To my earth angels and #1 cheerleaders: Mommy and Daddy, we did it!
To my loving and supportive little sister Jem, you’re next!
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Scree plot of 1st and 2nd of breast cancer symptoms ranking by physicians
Critiques of cancer discourse in the U.S. identify a need for research that equally weighs the multiple voices of cancer and the various factors that influence individuals' varying cancer experiences. In light of growing attention to cancer disparities, many researchers have used culture to understand variation in cancer experiences. This dissertation takes advantage of developments in culture theory and systematic ethnographic research methods to explore how variations in individual’s cancer experiences are influenced by culture (cancer knowledge) and social context. It is informed by a combination of participant observation, semi-structured ethnographic interviewing, and structured elicitation tasks data from a cohort of 59 adult women and 20 physicians in Mayaguez, Puerto Rico. This discussion showcases two important voices in breast cancer discourse, care-seekers (women) and care-providers (physicians). The care-providers’ and care-seekers’ narratives suggest that administrative requirements imposed by MCOs to improve efficiency of services on the Island continue to create disparities in women’s access to care, such as specialized care important for breast cancer diagnosis and treatment. Similarities in women’s and physicians’ knowledge of breast cancer suggest a shared understanding of some
aspects of breast cancer between the groups. Differences in the groups’ understanding of breast cancer coexist along with those shared ideas. Care-seekers and care-providers agree about what causes breast cancer but they also demonstrate distinct cultural models about what can be done to prevent breast cancer and how the condition affects the body. This variation in knowledge, when located within the groups’ specific contexts, implies that context influences how the groups create breast cancer meaning and experience the condition.
An increase in cancer morbidity and mortality has stimulated anthropological research on cancer and the unequal distribution of its suffering (Csordas 1989; Balshem 1991; DiGiacomo 1999; Chavez, et al. 1995, 2009; Jain 2007b). In light of growing attention to cancer disparities, many researchers have used culture to 1) understand variation in cancer experiences and 2) critique the over appreciation of recommended medical “truths” about cancer over lay cancer experiences (Moore 1994; McMullin, Weiner 2009; Perusek 2009; Jain 2007). These critics argue that cancer and the individual’s understanding of the illness are complex phenomena that do not easily map onto the dominant cancer discourse. This critique of cancer discourse in the U.S. identifies a need for research that equally weighs the multiple voices of cancer and various factors that influence individuals’ varying cancer experiences (Moore 1994, Pasick, Burke 2008, McMullin et al. 1994).

This dissertation takes advantage of developments in culture theory and systematic ethnographic methods research to provide a multi-voiced account of cancer knowledge. It is informed by 12 months of ethnographic field research in Puerto Rico that used a combination of participant observation, semi-structured ethnographic interviewing, and structured elicitation tasks suitable for cultural consensus analysis. This dissertation addresses two specific objectives:
1. To explore how women’s and physicians’ breast cancer experiences vary based on their locations within Puerto Rico’s healthcare system

2. To describe and compare women’s and physicians’ cultural knowledge of breast cancer and its relationship to their social context

This dissertation showcases two important voices in breast cancer discourse, care-seekers (women) and care-providers (physicians), and illustrates the importance of their voices in understanding breast cancer meaning. It argues that both cultural knowledge and social context are important in understanding women and physicians breast cancer experiences. Through its discussion of the Puerto Rican healthcare system, this work illuminates the following: 1) how political and economic policies based in the U.S. mainland simultaneously drive and hinder the Island’s healthcare system’s ability to provide breast cancer care to its population; 2) the interdependent relationship between cultural belief and Puerto Ricans’ social-structural context; and 3) how this relationship shapes breast cancer experiences and access and use of breast cancer services.

**Cancer and Anthropology**

Unlike other chronic diseases, which can be managed by medications and lifestyle changes (diet and exercise), the uncertainty that surrounds cancer fosters illness narratives impregnated with fear, death, and ambiguity (Aronowitz 2007; Manderson 2011; Dein 2004; Jain 2007a; Engelberg 2006; Perusek 2012). Cancer narratives provide a glimpse into individuals’ cognitive depiction of how cancer (risks, symptoms/sign, cause, and treatment) knowledge is influenced by and influences individuals’ health experiences (Moore 2001; Chavez et al. 2005; Hunt 1998; Lind et al. 1989; Balshem 1991; Salamonsen et al. 2012). In addition, the discovery of the breast
cancer genes (BRAC 1 and 2) and genetic testing have resulted in research that investigates the ethics of genetic testing and its influence on women's health seeking behavior (Press et al. 1997; Press et al. 2005; Vadaparampil et al. 2010; Gibbon 2007, 2013). The uncertainty of a cure and the limits of cancer knowledge have resulted in research that explores individuals’ perception of death and its relationship to their cancer experiences (Hruschka, Hadley 2008; Hruschka 2009; Salazar 1996; Hunt 1998; Gordon 1990). This dissertation incorporates photographic narratives and participant observation to provide an in-depth description of factors that influence women’s and physicians’ breast cancer experiences.

Medical anthropologists’ focus on cancer has also engendered critiques about the “medicalization of medical anthropology” and the loss of its critical perspective (Browner 1999). In response to such critiques, McMullin and Weiner (2009) posited that the basic nature of cancer, its rejection of confinement and inherent mobility, aligns with medical anthropologists’ analytical efforts to preserve differences and avoid reductionism. Critics have also noted that anthropologists’ focus on the individual’s lived experience of cancer among underserved and high-risk populations may inadvertently present culture as the problem and ignore social-structural issues such as access to healthcare (DiGiacomo 1999; Dein 2004). This dissertation’s avoids this trap by examining cultural knowledge of cancer in the context of social-structural constraints, material resources, and power dynamics between care seekers and care providers.

**Cultural Knowledge and Illness Experiences**

Anthropologists and other social scientists have developed a variety of data collection and analytical methods to examine culture or cultural knowledge of illness

Kleinman and colleagues (1978) introduced the concept of explanatory models as a framework for understanding how patients and healers understand illness and negotiate treatment. Explanatory models (EMs) consist of people’s beliefs about what an illness is, what causes it, how it affects them, and what can be done to heal it (Kleinman et al. 1978; Kleinman 1981). The focus is on patients’ perception and experience of illness as a socially disparaged state, in contrast to the biomedical definition of disease as an altered physiological state (Kleinman et al. 1978; Kleinman 1981). The distinction between illness and disease and the construct of explanatory models of illness have been widely adopted in anthropology and clinical medicine in three ways:

- as an analytic framework for understanding illness experiences (e.g. Hunt and Arar 2001; Weller et al. 2012)
- as a pedagogical device to teach clinicians about the role of culture in medicine (e.g. Kirmayer 2004; Bhui, Bhugra 2004)
- as a clinical tool to elicit patients’ understandings of illness and negotiate treatment (e.g. Kleinman, Benson 2006)

Kleinman proposed eight questions to help clinicians elicit patients’ EMs. The open-ended questions prompt respondents to name the illness, identify its causes, discuss its effect on their body, and express their treatment preferences and desired outcome (Kleinman 1981). Over the years, other researchers have expanded on Kleinman’s approach to develop tools for eliciting EMs (Weiss, et al. 1992; Groleau, Young et al. 2006; Bhui, Bhugra 2002).

The concept of explanatory models lends itself to methods and theory from
cognitive anthropology, which defines culture as a shared and learned pool of information used by individuals to produce and interpret their social environments and behaviors (D'Andrade 1981; Goodenough 1999). However, this potential synthesis has been underdeveloped. Kleinman and colleagues (1978) argue that illness is culturally constructed, and they refer to the “cultural construction of clinical reality.” But they do not present an explicit theory of culture or methods for evaluating the extent to which explanatory models are specifically cultural, as opposed to idiosyncratic. The advantage of incorporating methods and theory from cognitive anthropology is that it provides a formal theory and method for assessing the cultural component of individuals’ explanatory models. Kleinman’s eight questions and EMs tools (e.g., MINI) do not permit distinctions between the individual and aggregate components of individuals’ EMs of illness.

Yet, when regarded as the formative stage, Kleinman’s eight questions can be combined with other methods, including structured elicitation, to identify patterns of agreement and variation in cultural knowledge of illness, in this case breast cancer (Groleau, Young et al. 2006; Romney, Weller et al. 1986; Weller, Baer 2002; Weller, 2007; Dressler 2004). A research design that combines these methods facilitates in-depth descriptions of intracultural variation (D'Andrade 1981; Weller, Romney 1988; Romney, Weller et al. 1986; Chavez et al. 1995) and makes it possible to explore how individual differences in cultural knowledge relate to variations in their social context (Chavez et al. 2001; Luque et al. 2010). This project builds on Kleinman’s explanatory models by combining it with theory and methods from cognitive anthropology to examine intracultural variation among women and physicians’ cultural knowledge of
breast cancer and its relationship to their social context.

Critics argue that Kleinman’s construct of explanatory models is limited by its focus on individuals, to the exclusion of social context (Young 1982; Good 1986). In response, some anthropologists have argued that the clinical environment should be regarded as more than just a place of knowledge and treatment; it also forms a social system (Leslie 1980). This critique spurred the development of research that treats biomedical knowledge and medical pedagogy as a cultural system with distinct discourses, social roles (e.g., students and physicians), and modes of reasoning (Lock, Nguyen 2010). This dissertation responds to this critique by (1) discussing both women’s and physicians’ cultural knowledge, (2) accounting for how their past experiences influence their cultural knowledge, and (3) locating women’s and physicians’ cultural knowledge within their individual social contexts.

Social Context

Researchers take various approaches to the study of social context influences on health. A common but limited approach is to approximate individuals’ position in social hierarchies using the construct of socioeconomic status, commonly measured as a combination of education, occupation, and income (Braveman et al. 2005; Duncan et al. 2002). Alternatively, some research conceptualizes social-structural factors as external forces that hinder or facilitate health behavior (Dressler et al. 2005; Zambrana et al. 1999). The latter approach underlies an emerging theoretical framework in medical anthropology that Dressler and colleagues (Dressler 2001, 2007; Dressler et al. 2005) identify as structural-constructivism. This framework, influenced by Bourdieu (1990), focuses on human experience at the intersection of cultural meaning and social structure.
This dissertation contributes to the emerging theoretical framework of structural-constructivism (Dressler, 2001) by exploring women’s and physicians’ cultural knowledge of breast cancer and the social-structural factors that constrain or enable women’s ability to use medical services and physicians’ ability to provide care. It builds on existing research to (1) describe cultural knowledge of breast cancer in social context and (2) explore how cultural knowledge and social-structural factors influence women’s use of and physicians’ provision of medical services. This project thus contributes to a growing body of research in medical anthropology that aims to assess how social structure and cultural meaning facilitate or hinder health behavior and health outcomes (Dressler, Bindon 2000; Gravlee, Dressler et al. 2005; Reyes-Garcia et al. 2010).

An important model for this approach is Leo Chavez and colleagues’ (1995, 2001) research on cultural knowledge of cervical cancer risks and women’s decisions to use screening exams. Chavez et al. found that, while social-structural factors (namely poverty and insurance status) were the strongest predictors of women’s use of Pap screening, cultural beliefs still mattered (Chavez et al. 2001). This dissertation replicates Chavez and colleagues’ work for the case of breast cancer and extends it by broadening the discussion of cancer experience to examine the relationship between knowledge of breast cancer risks, prevention, symptoms, treatments and social context. This approach uses Kleinman’s explanatory model as a guide to divide the breast cancer domain into four subdomains to better understand how individuals construct breast cancer meaning along the lines of what causes it (risks), how it affects them (symptoms), and what can be done to prevent and heal it (preventive measures and
treatment). It is only the second study (and the first in Puerto Rico) to use this approach to operationalize culture and explore the influence of cultural knowledge and social-structural factors on cancer experiences. The use of methods comparable to those of Chavez et al. will provide a valuable cross-cultural comparison and inform the development of structural-constructivist approaches to the anthropology of cancer.

