HARD .....   | 2 |
| NEITHER..... | 3 |
86. Did you experience any pain or discomfort using the self-sampler?
- |                      |   |
|----------------------|---|
| YES .....            | 1 |
| NO .....             | 2 |
| MILD DISCOMFORT..... | 3 |
87. Did you feel comfortable using the self-sampler at home?
- |                      |   |
|----------------------|---|
| YES .....            | 1 |
| <b>(SKIP TO 89.)</b> |   |
| NO .....             | 2 |
88. If you felt uncomfortable, why?
- |                           |   |
|---------------------------|---|
| UNSURE OF TECHNIQUE.....  | 1 |
| TRUST PHYSICIAN MORE..... | 2 |
| EMBARRASED.....           | 3 |
| OTHER (SPECIFY) _____     | 4 |

**APPENDIX E (continued)**

89. How does using the self-sampler compare to having a Pap smear?  
BETTER ..... 1  
WORSE..... 2  
NO DIFFERENCE ..... 3  
NEVER HAD A PAP SMEAR ..... 4 **(SKIP TO 91.)**

90. Which method do you prefer?  
SELF-PAP ..... 1  
PAP SMEAR ..... 2  
NO PREFERENCE..... 3

91. Would you recommend using the self-sampler to your female family members and friends?  
YES ..... 1  
NO ..... 2

92. Is there anything else that you would like to tell us about your experience with the self-sampler that was not asked of you in this survey? Please share your thoughts. **(PLEASE RECORD COMMENTS).**
- 
- 
- 
- 

**THOSE ARE ALL THE QUESTIONS I HAVE FOR YOU.**

(GIVE INCENTIVE TO PARTICIPANT)

**THANK YOU AGAIN FOR YOUR TIME AND PARTICIPATION IN THIS PROJECT. HERE IS MY CONTACT INFORMATION IF YOU HAVE QUESTIONS AT ANY TIME.**

## **ABOUT THE AUTHOR**

Janelle M. Menard is a medical anthropologist whose work focuses on health seeking behaviors and cultural constructions of illness in French and Creole-speaking Caribbean populations and these immigrant populations in the U.S. She has conducted ethnographic fieldwork among women in Martinique on medical treatment choice in a pluralistic medical system, and in the U.S. on breast and cervical cancer among Haitian immigrant women in West, Central, and South Florida. Ms. Menard has also worked extensively with community-based organizations in West and Central Florida to improve access to health screenings and to develop and deliver culturally meaningful cancer education for Haitian immigrant women. She was chosen for both pre-doctoral and post-doctoral positions at major cancer centers in Florida to conduct ethnographic and community-based health research to benefit medically underserved women.