**Research Setting**

Puerto Rico is an appropriate setting for this research because of its position relative to global narratives about breast cancer treatment and prevention. The history and culture of the Island retain evidence of its Caribbean identity (Pico 1971; Koss-Chioino 1992; Koss-Chioino, Espinosa 2009; Grosfoguel 2003). Yet, as a Commonwealth of the United States, Puerto Rico occupies a unique legal and political status in the Hispanic Caribbean. Indeed, the United States’ influence on Puerto Rico may be particularly evident in medicine. The University of Puerto Rico has long-standing cancer research programs funded by the U.S. National Institutes of Health, and many researchers and physicians have trained on the mainland. Puerto Rico’s status in relation to both the broader Caribbean and the United States has stimulated other research on the cultural context of illness and healing (Koss-Chioino 1992; Fabian, Cabanillas et al. 2011; Guarnaccia et al. 1996) and makes it a fascinating place to explore possible cultural differences and similarities between physicians and their patients.

Puerto Rico’s current economic climate is similar to that of Detroit, Michigan circa July 2013, before it filed for bankruptcy (Lichterman, Woodall 2013; Walsh 2015). However, this option of economic assistance is not available to the Island because of its commonwealth status with the United States (Holodny, 2015). In 2013, 8.5 percent of
the Island’s population (16 years and over) was unemployed compared to 6.2 percent of the U.S. mainland. Additionally, in the same year, Puerto Rico’s poverty rate (45.1 percent) was approximately twice that of the poorest U.S state, Mississippi (22.7 percent) (U.S. Census Bureau 2013b).

Despite its poor economic climate the Island’s population experiences better rates for indicators of healthcare access and coverage than U.S. mainland citizens, particularly Puerto Ricans on the mainland. Some researchers have tied these differences in health outcomes to the Island’s healthcare system (Portela, Sommers 2015). One of the main factors that remain different between the two populations is Puerto Ricans’ increased access to care. The Island’s public and private insurers provide healthcare coverage to approximately 90 percent of its population (Crescioni 2014). Puerto Rico’s high insurance status rate and its cancer screening mandates has resulted in lower uninsured (7.4% compared to 15%) and smoking (14% compared to 20%) rates and higher rates of mammograms (85% compared to 81%) and pap smears (86% compared to 85%) (Portela, Sommers 2015).

Nevertheless, the Island has experienced increased rates of breast cancer morbidity, but mortality has remained constant between 1987-2003, Puerto (Figueroa-Vallés, Ortiz-Ortiz et al. 2012). Differences in morbidity and mortality rates have been linked to advancement in preventive medicine (Figueroa- Vallés, Ortiz-Ortiz et al. 2012). This project not only build on previous ethnographic work in Puerto Rico that used explanatory models to discuss women’s health experiences but it also complement existing and ongoing breast cancer research on the Island (Koss-Chioino 1992; Torres-Cintrón et al. 2010; Vadaparampil et al. 2010; Fabian, Cabanillas et al. 2011).
Finally, similar to the U.S. mainland Puerto Rico is currently experiencing a reformulation of its healthcare system. As illustrated by its economic situation the Island’s commonwealth status means that mainland’s policies do not or only partially apply to Puerto Ricans on the Island. So what does the Affordable Care Act (ACA), mean for healthcare on the Island? As suspected, all of the Act’s benefits do not apply to the Island’s population. For example, the individual and employer insurance and Medicaid expansion mandates are not applicable to Puerto Ricans on the Island (Puerto Rico Health Insurance Administration 2014). Yet, even though the U.S. Congress has waived the Island’s need to implement the mandates, the Puerto Rican Department of Health has decided to implement some ACA policies (e.g., prohibition on lifetime and annual limits and coverage of preventive health services) in efforts to improve the health of its populace (Puerto Rico Health Insurance Administration 2014; Tavenner 2014).

Interestingly, one of the main changes that does apply to the Island threatens its already reduced access to federal funding (Artiga, 2013; Puerto Rico Health Insurance Administration 2014). Since the 1960s Puerto Rico has experienced disparities in federal funding for its Medicare and Medicaid program, when compared to the mainland. With more than half of its population dependent on Medicare and Medicaid funded services, Puerto Rico continually borrowed monies to fund these federal programs. Today $23 billion of the Island $73 billion debt is for monies borrowed to fund its underfunded Medicaid program (Alvarez, Goodenough, 2015). Under the ACA the Island continues to experience caps and lower refunds for its Medicaid expenses, than U.S. mainland states (Artiga, 2013; Puerto Rico Health Insurance Administration 2014). In January, Puerto Rico will also experience cuts in its Medicare Advantage program
(Alvarez, Goodenough, 2015). These policies, inappropriate for Puerto Rico’s public/private healthcare system’s structure, will continue to strain the Island’s economy and ultimately hinder Puerto Rico’s ability to provide care to its populace and women’s access to healthcare.

On the Island, ACA generates apprehension about its ability to further burden the Island’s already fragile healthcare funding structure and creates many questions about Puerto Rico’s healthcare system’s future. The island’s unique historical and current relationship with the U.S., its current economic and health profile, and uncertain healthcare future makes its an optimal location to explore how U.S. mainland federal aid (e.g., Medicaid and Medicare) interact with cultural knowledge and social-structural factors to influence physician’s and women’s breast cancer experiences (Mulligan 2010; Hamman, Kapinos 2015). The project’s findings will contribute to the inquiry about the relationship between culture, social context, and health experience through its multi-voiced account of breast cancer knowledge among Puerto Ricans on the Island.

**Research Design Overview**

This dissertation uses two phases (exploratory and confirmatory) of data collection and analytical methods to address its two objectives (Figure 1-1). Research design begins with unstructured and semi-structured methods of data collection suitable for exploratory questions (Objectives 1 and 2) and progresses to structured data collection methods appropriate for the confirmatory questions (Objective 2) (Gravlee 2011). The exploratory phase includes participant observation, and semi-structured and structured (free lists, pile sorts, and socio-demographics) ethnographic interviews. The
confirmatory phase consists of structured interviews (rankings and socio
demographics).

**Sample and Recruitment**

Fifty-nine lay women (ages 40-75) and 20 physicians (women and men) for a
total of 79 participants (Figure 1-2, Figure 1-3) were recruited. The targeted age range
was selected and is appropriate because it takes into consideration screening
mammogram recommendations before and after the U.S. Preventive Services Task
Force (2009) report. Physicians were included to better explore variations between
women’s (care seekers) and physicians’ (care providers) breast cancer knowledge in
Puerto Rico. Overall sample size was based on the level of expected variability in
cultural knowledge; the more variable a domain is, the larger the number of required
respondents (Weller 1987). Previous research has shown data saturation after twelve
ethnographic interviews in well-specified contexts (Guest, Bunce et al. 2006).

**Data Collection**

Data for the two phases were collected between March 2014 and December
2014. I collected all data for the exploratory phase. I employed one bilingual research
assistant for all phases of the study. The research assistant was a 4th year Psychology
student at the University of Puerto Rico at Mayaguez. She was originally hired to
provide transcription services but her geographical and colloquial knowledge became
very instrumental during community interviews and data analysis. Spanish was used
during all data collection phases unless a participant requested to use English.
Community women and patients completed their interviews in Spanish. Physicians were
more eager to complete their interviews in English. However, most physicians agreed to
conduct the interviews in Spanish to help improve my Spanish proficiency. One
physician explained that it was easier to conduct the interviews in English because his medical training was bilingual (textbooks were in English but instructions were in Spanish) and current medical correspondences (e.g., labs, patient records) are in English.

**Exploratory phase**

Participant observation. The 12 months of participant observation focused on understanding women's and physicians' breast cancer experiences and women's use of preventive services (e.g. well-woman visits, mammogram and/or sonomamograms) in the context of everyday life or professional context, respectively (Spradley 1980; Unger-Saldaña, Infante-Castañeda 2011). In summer 2012 and 2013 and fall 2013, I visited the University of Puerto Rico and established relationships with faculty members at the University of Puerto Rico who agreed to facilitate communication with local private and public physicians through their existing relationships and research collaborations. I worked with two University of Puerto Rico at Mayaguez faculty members in the Social Sciences Department and Applied Social Sciences Research Center and three local practicing physicians in Mayaguez to gain access to local private and public physicians, patients, and community members in Mayaguez. Participant solicitation cards were also handed out a local hair salon, shared with Facebook friends in Mayaguez, and posted on the UPR Mayaguez Student Facebook page.

Everyday observations and conversations were recorded by writing daily field notes (Emerson et al. 2011). To gain access to relevant social contexts, I volunteered at university sponsored domestic violence support groups. While my initial plans were to volunteer at a local breast cancer support group, I later learned there were no local breast cancer support groups in Mayaguez. An Island Susan Komen representative
informed me that the closest program was approximately an hour away by car. I was not able to volunteer at the local American Cancer Society chapter but was permitted to interview some employees.

I also was granted the opportunity to accompany women in day-to-day activities such as attending social activities (i.e., going to church and holiday socials). Social activities helped to provide information about the regularity of breast cancer discussions and women’s reaction to the topic in social settings. Observing women during their medical consultations was important because the opportunities provided information to support medical-decision behaviors and experiences reported in the semi- and structured interviews. Observation of and participation with the women in the community and clinical settings was important because it enabled the discovery and exploration of factors that influence women’s everyday medical decision-making processes in routine community and clinical settings (Handwerker 2002; Spradley 1980; Goldade, Nichter 2010). Everyday conversations and observations provided me with insight into women’s experiences that would not have been possible to obtain in more structured interviews, and it helped to generate new hypotheses and refine existing ones (Bernard 2011).

I also shadowed physicians during their clinical rotations at selected private and public practices in Mayaguez, Puerto Rico. Shadowed physicians can be divided into two groups: primary care and specialists. On the Island primary care physicians include generalists, internal medicine physicians, and obstetric-gynecologists. Specialization specific to the study included general surgery, plastic surgery, and oncology. Since most primary care physicians do not accept La Reforma (Medicaid on the Island) patients, it was important to also include both groups of physicians, those who accepted
La Reforma and those who did not. All primary care physicians and the oncologists owned private practices but also provided hospital consultations to their patients.

Primary care physicians’ responsibilities include completing paperwork to admit their patients to the hospital as well as monitoring them during their hospitalization, if it is at their associated hospital. Therefore, shadowing these physicians provided important information about how physicians work within the Puerto Rican healthcare system and balance responsibilities in the Island’s public and private healthcare sectors. Shadowing surgeons provided opportunities to observe breast relevant surgical procedures (biopsies, lumpectomies, reconstructive surgery). When I inquired about obtaining a mammogram or observing the procedure all the physicians I approached informed me that they would not recommend it because of the risk (exposure to radiation) associated with the procedure. While part of me wanted to continue to pursue the procedure my research about breast cancer risk allowed me to respect the physicians concern for my safety. Participant observation data in Mayaguez’s private medical practices and hospitals has provided information about the physicians’ professional context and permitted discussions about similarities and differences between physicians’ and women’s experiences of breast cancer and the Island’s healthcare system.

**Sociodemographic data and health or occupational histories.** Semi-structured and structured interviews included close-ended questions about standard demographic variables (e.g., age, education, and income) and health history for women (e.g., mammogram status, access to a regular healthcare provider, and social support) or occupational history for physicians (e.g., medical specialization and years in
practice). Sociodemographic and health or occupational histories data were collected to measure participants' social-structural context. They aid in the discussion of participants' life experiences and attributes in relation to social-structural factors' influences on cultural knowledge and health behavior. These factors were used to compare with the findings from participant observation and semi-structured and structured interviews to examine the contextual influences on women's and physicians' cultural knowledge of breast cancer (Objectives 1 and 2).

**Semi-structured interviews.** Semi-structured interviews were conducted with lay women and physicians to collect narratives about how they experience and attribute meaning to breast cancer (Bernard 2011). Semi-structured interviews for lay women were designed based on information collected from participant observation. Physicians’ semi-structured interviews were guided by information collected from the breast cancer literature and participant observation. The three types of semi-structured interviews used were: one of two systematic ethnographic techniques (free lists or a pile-sorting) and a photographic narrative question. The semi-structured interviews were guided by an interview guide and conducted in a private location (at home or private practice) (Bernard, Ryan 2010). They were administered in Spanish or English and recorded.

**Free list.** First, free list questions were used to elicit the elements of cultural knowledge about breast cancer (Weller, Romney 1988). Forty-five (30 women and 15 physicians) free list interviews were conducted (Figure 1.2). Each interview session consisted of three sections: socio-demographic attributes, photographic narrative, and a free list task. Free listing defines the cultural domain of breast cancer in terms that are most meaningful to participants, without imposing an a priori analytic framework (Weller,
Romney 1988; Borgatti 1998). This is simple and rapid, but is a powerful method that provides a quantifiable measure of individuals’ knowledge of a domain. While it may not produce an exhaustive list, it provides a metric that allows researchers to identify aggregate levels of agreement and explore patterns of intergroup variation (Gatewood 1983; Boster 1987; D’Andrade 1981).

The interviews ranged between forty-five minutes to one hour. Using Kleinman’s explanatory model as a guide, the domain of breast cancer was divided into four subdomains (preventive measures, symptoms, risks, and treatments) to better understand the domain and to provide a rich description of women’s and physicians’ cultural knowledge of breast cancer. During free list interviews, participants were asked to list all the preventive measures, symptoms, risks, and treatments associated with breast cancer.

**Unconstrained Pile sort.** Second, unconstrained pile sorts were used to discover the semantic structure of women’s and physicians’ cultural domain of breast cancer (Weller, Romney 1988). Forty-nine (29 women and 20 physicians) pile sort interviews were conducted (Figure 1-2, Figure 1-4). Based on free list results, I selected approximately thirty-nine items (for women) and thirty-eight items (for physicians), individually printed them on index cards, and asked respondents to sort them into groups that belong together. There were no limits on the number of groups respondents were permitted to make. After respondents created their piles, they were asked to discuss why they sorted words as they did.

**Photographic narratives.** Women and physicians were also asked to describe how the healthcare system in Puerto Rico functions, based on their personal or
professional experiences (Objective 1). The photographic narrative question was included in the semi- and structured interviews. Participants were presented with a blank sheet of drawing paper and lead and colored pencils and asked to draw or write a brief summary to explain the Island’s healthcare system. The photographic narrative data was combined with participant observation data, other semi-structured interviews, and structured interview data to provide additional information about physicians’ and women’s experiences of Puerto Rico’s healthcare system.

The semi-structured format provided women and physicians with the flexibility to determine the pace of the interview (Bernard 2011). The integration of free listing, pile sorting and photographic narratives permits the systematic definition of women’s and physicians’ cultural knowledge about breast cancer and ensures the cultural validity of subsequent interviews.

Confirmatory phase

**Structured interviews.** Structured interviews were administered to both physicians and lay women. Forty-nine interviews were conducted with the same group of participants (29 women and 20 physicians) from the pile sort interviews (Figure 1-2). Rankings data was used to describe similarities and differences within and between women’s and physicians’ cultural knowledge of breast cancer and to explore the relationship between cultural knowledge and social context (Objective 2) (Weller, Romney 1988). Based on the results of free listing 25, 29, and 25 words were selected from the prevention measures, risks, and symptoms, respectively. The words were then individually printed on index cards. Participants were asked to organize the words for each sub-domain from the most important to the least important. After the women and physicians ranked the items, they were asked to discuss their ranking decisions.
Rankings data provided the information necessary to illustrate how women’s and physicians’ cultural knowledge of breast cancer relates to their social context with women (Objective 2).

Data Analysis

Exploratory phase

**Participant observation.** During fieldwork, an iterative approach was used to develop a codebook to define themes (MacQueen et al. 1998). Content and narrative analysis were used to identify common themes that occur during observations and conversations with women and physicians during their day-to-day activities and in their occupational spaces (Bernard, Ryan 2010). Theme frequency, associations among themes, and differences and similarities between women’s and physicians’ narratives and experiences of breast cancer preventive measures, risks, symptoms, and treatments were evaluated (Objectives 1 and 2).

**Semi-structured interviews.** Cultural domain analysis was used to identify the items that make up women’s and physicians’ cultural knowledge of breast cancer symptoms, risks, prevention measures, and treatments from the participants’ free lists. Cultural domain analysis has been used by anthropologists and psychologists to discuss individuals’ knowledge (Boster 1987; Weller, Romney 1988; Borgatti 1994; Gravlee et al. 2013). Cultural domain analysis of free list data is based on three assumptions: 1) when prompted to free list, participants will list items from most familiar to least familiar, 2) participants with more knowledge about a domain will list more items, and 3) the more group members list an item, the more salient or important it is to the group's understanding of that the domain (Quinlan 2005; Weller 2014).
First, ANTHROPAC 4.98© and Microsoft Excel were used to identify the items most frequently mentioned by each participant and group (Borgatti 2010). Second, scree plots of the women’s and physicians’ lists were used to identify a cutoff measurement for salience (Bernard 2010; Weller 2014). Third, an average of the group’s cut off measurements for the four domains were calculated and used to select the most frequently mentioned items discussed in this chapter. Finally, ANTHROPAC 4.98®, STATA 13.1®, and UCINET® for Windows were used to explore the length and content of the groups’ lists, ultimately identifying patterns of variation in women’s and physicians’ knowledge about breast cancer (Borgatti 2010; Gatewood 1983; Quinlan 2000). Multidimensional scaling (MDS), an exploratory visualization method, was also use to identify levels of agreement between groups across the four domains (Objective 2). This visual provides information about the relationship between the points. The closer the point, the more the respondents’ agreed about the breast cancer items. The Kruskal Stress score, a goodness of fit measure, refers to the level of distortion required to render the points into a 2-dimensional visual. A stress score of .2 or lower is acceptable.

Pile sort data were analyzed to explore how women and physicians perceive the relationships among words in the sub-domains of breast cancer. Cultural domain analysis of pile sort data is based on three assumptions: 1) that each respondent has a cognitive spatial map that organizes sematic items of a domain, 2) that these semantic items are distributed based on their level of similarity, and 3) when asked to pile sort respondents will engage in yes/no similarity judgments that produce a distance measure
in which similar items are paired together, illustrating shorter distance among similar items when compared to dissimilar items (Borgatti 1998).

MDS of pile sorts was used to 1) present a visual representation of women’ and physicians’ semantic maps for the four breast cancer subdomains, 2) identify levels of agreement between groups, and 3) compare the structure of respondents’ breast cancer domain, ultimately identifying patterns of variation in women and physicians knowledge about breast cancer (Borgatti 2010; Gatewood 1983; Quinlan 2000) (Objective 2).

Photographic narratives were analyzed to locate women’s and physicians’ cultural models within their past and current social contexts. Since the photographic narratives included written graphics and text, as well as transcript text data, analysis occurred in two phases. During the first phase, the written and drawn data was reviewed to compare how women and physicians illustrated the structure of the Island’s healthcare system. In the second phase, narrative analysis was conducted in three stages. Narrative analysis was used to identify common themes within and between women’s and physicians’ narratives to explore how structural changes brought on by a reforming healthcare system influence care seekers’ (women) and providers’ (physicians) breast cancer experiences in Puerto Rico (Bernard 2010; Miles, Huberman 1994). First, to ensure data quality, I compared fifty-five of the eighty narrative transcriptions with their associated audio recordings. Second, I reviewed all of the transcripts to identify and define overarching conceptual and relationship codes that characterize women’s and physicians’ breast cancer experiences (Bernard 2010; Miles, Huberman 1994; Ignatow 2009). Third, identified codes were applied to all narratives
and used to define shared and group-specific themes. Exemplar excerpts used in the following discussion were first translated from Spanish to English by the author and crossed referenced with a native speaker (research assistant) to ensure accuracy.

**Confirmatory phase**

**Ranking analysis.** Informal cultural consensus analysis was used to describe and compare women’s and physicians’ cultural knowledge of breast cancer (Objective 2) (Romney, Weller et al. 1986). Cultural consensus analysis was used to build on the cultural domain analysis results (e.g., free lists and pile sorts). It was used to analyze the rank order data. Researchers have used consensus analysis of ranking data to link intra- and intergroup variations in levels of agreement with medical decision-making (Romney, Weller et al. 1986; Romney 1999; Smith et al. 2004). Cultural consensus analysis evaluates patterns of agreement among a sample of individuals (Romney, Weller et al. 1986; Aunger, Romney 1999). It does three things relevant to Objective 2. First, it tests the assumption that individuals draw on a shared pool of cultural knowledge. I used this feature to test whether women (patients and community members) and physicians draw on a single pool of cultural knowledge about breast cancer when ranking breast cancer risks, preventive measures, and symptoms. Previous theory sets up the expectation that women and physicians will, in fact, have distinct pools of cultural knowledge (Chavez et al. 1995). This expectation was partially supported by the study’s findings (Objective 2).

Second, cultural consensus analysis operationalizes individual cultural knowledge as individual’s agreement with the aggregate pattern of responses. I used this feature to measure women’s and physicians’ individual cultural knowledge of breast
cancer (Objective 2). Third, it estimates the culturally appropriate answer to a set of questions (e.g., ranking items from free list results). I used this feature of consensus analysis to estimate women’s and physicians’ shared cultural knowledge of breast cancer (Weller, Baer 2002) (Objective 2).

The culturally appropriate (“correct”) answer is measured by calculating the correlation between individuals’ ranking and the consensus rankings of the aggregate group (Weller, Baer 2002; Handwerker 2002; Gravlee, Dressler 2005). This approach regards the “correct” answer as a dynamic concept (rather than a static empirical fact) that varies between and within groups based on group members’ exposure to the domain of interest. This permits researchers to explore how context such as material constraints influences the flow of knowledge and individuals’ ability to use it to navigate their daily lives, in this case, breast cancer experiences. Therefore cultural consensus analysis was first used to discover the answer that is relatively “correct” for the women sample and physician sample. Then the groups’ correct answer keys were used to 1) determine women’s and physicians’ cultural knowledge or level of cultural literacy (Borgatti 1999) of breast cancer (on an individual and aggregate level) and 2) explore how women’s and physicians’ level of agreement relate to their social context.

**Dissertation Overview**

Chapter 2 aims to illustrate the relationship between Puerto Rico’s healthcare system, political economy, and women’s health experiences on the Island. Puerto Ricans, the second largest Hispanic subgroup, hold a unique status as U.S. citizens of Caribbean origin. As a Commonwealth of the United States, Puerto Rico occupies a unique legal and political status in the Hispanic Caribbean. The history and culture of the Island
retain evidence of its Caribbean identity. Yet, Puerto Rico’s healthcare system and economic dependence on the U.S. provide the opportunity to explore how historical, cultural, and structural factors interact to influence women’s health experiences. This chapter 1) examines the development of Puerto Rico’s political and economic structures, 2) analyzes Puerto Rico’s healthcare system and individuals’ health-related behaviors within the country’s historical context, and 3) locates the discussion within medical anthropology.

Chapter 3 reviews existing evidence that support the importance of culture and social context in cancer research and explains how this work contributes to cancer research in anthropology and public health. The growing attention to health disparities has stimulated cancer research that uses culture to explain variations in individuals’ and groups’ cancer experiences. Culture has been used to explain differences in cancer knowledge, medical decision-making, and illness management between and within groups (ethnic/racial, gender, and lay vs. biomedical). Some researchers have cautioned that cancer research that focuses only on culture fails to account for the structural factors that also contribute to variation in cancer experiences. This chapter responds to these critiques by 1) exploring why both culture and social context matters and 2) illustrating the advantage of cancer research that accounts for both culture and social context.

Chapter 4 uses physicians and women’s narratives to describe women’s and physicians’ experiences of Puerto Rico’s current healthcare system and its on going healthcare reform. It equally weighs the voices of prominent players in breast cancer discourse and healthcare reform, physicians (care providers) and women (care seekers)
to 1) deliver an in-depth description of factors that influence women’s and physicians’ breast cancer experiences and 2) explore how the Island’s predominantly Medicaid-funded public insurance structure influences women’s access and use of available breast cancer resources on the Island.

Chapter 5 uses culture theory and systematic ethnographic methods to describe the content of women’s and physicians’ cultural sub-domains of breast cancer (preventive measures, risks, symptoms, and treatments) in Mayaguez Puerto Rico. It is part one of the dissertation’s two-part response to a call for research that explores the multiple voices of cancer (Hunt 1998; Balshem 1991; Chavez 2009; Jain 2007a). This discussion 1) identifies and compares the content of women’s and physicians cultural knowledge of breast cancer and 2) discusses how this multi-voiced approach begins to unpack the variation that defines cancer experiences.

Chapter 6 continues the discussion about women’s and physicians’ breast cancer experience in Mayaguez, Puerto Rico. It takes the discussion further by exploring how shared cultural knowledge of breast cancer between and among women and physicians interact with their social context to influence cancer experiences. It uses a dual focus on culture and social context to 1) explore variations in women’s and physician’s cultural knowledge of breast cancer and 2) examine how these levels of variation interact with social structural forces to influence women (care seekers) and physicians (care providers) breast cancer experiences. It represents another step in anthropologists’ attempt to understand the relationship between culture and social context and its impact on individuals’ varying experiences of illness such as cancer, a condition whose discourse continues to be shrouded in ambiguity and fear.
Chapter 7, the conclusion, summarizes how cultural knowledge and social context impact Puerto Rican women and physicians experiences with the Island’s healthcare system and their breast cancer experiences.
Figure 1-1. Study Timeline

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<th>Activity</th>
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<th>2015</th>
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<tr>
<td>Participant observation</td>
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<tr>
<td><strong>Phase 1- Exploratory (Objectives 1, 2 and 3)</strong></td>
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<tr>
<td>Semistructured and free list interviews (N= 30 Women, 15 Physicians)</td>
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<tr>
<td>Recruit participants</td>
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<td>Conduct interviews</td>
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<tr>
<td>Analyze</td>
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<td><strong>Phase 2- Confirmatory (Objectives 3 and 4)</strong></td>
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<td>Pile sort interviews (N= 29 Women, 20 Physicians)</td>
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<tr>
<td>Recruit participants</td>
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<td>Conduct interviews</td>
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<td>Analyze</td>
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<tr>
<td>Structured interviews (N= 29 Women, 20 Physicians)</td>
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<td>Recruit participants</td>
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<td>Conduct interviews</td>
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<tr>
<td>Analyze</td>
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Figure 1-2. Sampling
Figure 1-3. Participant solicitation cards. Hair Salon A) and Facebook B) (Photos courtesy of author, June Carrington)
Figure 1-4. Pile sort Physician A) and Community Woman B) (Photos courtesy of author, June Carrington)
CHAPTER 2
POLITICAL ECONOMY AND HEALTHCARE IN PUERTO RICO

The *Estado Libre Asociado* (Free Associated State) or the Commonwealth of Puerto Rico is home to approximately 3,700,000 inhabitants (U.S. Census 2013). Puerto Rico’s colonial history and commonwealth status has created a political state that is simultaneously domestic and foreign to the United States (U.S.) (Briggs 2002; Nelson 2005). For example, as a Commonwealth, the U.S. still maintains political power to veto and control all decisions made by Puerto Rico’s local government (Dietz 1976; Briggs 2002; Gosfrugal 2003). In the Island’s 1998 plebiscite to assess its association with the U.S, more than one half of the voters voted for neither independence nor annexation from the U.S., but for an improved version of their Commonwealth status (Duany 2000). In 2011, the majority of Puerto Rican voters did not want Puerto Rico to retain its current status and selected statehood as the most preferable non-territorial options (Garrett 2013).

Today forty-five percent of Puerto Rico’s population lives below the federal poverty line, higher than Mississippi, the poorest state in the U.S. Union (U.S. Census Bureau 2013b). The Island’s political and economic developments are intimately tied to advancements in its healthcare system. Puerto Rico’s relationship with the U.S. has led to its adoption of capitalist ideologies that influenced its economic transitions and the creation of a healthcare system that mirrors that of the U.S. The Island, similar to the U.S., continues to use market-based solutions to address its social problems (Nelson 2005). This chapter aims to link Puerto Rico’s current economic and healthcare environment to its unique history with Spain and the U.S. by 1) examining the development of Puerto Rico’s political and economic
structures, 2) analyzing Puerto Rico’s healthcare system and individuals’ health-related behaviors within the country’s historical context, and 3) locating the discussion within the anthropology of healthcare reform and service delivery literature.

**Political Economy of Puerto Rico**

**1493: Spanish Colonization**

The Spanish discovery of Puerto Rico set in place a history of political and economic development guided by limits enforced by foreign powers, first Spain and later the U.S. (Dietz 1986). Christopher Columbus discovered Puerto Rico on Tuesday, November 19th, 1493. It was originally named *Boriquén*, “Land of the Proud Lord” by its inhabitants (Dietz 1976; Dietz 1986). Initially, the Island poor in resources was regarded as a military garrison and a port along the Central and South American trade route (Dietz 1986; Carrion 1983). At the time of its discovery, approximately 60,000 Taino and Amerindian Arawak Indians inhabited the Island (Scarano 1993).

By 1513, the indigenous inhabitants of the Island were greatly reduced as a result of war, epidemics, and hard labor. In need of a labor force for its sugar industry, Spain replenished the Island’s work population with forced labor, slaves from Africa. The colony’s economy was depended on slavery until it was abolished in 1873 (Dietz 1976; Arbona, Ramírez de Arellano 1978). In 1897, a weakened Spain unable to maintain control of its colonies granted Puerto Rico autonomy (Dietz 1976). At the time of its autonomy, Puerto Rico had a colonial economic structure. All materials produced on the Island were exported to Spain while food and other needed products were imported from the dominant economy (Dietz
1976). This economic structure would continue under United States rule. Puerto Rico’s newfound autonomy was short lived. It ended in 1898 when Puerto Rico was ceded to the United States at the end of the Spanish American War (Carrion 1983; Dietz 1976; Scarano 1984). Since then, the Island has never regained complete autonomy.

1898: U.S. Acquisition

Puerto Rico was given to the United States by Spain under the Treaty of Paris in December 1898 for compensation for damages suffered during the war (Aranda 2007; Dietz 1976). By 1898, Puerto Rico was made up of various ethnicities: Africans, Europeans, Tainos, and Amerindian Arawaks (Rivera-Batiz, Santiago 1996). James Dietz (1986) posits that the United States’ invasion and colonial supervision of Puerto Rico was a strategic plan of expansion to protect its economic interest in capitalism and democracy. Similar to Spain, Puerto Rico provided the U.S. with labor and military resources to build its empire and expand into the Latin Americas (Dietz 1976). During the first half of the 1900s, the U.S. ruled the Island through military occupation.

In 1900, the U.S. Congress passed the Foraker Law and ended military occupation of Puerto Rico. The law provided only the U.S. Congress and the U.S. President the ability to appoint U.S. civilians as government officials on the Island (Dietz 1986). The Foraker Law strategically allowed America to regulate Puerto Rico’s economic and political development through its control of laws and trade relations (Dietz 1976). In 1917, the Jones Act was passed in response to Puerto Ricans’ demand for self-rule (Dietz 1986). When the Supreme Court interpreted the law, the provision of the Act regarded Puerto Rico as something that belonged
to the U.S., not a part of it. So, the constitutional rights given to mainland citizens did not apply to Puerto Ricans (Dietz 1986). This Act did little to provide the Island with autonomy. Rather, it granted all Puerto Ricans U.S. citizenship and made Puerto Rican men eligible for military draft. It was also made clear that those who wanted to retain their Puerto Rican citizenship would be required to renounce their United States citizenship, thus losing the rights associated with that status (Dietz 1976).

Between 1898 and 1930, Puerto Rico’s sugar-based agriculture economy increased its use of machines and factories, ultimately increasing its sugar production. This factory-based approach to sugar production capitalized on technological advancements to create large sugar producing centers. These centers monopolized on the land and displaced small farmers (Dietz 1986; Carrion 1983). One of the immediate effects of this approach was the creation of a wage labor class on the Island. It success was also bolstered by the Foraker Law and Jones Act which strengthened the Island’s dependency on the U.S. through trading tariffs that locked Puerto Rico into a colonial trading pattern with the U.S. Consequently securing the U.S. mainland as the only buyer of the Island’s products. So similar to its time under Spain, Puerto Rico’s products were exported only to the U.S. while imports such as food came from the mainland (Dietz 1986; Carrion 1983). Further, solidifying the Island’s reliance on the U.S.

By 1920, four U.S. firms controlled about half of Puerto Rico’s sugar production. The U.S also dominated the Island’s tobacco production and distribution. By 1930, tariff restrictions meant that 95% of the Island’s exports and
90% of its imports were to and from the mainland (Dietz 1986). Puerto Rico experienced an increase in its per capita income, but this benefit was not equally distributed. Puerto Rico’s income disparities were divided by geography (the U.S. and Puerto Rico) and class (the wealthy, the working class, and the unemployed). These inequities in benefits affected the quality of life on the Island. The unemployed and working class did not experience improvements in their living conditions. Inequality in income and quality of life among Puerto Ricans would be exacerbated in the following decades as a result of the Great Depression (Dietz 1986).

The Jones Act did not eliminate Puerto Ricans’ protest against U.S. colonization. Between 1917 and 1930, Puerto Rico’s Nationalist Party’s protests against U.S. colonization were met with military responses. These clashes generally resulted in bloody events in Puerto Rico’s history. One memorable protest was named the Massacre of Rio Piedras because of the deaths and imprisonments associated with the event (Dietz 1976). The Foraker Law and Jones Act established the blueprints for Puerto Rico’s political and economic dependent relationship with the U.S. (Dietz 1976).

1930s: The Great Depression and Nationalism

In the early 1930s, the Great Depression fostered an economic crisis in the United States. It forced the nation to revisit its relationship with capitalism and Puerto Rico. Holding true to the statement, “when the U.S. sneezes the world gets a cold,” the effects of the U.S. Depression were exacerbated in Puerto Rico. Puerto Rico’s agriculture industry based on sugarcane began to collapse. Its high
rates of unemployment increased, and many waged workers joined their unemployed countrymen (Dietz 1986).

Existing disparities across income and gender lines meant that all Puerto Ricans did not experience the effects of the Depression equally. Even though women’s participation in the labor force increased in the 1930s, they still made less than their male counterparts (Dietz 1986). This was primarily linked to hierarchies in positions between men and women. In the Island’s needlework and embroidery factories, women were generally employed as workers while men were supervisors or foremen (Dietz 1986). In response to the low quality of life on the Island (Figure 2-1), local politicians, specifically the Nationalist Party, organized labor unions and protests that demanded independence from the U.S. The protests and increased violence on the Island in the 1930s ushered in the transformation of the 1940s.

The 1930s are recognized as the birth era of Puerto Rico’s cultural identity (Duany 2000). An identity that was constructed through nationalists’ discourse that defended the Island’s values and customs against the U.S. Puerto Rico’s nationalist discourse was constructed along a "binary opposition between American and Puerto Rican culture" (Duany 2000:10). A culture composed of language (English vs. Spanish), religion (Catholic vs. Protestant) and origin (Anglo vs. Hispanic). Jorge Duany (2010) has argued that while Puerto Rican nationalists attempted to create a homogenous culture that is distinct from the U.S., they failed to account for the fragmented and heterogeneous characteristics evident in the Island’s history and people. He also notes that the continual creation of Puerto Rico’s cultural identity has and continues to be contested by non-academics, the
Puerto Rican diaspora, the poor, different races on the Island, and women (Duany 2000). Sidney Mintz’s (1966) work in Puerto Rico also supports the existence of a Puerto Rican “culture” defined by diversity. Mintz’s account of Puerto Rico’s national culture describes it as a small distinct series of subcultures rather than a homogenous culture (1966).

1940s: Operation Bootstrap

The 1940s saw the introduction of a new capitalist model of development in the United States and on the Island (Dietz 1976; 1986). On the mainland, economic theorists blamed the Depression on the government’s failure to invest in private corporations. This new approach, supported by Keynesian economists, argued that the U.S. and Puerto Rico’s economic problems could be solved through the government’s implementation of policies that would provide incentives for private companies to increase their production. Increased productions would result in increases in demand, which would increase the need for workers and decrease unemployment. This capitalist model and its promises of a better future fueled the laws implemented on the Island in the 1940s (Dietz 1986).

As the U.S. entered its second world war, the Popular Democratic Party (Partido Popular Democratico, PPD) replaced the Nationalist Party as the voice of an exploited populace (Dietz 1976; Baver 1993; Briggs 2002). In 1940, Luis Munoz Marín, a member of the PPD, was elected Senator. In 1948 he would become Puerto Rico’s first elected governor, after the U.S. Congress permitted the Island to create its own constitution (Dietz 1986). The PPD presented itself as a party that would give voice to the labor workers and address the poor socioeconomic situation on the Island (Lapp 1995). While Munoz Marín initially supported a push
for Puerto Rico’s independence, he later became an avid supporter of the Island’s Commonwealth status. To achieve this, the PPD supported a break away from Puerto Rico’s sugar based economy and welcomed the proposed capitalist model in efforts to increase industry on the Island (Dietz 1986).

In 1947, the new capitalist model was implemented in Puerto Rico with the passage of Operation Bootstrap (Rivera-Batiz, Santiago 1996; Baver 1993). This law opened the Island to mainland capitalists. It replaced an early initiative, the Public Ownership Program (Fomento), which used private incentives to increase local businesses on the Island (Dietz 1976, 1986). Even though Puerto Rico, unlike other developing countries, was politically stable and offered low wages, it lacked infrastructure. Tax holiday laws, passed under Operation Bootstrap, were the local government’s attempt to encourage U.S.-based industries to develop on the Island and ultimately build infrastructure. These laws provided incentives such as labor (high unemployment), exemption from federal income and local taxes for 10 to 30 years, wage incentive programs, and infrastructure benefits (Dietz 1986).

The local government and working class paid for the majority of these incentives while the revenue was shipped to the mainland (Dietz 1976). The Operation Bootstrap law, like the Foraker Law and the Jones Act, strengthened the Island’s unhealthy dependence on the U.S. for development initiatives (Safa 1995). This dependency would continue to prevent autonomous economic and political development on the Island (Dietz 1986).

Similar to its predecessors, Operation Bootstrap made it difficult for Puerto Ricans to improve their standards of living because it increased U.S. capital at the
expense of local capital (Carrion 1983; Lapp 1995; Baver 1993). The law was supposed to increase employment; instead it increased unemployment on the Island. The distribution of capital was not the only case in which inequalities continued. The benefits of industrial development on the Island (improvements in living conditions, decreased mortality rate, and increased life expectancy) (Table 2-1) were unequally distributed along class lines that existed on the Island before the 1940s (Dietz 1986; Safa 1995).

1952: The Commonwealth of Puerto Rico

At first glance Puerto Rico’s 1950s legislations (e.g., commonwealth status) suggests the Island’s development of a self-governing structure to ensure its separation from the U.S. However, similar to previous laws in Puerto Rico the series of laws that granted the Island its commonwealth status served to strengthen its dependence on the U.S. mainland, reinforcing its domestic yet foreign status. In 1950 the U.S. Congress passed Public Law 600. The law gave Puerto Rico permission to create its own constitutional government, if a referendum supported it. It required that any law created and adopted by the Puerto Rican local government be approved by the U.S. Congress (Dietz 1986). In 1952, the U.S. Congress approved the Puerto Rican Constitution and the Island became an Estado Libre Asociado or Commonwealth of the United States. The Constitution did not alter the U.S.’ ability to apply laws in Puerto Rico and similar to earlier laws, it strengthened U.S. control over the Island’s political and economic growth (Dietz 1976; Rivera-Batiz, Santiago 1996). As a Commonwealth, Puerto Rico is not regarded as a part of the American union or an independent country. Puerto Ricans do not pay income taxes and have a non-voting representative in
Congress. While Puerto Ricans are allowed to elect their own Governor, they are not allowed to vote in Presidential elections (Rivera-Batiz, Santiago 1996).

1960s: Food Stamps

The Island’s commonwealth status and economic boom of the 1950s failed to provide the socioeconomic improvements promised by the PPD in the 1940s (Pico 2006). In the mid 1960s, the local government attempted to improve its economic situation and implemented the Petro-Chemical Program, an attempt to diversify Puerto Rico’s economy (Baver 1933; Rivera-Batiz, Santiago 1996). The program was supposed to attract U.S. industries whose products would be used as inputs for existing manufacturing companies on the Island. Sadly, this strategy failed because it was implemented during the 1970s, when America started to experience a recession. Once again, this failed economic strategy translated into increased unemployment on the Island (Rivera-Batiz, Santiago 1996).

The 1960s culminates the Island’s epidemiological transition with decreased rates of communicable illnesses and increased rates of chronic illnesses (Figure 2-1). However by the early 1960s, the unequal distribution of benefits from the industrial era (1940s to 1960s) was demonstrated by inequalities in wealth on the Island (Pico 2006). During the industrial area, the poor became poorer and the rich became richer (Pico 2006). Similar to the 1930s, inequalities in income on the Island meant that as Puerto Rico’s Gross National Product (GNP) increased, its health indicators (e.g., birth rate and life expectancy) (Table 2-1), unemployment, and poverty also increased. In efforts to address the increasing poverty on the Island, the United States granted Puerto Rico access to the Federal National Nutritional Assistance Plan (FNAP). FNAP (food stamps) provided the Island with
federal funds to provide eligible low-income families with monthly stipends for food. Qualified families initially received cash, which was later changed to checks (Pico 2006).

Food stamps were a short-term solution to Puerto Rico's escalating poverty. However, since it only addressed the outcome and not the cause of the Islands' increasing unemployment - a declining commercial agricultural system - food stamps became a small bandage to a larger problem (Safa 1995). The usage restriction of the food stamps program- only supermarkets- decreased local capital by decreasing the use of local stores and the existing bartering system (Pico 2006; Briggs 2002, Rivera-Batiz, Santiago 1996). Consequently, like previous aid initiated by the U.S., food stamps increased Puerto Ricans dependency on food imported from the U.S., especially fast food (Pico 2006).

The use of welfare in Puerto Rico engendered critiques from the Island and the mainland (Rivera-Batiz, Santiago 1996). The former group argued that increases in minimum wage made Puerto Rican workers demand higher income, which was never granted and in turn increased the populace dependency on aid. The latter group, in accordance with the notion the of the "welfare mother," posited that public assistance programs on the Island increased poverty among women because it made them have more children in single headed households. This, in turn, perpetuated their dependency on aid and poverty (Nelson 2005; Rivera-Batiz, Santiago 1996; Safa 1995; Briggs 2002).

1970s Migration

In the 1970s, Puerto Rico’s dependency on the U.S. continued. By 1970 the Island was the 5th largest customer of U.S. goods. The rapid industrialization of
the Island’s economy negatively impacted its working class. The mainland industries’ decision to use technology over the abundant labor force meant more profit for the firms, not the working class. In the 1970s, the local government attempted to address the Island’s poor socioeconomic conditions by raising wages. However, even though minimum wage regulations were applied, they were enforced on an industry-by-industry basis (Dietz 1976). During this time, minimum wage on the Island was lower than that in the south, the lowest wage sector of the mainland. The hourly wage in Puerto Rico was $2.43, compared to $4.42 on the mainland ($4.69 in New York City (NYC) and $3.45 in South Carolina). Yet, the cost of living on the Island was similar to the cost of living in NYC (Dietz 1986). Puerto Rico’s high rates of unemployment and inequalities in income distribution meant that by 1970, 50% of the population was receiving food stamps and 70% were eligible (Dietz 1986).

The industrialization of Puerto Rico also increased migration from the Island and restructured Puerto Rico’s class system. Dietz (1986) asserts that Puerto Rico’s unemployment rate was reduced due to an increase in migration off the Island after WWII (Duany 2000). Cheap tickets between San Juan and NYC facilitated increased migration to New York City in search of jobs (Duany 2000). Between 1945 and 1965, approximately 1/4 of the Island’s population migrated to the mainland, this increased to 44% in 1990. By 1997, 3.1 million Puerto Ricans were living on the mainland compared to 3.7 million on the Island (Duany 2000).

These waves of migration influenced by the Island’s unstable economy restructured the Puerto Rican family. Between 1960 and 1990, family households
(two or more individuals who are blood relatives) decreased from 92% to 84% and non-family households (one or more individuals who are not blood relatives) increased from 7.9% to 16% (Morales del Valle 1998). Over the years, the patriarch structure of the Puerto Rican family changed. More females became the head of households and major household decisions were no longer relegated to their male counterparts (Safa 1995; Garica-Preto 2005). Laura Briggs (2002) has argued that this change has been used by critics on and off the Island to label Puerto Ricans as a lazy welfare dependent population. The U.S. and local government has used this image of Puerto Ricans to support their application of market-based approaches that paternalistically push welfare recipients to find jobs and better their future (Nelson 2005; Briggs 2002; Angueira 2001).

The image of the welfare dependent Puerto Rican has been married to gendered stereotypes that regard women as the cause of the Island’s poverty and has made them the targets of reform (Briggs 2002; Safa 1995). For example, The Personal Responsibility and Work Opportunity Reconciliation Act (1996) was passed in efforts to decrease poverty on the Island by decreasing the number of individuals (predominately women) enrolled in the welfare system (Angueira 2001; Nelson 2005). It implemented protocols designed to encourage women to find jobs. While the act decreased the number of welfare recipients, it was out of context in Puerto Rico. The Act’s emphasis on finding a job immediately did not take into consideration that Puerto Rican women on welfare did not have the required education or skills to find proper jobs. Therefore, when they secured jobs, they normally were low paying jobs in very bad conditions that did not provide jobs
benefits (Briggs 2002). While the Act encouraged some women to find jobs, it left others without resources to take care of their families (Angueira 2001).

By the mid-1970s, with the U.S. experiencing inflation and a recession, the Island began to lose major firms, who left in search of cheaper labor. In 1975, Governor Hernandez Colon created a committee to understand what the future held for the Island (Dietz 1976). According to Dietz, the Committee’s recommendations instructed the Island to make the poor poorer, cut spending on social welfare efforts, and limit wage increases in order to address its economic hardship (1976). In 1976, the 936 Incentive Law, an amendment to the Tax Reform Act of 1976, was passed in efforts to address the failures of Operation Bootstrap and the Petro-Chemical Program.

The 936 Initiative Law allowed U.S. companies in Puerto Rico to apply their earnings to their parent companies on the mainland, if they held their earnings on the Island for six months and used it to invest in the Island’s local economy (Rivera-Batiz, Santiago 1996). Continuing the pattern of Puerto Rico’s dependency on the U.S. for economic development, the law benefited U.S. industries and not the Island’s labor force. When U.S. corporations began to leave, the Island plunged into another economic crisis (Rivera-Batiz, Santiago 1996).

**1980s - Present: Economic Instability and Crime**

Francisco Rivera-Batiz and Carlos Santiago (1996) paint the 1980s and 1990s as a time of rising unemployment rates, high poverty, and increased social inequality, substance abuse, and crime in Puerto Rico. The quality of life in Puerto Rico during this time has been linked to the Island’s long history of dependency on the U.S., in which the negative effects of the U.S. economy are intensified on the
Island (Pico 2006; Rivera-Batiz, Santiago 1996). For example, between the 1970s and 1990s when the U.S. economy fluctuated and experienced a recession, the factories that were sent to Puerto Rico enticed by incentives began to close and the rates of unemployment increased. While the U.S. experienced a ten percent unemployment rate (1982), Puerto Rico experienced a higher rate, approximately 22% (1986). Moreover, in 1989 when the U.S. recovered from its recession and the unemployment rate decreased to 5%, Puerto Rico still experienced a 20% unemployment rate in 1990 (Rivera-Batiz, Santiago 1996).

This Puerto Rico, just decades ago, was regarded as a model place for economic and political development and an open-market democracy. Its economic transition from agricultural industry has resulted in a rural to urban migration on the Island. In 1940, two-thirds of the population was rural dwellers; by the 1990s two-thirds were urban dwellers (Rivera-Batiz, Santiago 1996). In 1993, Puerto Rico was considered one of the richest countries in Latin America with the highest income per capita. It was recognized among the middle-income countries in the world and ranked higher than Greece and South Korea (Rivera-Batiz, Santiago 1996). Yet, its unemployment rates was above 30%, more than the 25% unemployment rate in the U.S. during the Great Depression (Rivera-Batiz, Santiago 1996).

In the 1990s, Puerto Rico’s unstable economy resulted in an increase in crime on the Island. This increase in violence, which continues today, has been tied to drug use (Pico 2006). The Island’s geographical and political location has made it an important location in the cocaine trade between Columbia and United
States (Pico 2006). In 1998, the government publicly initiated raids in its urban locations labeled as sites of drug centers in efforts to address the Island’s escalating crime. Murder rates, which had declined in the 1960s and 70s, began to increase. In 1992 there were 24.1 murders per hundred thousand persons compared to 9.8 in the U.S. in 1991 (Rivera-Batiz, Santiago 1996). In 2004, the Island’s Department of Health report a 19.5 murder rate (per hundred thousand persons) (2006).

Throughout its history, the Island has experienced changes in autonomy, family structure, gender roles, and poverty. Puerto Rico has enjoyed benefits in its economic and political development because of its association with Spain and the United States, but this relationship has been a double-edged sword (Pico 2006; Briggs 2002; Rivera-Batiz, Santiago 1996). When compared to states in the U.S. Union, Puerto Rico’s indicator-- disposable income per capita-- resembles Latin American countries rather than the United States. Puerto Rico’s relationship with the U.S. facilitated years of development policies and waves of migration to and from the Island. This flow of individuals maintains a constant stream of political, economic, and social influences from the mainland to the Island. The demographics of the Island’s migrants transitioned from low-wage laborers in the 1950s to professionals in 1990s. This shift in migrants, tied to the Island’s political economy, also influences and has been influenced by Puerto Rico’s healthcare system.

**The Puerto Rican Healthcare System**

Since the 15th century, external forces have influenced the health of the Island’s inhabitants, first Spain and then the U.S. During the 19th century the
provision of healthcare on the Island was guided by a two-tier structure: the local
colonial government and municipalities. The local colonial government
responsibilities included professional licensing of physicians and practicantes (the
equivalent of today’s physician assistant), epidemiological surveys, preventive
care, and hospital services (Arana-Soto 1974). The municipalities provided basic
medical and hospital care to the medically indigent (Arbona, Ramírez de Arellano
1978; Arana-Soto 1974). Every municipal clinic employed doctors who provided
care to about 80% of the population for free. The provision of free healthcare by
the government is mirrored in Puerto Ricans’ current expectations that the
government should provide free care to its population and that physicians should
provide care without being incentivized by money (Mulligan 2007).

In 1833, there were approximately 98 externally trained (in Spain, Santo
Domingo, and the U.S.) healthcare providers (53 physicians and 45 practicantes)
(Cruz Monclova 1970). There was one physician for every 6,700 individual. Of the
53 physicians, 18 practiced in the three main cities at the time (San Juan, Ponce,
and Mayaguez) while 35 practiced in the eight smaller towns on the Island
(Arbona, Ramírez de Arellano 1978; Arana-Soto 1974). By the mid-19th century,
physicians held dual roles as municipal physicians and directors of municipal
charities. Physicians or practicantes also served alongside a municipal judge, a
priest, a military commander, and two honored citizens on a sanitary commission.
After 1814, there was a sanitary commission in each municipality, which oversaw
municipal level health concerns (Arbona, Ramírez de Arellano 1978).
1898: Initiation of Healthcare System

The Puerto Rican healthcare system has been regarded as something that needed improvement and reform since the Island was ceded to the United States in 1898 (Trujillo-Pegan 2003; Arbona, Ramírez de Arellano 1978) (Table 2-2). The health history of the Island has two different stories: one told by the U.S. military and the other by the Island’s inhabitants. In the former story, Puerto Ricans were sick from communicable diseases and needed the help of the U.S. In the latter, Puerto Ricans were not necessarily sick; they were systematically starved because they were separated from their land and forced to become wage laborers (Mulligan 2007; Santiago-Valles 1994).

Since its inclusion into the U.S., Puerto Rico’s healthcare system has experienced approximately eight healthcare reforms (Mulligan, 2007) (Table 2-2). Episodes of reform on the Island generally focused on a particular population who was labeled as those who needed fixing. This pattern began in the 1900s under U.S. military occupation when sick “Porto Ricans” needed help and continued into the 20th and 21st centuries when the local government suggested reform to help the Island’s medically indigent (Arbona, Ramírez de Arellano 1978).

The first health initiatives in Puerto Rico were implemented under U.S. military occupation. These health initiatives focused on cleaning up the Island in efforts to protect U.S. military servicemen, regarded as a illness bridge between Puerto Ricans and mainland citizens (Trujillo-Pegan 2003). The objective of the first health studies on the Island was to identify high-risk areas to implement quarantines, to prevent contamination from spreading to the U.S. mainland. Eight hundred thousand Island inhabitants (4/5 of the population), depicted as dirty and
in need of intervention, were vaccinated against smallpox. A year following
acquisition, the Board of Health, a military-based committee, was formed. The
committee included four military servicemen and two local physicians. It worked
closely with municipal level officials to provide health services (sanitizing and
improving hygiene practices) to the local populations (Trujillo-Pegan 2003). The
Board of Health was later replaced in 1900 when a civilian government was formed
in Puerto Rico. A governor headed the civil government, an executive council
appointed by the President of the United States (Trujillo-Pegan 2003).

Appointed health official, Bailey Ashford, identified anemia as a condition of
concern because it affected a large percentage of the Island’s population.
Ashford’s initiatives against anemia led to the discovery of hookworm disease in
the New World. After its discovery, a commission was created to address
hookworm on the Island. The commission oversaw the creation of a decentralized
healthcare system made-up of various departments throughout Puerto Rico
(Arbona, Ramírez de Arellano 1978).

1911-1930: Puerto Rico’s Department of Health

In 1911, the first local and independent healthcare system was created in
Puerto Rico (Arbona, Ramírez de Arellano 1978). In 1917, this system was
replaced by the Department of Health when the Jones Act was passed. A
commissioner appointed by the U.S. oversaw the Department of Health (Arbona,
Ramírez de Arellano 1978). This new Department of Health assumed responsibility
for the anemia campaign implemented by Bailey Ashord. In 1919, the Department
of Health started an Institute of Tropical Medicine and Hygiene. In the early 1900s,
the rate of anemia on the Island was more than 80% (Arbona, Ramírez de Arellano
1978). This was despite the efforts of the Ashford’s Commission on Anemia and the Department of Health.

In efforts to address the Island’s high rates of anemia, the Commissioner of Health in Puerto Rico invited the Rockefeller Foundation to conduct a study to examine hookworm and anemia on the Island (Trujillo-Pegan 2003). The study began a partnership between the Island’s Department of Health and the Rockefeller Foundation (Arbona, Ramírez de Arellano 1978). This new partnership would result in the Rockefeller Foundation providing future funds to support health in Puerto Rico. The Foundation’s first form of support was its provision of aid to develop the Island’s local public health service and health professionals, an attempt to control malaria on the Island (Arbona, Ramírez de Arellano 1978).

In the early 1920s, The Department of Health initiatives focused on the provision of both preventive and curative services on the Island. It functioned as a central office that oversaw municipalities’ provision of healthcare. Each municipality included an environmental health inspector (focused on tuberculosis), a dispensary, venereal disease unit, and a mother and child unit. In 1924, a system-wide organization of healthcare on the Island began to take form. During this year, the Department of Health used aid from the Rockefeller Foundation to bring together all of its municipal health services under one public health unit (Trujillo-Pegan 2003).

Similar to future health reforms in Puerto Rico, the local Department of Health used the United States healthcare system as a model. This new public health system was made up of a central public health unit, which functioned as a
separate entity from the municipal governments. Municipals public health units, governed by the municipal government, were below the central public health unit. This new public health structure was dependent on the municipal system established under the Spanish. Each municipality was a distinct public health unit that provided preventive services (targeted towards diarrhea, tuberculosis, and malaria) and curative services (Arbona, Ramírez de Arellano 1978). The creation of Puerto Rico’s Public Health System co-occurred with advancements in medical education on the Island. In 1924, the School of Tropical Medicine was created through a collaboration between the University of Puerto Rico and Columbia University (Arbona, Ramírez de Arellano 1978).

1930s: The Puerto Rican Emergency Relief Administration (PRERA)

By the early 1930s, the American Great Depression resulted in an economic crisis on the Island and increased poverty. In 1933, the Roosevelt administration created the Puerto Rican Emergency Relief Administration, later the Puerto Rican Reconstruction Administration (PRERA), to address Puerto Rico’s economic crisis (Arbona, Ramírez de Arellano 1978). PRERA funds were used to support the Island’s malaria control programs and birth control services. The use of economic relief funds to control women’s reproduction as solutions to the Island’s economic problems supports Briggs assertion that over the years U.S. economic aid on the Island has perpetuated gendered ideologies of the poor (Briggs 2002). PREFRA is a model example of how the Island’s political and economic dependency on the U.S. creates a channel through which mainland based capitalist ideologies influence how Puerto Rico structured and continues to refine its healthcare system.
In 1934, Puerto Rico’s Department of Health asked the U.S. Public Health Service to carry out an epidemiological survey of the Island. This survey was carried out by Joseph Mountin and provided two recommendations to reduce the Island’s illness burden: develop a district structured healthcare system, and implement preventive initiatives that target infectious diseases (malaria, hookworm, dysentery, and tuberculosis) and nutrition (Arbona, Ramírez de Arellano 1978). Creating yet another channel through which mainland-based ideas of health and healthcare provision can be adopted into the Island’s approach to healthcare.

Between 1938 and 1940, Puerto Rico’s Department of Health used funds from the Workers Progress Administration to implement Mountin recommendations. During that time, four general hospitals that housed 280 beds were built in Fajardo, Bayamon, Arecibo, and Aguadilla. When combined with the already existing hospital in Ponce, these five hospitals formed the blueprint for the Island’s district structured healthcare system (Arbona, Ramírez de Arellano 1978). The five hospitals were used to divide the Island into five districts, and each hospital was assigned municipalities, located within their demarcated district (Arbona, Ramírez de Arellano 1978). Between the 1930s and 1940s, the Department of Health also built clinics in isolated areas of the Island. These clinics, staffed by a nurse and a physician, provided public health initiatives such as milk for mothers and immunizations (Arbona, Ramírez de Arellano 1978).

1940s - 70s: Regionalized Health, Medicare, and Medicaid

Healthcare and politics are closely linked in Puerto Rico’s history. Therefore, it is important to discuss the links between the Island’s political parties and advancements in its healthcare system. The Popular Democratic Party (PPD) has
been identified as the first and important political party in the development of Puerto Rico’s healthcare system. Luis Munoz Marín, first elected Governor of the Island, and the PPD campaigned for improvements that included land reform, social economic development, and expansions in healthcare services. Munoz Marín and the PPD health expansion agenda fostered policies that restructured the Puerto Rican healthcare system (Mulligan 2007; Arbona, Ramírez de Arellano 1978). The construction of the Islands’ Constitution and the local government’s definition of healthcare in their Bill of Rights was another episode in the U.S. and Puerto Rico relationship in which U.S. ideologies were adopted at the expense of local beliefs. The initial constitution for the Commonwealth of Puerto Rico included a clause, Section 20, about the right to healthcare (Arbona, Ramírez de Arellano 1978; Briggs 2002). However, the U.S. Congress required that the clause be deleted before the constitution was ratified.

The development of the centralized regional healthcare system in Puerto Rico between the 1940s and 70s inaugurated a new relationship between the U.S. and Puerto Rico. Puerto Rican healthcare provided the U.S. with an opportunity to develop and showcase a modeled centralized national healthcare system based on a systematic approach to the provision of health. This model would later be exported to developing countries and health organizations such as the World Health Organization. The supporters of this systematic approach to healthcare regarded it as a modern way of improving population health by creating balanced flow of information and services between the central level (responsible for ensuring
system-wide quality) and the decentralized local levels (responsible for ensuring community involvement) (Arbona, Ramírez de Arellano 1978).

This centralized systematic approach to healthcare in Puerto Rico was more a succession of cycles of reform based on studies and recommendations rather than just one specific moment (Mulligan 2007) (Table 2-2). During WWII, in 1942, the healthcare system on the Island was divided into five districts headed by a single medical supervisor. When WWII ended in 1945, Puerto Rico was included in the U.S. Social Security Act and the Department of Health created a Public Welfare Department (Arbona, Ramírez de Arellano 1978). Even though the Welfare Department and the Department of Public Health were housed under the Department of Health they operated independently (Arbona, Ramírez de Arellano 1978).

Between 1947 and 1950, the Department of Health restructured the healthcare system on the Island again. Under this new system, healthcare centers housed under the Department of Health were created to oversee health services in the Island’s municipalities (Arbona, Ramírez de Arellano 1978). This restructuring initiative was funded partly by the local Puerto Rican government and the Hill Burton Act (1946). This change meant that administrative and financial responsibilities of the municipal clinics and hospitals shifted from the local municipal government to the Department of Health. The Department assumed responsibility for healthcare, welfare, and environmental services at the local and central level.
The Hill Burton Act also required that the Department of Health administer hospital surveys (Arbona, Ramírez de Arellano 1978). Recommendations from the surveys resulted in a four-tier level healthcare structure. The tertiary care level included a base hospital located in San Juan that provided specialized care and served as a teaching hospital at the University of Puerto Rico. The secondary care level included district hospitals that provided care to 7 to 18 municipalities. The primary level included health centers, one per municipality, which provided public health and welfare services. The fourth level included healthcare units located in remote areas. These units provided public health and medical consultation services (Arbona, Ramírez de Arellano 1978).

Changes in Puerto Rico's economy and social structure also influenced the reform goals of its healthcare system. The Island new industry-based economy of 1950s contributed to the rapid growth in the Island’s labor force and urban population. In efforts to provide care to its changing population, Puerto Rico's healthcare focus shifted to initiatives that would modernize healthcare on the Island, improve family health (e.g., family-planning), and build a healthy workforce (Santiago-Valles 1994). The 1950s healthcare system was regarded as inefficient due to disconnections in communication between its four levels.

In 1953, the Bayamón Project was implemented to assess the Island’s healthcare system and provide solutions concerning the provision of better care in a limited resource environment. The project was a collaboration between the Rockefeller Foundation, the Island’s Department of Health, and the University of Puerto Rico. The Bayamón Project is important in Puerto Rico’s healthcare history.
because 1) it was the first health study under the new Commonwealth of Puerto Rico and 2) it initiated the regionalization of healthcare in Puerto Rico (Arbona, Ramírez de Arellano 1978).

The project was carried out in the district hospital close to San Juan, in Bayamon, that provided care to the large metropolis. The project consisted of two phases: a survey and an implementation phase. The survey phase used both qualitative and quantitative methods to 1) identify how current healthcare (public and curative) and welfare services could be provided more efficiently and 2) identify indicators that could be targeted for future reform. In 1955, the study concluded and its findings confirmed that Puerto Rico’s fragmented healthcare system hindered its ability to provide efficient care. The study recommended a regionalized reform that would coordinate health services based on a regional system. The suggested regional system’s administrative, financial, and educational procedures would address the deficiencies in the Island’s current fragmented system (Van Dyke 1961; Arbona, Ramírez de Arellano 1978).

In 1956, the implementation phase of the Bayamon Project, supported by funds from the Rockefeller Foundation, was executed. In 1958, the Regional Office for Coordination and Research was created to oversee the implementation phase. The new Regional Office for Coordination and Research would coordinate the Island’s base hospital in San Juan and the public health and welfare units throughout the Island. Unlike the previous district healthcare system, the regionalized system included three levels. The main difference between the district and the regional system was the central level, the highest level in the system.
(Arbona, Ramírez de Arellano 1978). The central level, an administration level, created and monitored the application of health protocols island-wide. The second level, five regional hospitals, provided secondary and tertiary care to 12 to 20 municipalities (each including 350,000 to 900,000 inhabitants). The third level, health centers, was the entry level to the system. It provided primary care (preventive and therapeutic). Similar to the previous system, there was one health center in each municipality (Arbona, Ramírez de Arellano 1978).

Disparate from previous systems, the regional approach aimed to create a decision-making structure that would use system-wide procedures to link its health centers and regional hospitals to its administrative level. While previous health reforms on the Island attempted to create a hierarchical healthcare system that centralized power in the capital and decentralized power among the municipalities, the regionalized healthcare reform was the first to do so (Arbona, Ramírez de Arellano 1978). This structure saw a shift in administrative power from the municipalities to the central administrative level. System-wide procedures were expected to improve the flow of information, technology, patients, and services, and ultimately, the continuity of patient care.

Education was another important focus of the system. It was suggested that the education of staff at all levels would permit efficiencies in administration and during the application of the system’s protocol. The University of Puerto Rico’s School of Medicine served as the education site for the new regionalized system protocols (Arbona, Ramírez de Arellano 1978). In addition to physicians, nurses were educated to be generalists. As general practitioners they would be able to
provide care in poor remote settings without physicians (Arbona, Ramírez de Arellano 1978). In addition to education, evaluation of the system was discussed as an important component of the new regionalization process. In its initial proposal, each region would include an evaluation of the implementation phase. However, regional level evaluation reports were never implemented. In 1960, the regionalized healthcare system, tested in the Bayamon, was implemented Island-wide. In the 1960s the Department of Health conducted a system-wide formal assessment of the regionalized system (Arbona, Ramírez de Arellano 1978). However, there was no evaluation that assessed the effects of regionalization on population health and patient care (Mulligan 2007).

In the 1960s, the Arbona and Trussell Study was implemented. This study was the second study, after the Bayamon Project, under the new Commonwealth of Puerto Rico (Mulligan 2007). It findings initiated another cycle of regionalized reform in the Puerto Rican healthcare system. The Arbona and Trussell study pointed to systematic deficiencies throughout the system. Its recommendations, adopted by the Department of Health, proposed stricter medical licensing requirements in an attempt to address infrastructure gaps in staffing. The study’s recommendations also suggested procedures to decrease duplication in services between the system’s three levels. It was the first health study on the Island that included national health insurance in its recommendations (Arbona, Ramírez de Arellano 1978).

On the mainland, during the 1950s an increasing number of elderly middle-class Americans began to politically campaign for better access to healthcare
services (Shi, Singh 2009). Before 1965, vulnerable groups such as the poor, elderly, and unemployed relied on family or charity to cover their healthcare expenses (Shi, Singh 2011). During the Johnson administration, a three-part program was adopted to increase healthcare access for the elderly (Medicare) and the poor (Medicaid) (Carter 1998).

Medicare was established by Part A and Part B (Title 18 of the Social Security amendment of 1965) for the elderly (Carter 1998; Shi, Singh 2011). Medicare provided federally-funded healthcare coverage to elderly Americans regardless of their income. More specifically, Part A of the program used monies from social security to finance hospital, short-term nursing home care, and post-hospital stays (Carter 1998; Shi, Singh 2011). Part B of the program covered physician costs and was partly financed by the individual and government. Medicare is a “mean-tested” program, which means that it only provides coverage to persons that fall below the state threshold (Carter 1998; Shi Singh 2001). In the following years, the program expanded and currently includes disabled and end-stage kidney diseased Americans. In 2003, a prescription drug benefit plan was added to Part B of the Medicare plan to provide assistance for medication cost (Shi, Singh 2011).

Part three of the Johnson administration’s three-part program, Medicaid, (Title 19 of the Social Security Amendment of 1965) was created for poor Americans (Carter 1998; Shi, Singh 2011). It was implemented in the 1950s as an alternative to socialized healthcare. It was a capitalist approach that supported free choice for the poor. It was argued that Medicaid would not only provide the poor
with access to healthcare but improve their health and ultimately their productivity, a benefit to the entire country (Nelson 2005). Matched-funding between the state and federal government financed the program. Allocation of funds would be based on the state’s per capita income (Shi, Singh 2009). Medicaid varies from state to state because each state has its own eligibility threshold (Carter 1998; Shi, Singh 2011).

In 1965, Puerto Ricans became eligible for Medicare and Medicaid (Arbona, Ramírez de Arellano 1978). In 1967, when the program was implemented in Puerto Rico, the Island was eligible for $20 million of federal funds (U.S. Congress 1995). Medicare gave disabled Puerto Ricans and those 65 and older access to the private sector (Arbona, Ramírez de Arellano 1978). It gave this population the ability to buy care from private providers. Consequently, transporting the mainland-based capitalist approach to health as a commodity to the Island.

The introduction of Medicare on the Island indirectly increased the gap between private sector and public sector services by undermining the quality and equity of care provided by the public sector (Arbona, Ramírez de Arellano 1978). This gap is evident in the 31 percent (16.5% to 47.5%) increase in Puerto Rican 65 and older who selected a private facility for care between 1966 and 1973 (Arbona, Ramírez de Arellano 1978). With increased monies being funneled into the private sector, private healthcare providers were able to use these monies to build bigger facilities with better technologies. This also caused an increase in the use of specialized services.
Since Medicaid is funded by the federal government and implemented by
the state government, every state has different versions of Medicaid (Shi, Singh
2009). This variation is also demonstrated in Puerto Rico's implementation of
Medicaid. Unlike its counterparts on the mainland, Puerto Rico's poor were not
explicitly offered free choice. The federal funds for Medicaid were regulated by the
Island’s Department of Health, the equivalent of the state entity on the mainland.
Even though the monies were managed by the public sector, Medicaid also
increased the gap between the public and private sector (Arbona, Ramírez de
Arellano 1978). Arbona and Ramírez de Arellano (1978) support this assertion by
noting an increase in physicians leaving the public sector for the private sector.
Physicians who did not make a complete transition into the private sector split their
time between the private and public sectors by referring their public patients to
their private practices (Arbona, Ramírez de Arellano, 1978).

Interestingly, when one compares Puerto Ricans’ health five years before
(1960) and after (1970) the implementation of Medicare and Medicaid one sees
improvements in major health indicators (e.g., life expectancy and infant mortality),
suggesting that these programs resulted in positive outcomes for health on the
Island (Table 2-1). However, Arbona and Ramirez de Arellano caution that one
alteration in the Island’s healthcare system’s structure, Medicare and Medicaid,
cannot be exclusively credited for the improvements in the population health
(1978). Rather changes in other factors (social, economic, and environmental)
which simultaneously occurred in Puerto Rico during this time should be included
to account for the improvements in population health during the 60s and 70s.
Therefore, one can infer that the implementation of Medicare and Medicaid, while important factors in the Island’s healthcare system after the 1960s, was only partly responsible for improvements in population health during this period.

1970s: Commission for Universal Health Insurance

In 1970, the University of Puerto Rico’s Graduate School of Planning carried out a study to evaluate the regionalized healthcare system. This study resulted in more refinement to the regionalized healthcare system. The recommendation from the study decreased the five regions of the previous system to three: Northeast, South, and West. These three regions were divided into sub-regions. The sub-regions were divided into areas, which included municipalities. Similar to the previous system the regional hospital was under the central level. Unlike the previous system, regional hospitals (450 beds) provided tertiary care, sub-regional hospitals (150 beds) provided secondary care, and healthcare centers and area hospitals provided primary care services (Arbona, Ramírez de Arellano 1978).

Continuing the pattern of reform based on study recommendations, in 1972, the Dean of the School of Public Health of Puerto Rico, Nine Curt, conducted the fourth study aimed at improving Puerto Rico’s healthcare system. The study’s recommendations were not adopted by the Island Department of Health, but unlike its predecessors, it supported the right to healthcare clause that was deleted from the initial Puerto Rican constitution (Mulligan 2007). According to Jessica Mulligan, the Nine Curt study’s recommendations regarded the concept of health as a public health right that was the obligation of the government (2007). It was also suggested that this right could only be provided through universal healthcare,
which could address identified deficiencies in the system (disparity’s in health between Puerto Ricans) (Mulligan 2007).

By 1976, the increase in healthcare costs made it a political platform for politicians on the Island. In 1977, The PPD lost to the New Progressive Party (NPP) and there was a revised focus on how to provide healthcare to the Island’s population (Arbona, Ramírez de Arellano 1978). At this time, Puerto Rico’s population health mirrored that of the mainland with increased incidents of chronic diseases and increased life expectancy (Table 2-1).

The 1970s was a time of economic inflation on the Island, influenced by the U.S. economy. This economic crisis was accompanied by changes in Puerto Rico’s demographics and morbidity patterns. An increase in cost of healthcare was attributed to the increased use of technology in medicine on the mainland and on the Island. In 1973, in order to assess the Island’s current healthcare system, the local Governor created the Commission for Universal Health Insurance (Comisión Sobre Seguro de Salud Universal). The Commission’s recommendations depicted the Island’s current regional healthcare system as one meant for a populace of the past. What was needed was a new approach that would decrease duplication of services between the public and private sector (Mulligan 2007).

The Commission’s recommendations represent the first time that local researchers explicitly supported the benefits of a market-based approach to healthcare. Similar to the Nine Curt recommendation, the Commission’s recommendations were not adopted. However, its recommendations regarded healthcare as a business whose efficient management would require a business
model (Mulligan 2007). In addition to the introduction of an economic model for health care, the concept of healthcare was also repainted as a commodity defined by risks. This definition reduced individuals' health to quantifiable indicators (illnesses and deaths). Monitoring and control of these indicators could then be used to improve management and provision of care (Mulligan 2007).

**1993 – 2000: La Reforma**

By 1991 Puerto Rico's health expenditure was 1.9 billion or 9.6% of its 12 billion GNP. This is equivalent to $218 per person. Forty-three percent of the Island's health expenditure were from private sources and 57% was from public sources. The 57% of health expenditure from public sources including 32% from Island fines (e.g., from traffic violations) and 25% from the federal government (Mulligan 2007). The Puerto Rican Department of Health had a budget of $1.1 billion, which was matched by federal funds ($350,000). While health plans were offered on the Island, they covered limited services because premiums were low. Low premiums were the norm in Puerto Rico because unlike the mainland, income was low. In 1993, there were 1.2 million Puerto Ricans eligible for Medicaid but only 938,000 received benefits (Mulligan 2007).

In 1993, Law 72 (*La Reforma*) was passed after another series of recommendations from a local Commission. In parallel with the 1993 Commission for Universal Health Insurance's recommendations, Law 72 supported the use of an economic model in healthcare provision. Puerto Rico's passage of Law 72 was its first step towards adopting a managed-care approach to healthcare, like the U.S. mainland (Common Wealth of Puerto Rico, 2011). Governor Pedro Rosselló and the NPP initiated *La Reforma* at a time when managed-care was not the norm.
on the Island (Alegría et al. 2001). La Reforma was the Island’s attempt to align its healthcare system with the American healthcare system. The Clinton administration’s healthcare plan was used as a template for the new system. Law 72, Section 7, created the Health Insurance Administration (in Spanish, Admistracion de Seguro de Salud (ASES)) to contract with private healthcare entities to provide health care to Puerto Ricans living under 200% of the federal poverty line (Common Wealth of Puerto Rico 2011; CMS 2012). This cutoff indirectly created the first class of uninsured Puerto Ricans (Mulligan 2007).

La Reforma attempted to address inequalities in healthcare by giving the Island’s poor access to private healthcare services (Rigau-Perez 2000). Since La Reforma was a health plan for the poor, Medicaid and local taxes funded it. At the end of its implementation, La Reforma was funded by three sources: local taxes (funded more than half of the plan), Medicaid, and other federal monies (Mulligan 2010). La Reforma introduced three changes that transitioned Puerto Rico’s healthcare system into a managed-care system: 1) the selling of public health facilities, 2) the use of Manage Care Organizations (MCOs) to provide care to its poor population, and 3) the creation of government infrastructure to contract care from the private sector. La Reforma regarded healthcare as a business. It was a business that could be managed through business logic in order to lower cost and improve efficiency. Opinions of the new system varied. Physicians regarded the reform as a disaster while recipients of the plan equated it to free choice, development, and healthcare insurance cards (tarjeta de salud) (Mulligan 2007:73).
Similar to the mainland, under this new market-based approach, the government switched roles from healthcare provider to regulator of private insurance companies and the poor became rational consumers of healthcare (Rigau-Perez 2000; Nelson 2005). The structural changes in a market-based system promises to decrease government involvement. It redefines the role of the government from direct provider of care to regulator. However, scholars have argued that market-based models in healthcare only change the pathways through which the government intervenes in the market (Lamphere 2005; Ferguson, Gupta 2002).

La Reforma’s use of MCOs also changed physicians into gatekeepers of specialized care. During La Reforma, the local government contracted with three MCOs: Medicare Card System (MCS), HUMANA, and Triple S. The MCOs divided the Island into three sections, and each MCO provided healthcare services to their assigned area. The contracts between the local government and the MCOs were written in English and were not consistently implemented across the Island. The application process for the three MCO’s required more than one verification appointment, which was missed by applicants due to access barriers (transportation, literary level, and proper documentation) (Mulligan 2007).

One year after the implementation of La Reforma, 1994, Puerto Rico’s healthcare system was divided into seven health regions. The seven regions were under Puerto Rico’s Medical Centers located on the University of Puerto Rico’s Medical Science Campus in San Juan. Each region had a regional hospital and varying numbers of area hospitals. Area hospitals served a group of three to six
municipalities. There were 78 municipalities and each municipality had a health center. *La Reforma* shared many critiques with Medicaid on the mainland.

The primary critique focuses on the Island’s decision to use a market-based approach to incorporate the private sector into the public, ultimately marrying the state and the market (Kingfisher, Maskovsky 2008). In this market-based system, healthcare is regarded as consumer based/industry distributed and structured around a business model (Lamphere 2005). This approach regards health as an individual responsibility and healthcare as a commodity. Under this model, a poor individual is expected to develop economically so that they can purchase their healthcare (Horton 2006; Kingfisher, Maskovsky 2008). Even though Puerto Rico’s market-based reform aimed to decrease the gap in quality of care received by the poor and the rich, differences in quality still remained (Alegría et al. 2001). A common critique of *La Reforma* is the decrease in access to care experienced by its patients. This delay was attributed to the increased number of referrals required by the public insurance. Unlike their privately insured counterparts, *La Reforma* required patients to obtain a referral from their primary care physician before they could access laboratory or specialist services. After specialist services are rendered, if further exams or labs were required, *La Reforma* patients were required to return to their primary care physician to obtain another referral. This process increased delay in screening and diagnosis, particularly because obtaining an appointment with a primary care physician included waiting-time that ranged from 2-4 weeks. Both the primary care physicians’ availability and that of individual patient (e.g., work schedule) influence this delay. Researchers have noted that the
use of private companies to provide public services categorize the recipients of public services as a homogenous group with hereditary behavior patterns (culture) that predispose them to being helpless, hungry for quick gratifications, and dependent on public assistance. This definition supports the use of strict market-based approaches to prevent dependency and misuse of services (Nelson 2005; Briggs 2002). The implementation of the Personal Responsibility and Work Opportunity Reconciliation Act (1996), which required welfare recipients to work in order to receive aid, is an example of this ideology in the provision of public services in the U.S. and Puerto Rico (Briggs, 2002). Moreover, the strict referral protocols for *La Reforma*, a government-funded program, is very similar to work requirements of the Work Opportunity Reconciliation Act.

Variations in quality of care experiences on the Island has also been linked to the relabeling of service recipients (the poor) as consumers in need of intervention or strict monitoring procedures (Boehm 2005; Lopez 2005; Nelson 2005; Maskovsky 2000; Alegria et al. 2001; Mulligan 2007, 2010; Briggs 2002). Briggs (2002) asserts that the labeling and relabeling of the “poor” in the U.S. and Puerto Rico has been guided by ideologies of race and gender. In her work in Puerto Rico, she demonstrates that healthcare incentives, funded by the U.S. and local government, have regarded Puerto Rican women as welfare mothers who perpetuate poverty (Briggs 2002). This belief has been used to support the application of market-based incentives that provide patriarchal guidance for women so that they may avoid their aid dependency nature and become independent consumers (Briggs 2002; Nelson 2005).
The relabeling of patients also includes the assumption that individuals will use information, created by quality measurement protocols, to rationally select the best health plan (Nelson 2005; Mulligan 2010; Lamphere 2005). This assumption about the rational economic consumer has been challenged by ethnographies that demonstrate various barriers that influence individual’s medical decisions (Mulligan 2007; Koss-Chioino 1992). In Puerto Rico, Mulligan’s (2007) work illustrates a care seeking process under *La Reforma* that was influenced by socioeconomic factors and gaps in the healthcare system (2007). Similarly, this dissertation demonstrates that both cultural knowledge and socio-demographic factors influence women’s use of preventive services, thus questioning the legitimacy of this assumption.

Critics have noted *La Reforma*’s technocratic approach to quality assessment and performance in this market-based system has increased providers’ administrative workload, which hinders their ability to provide adequate care. An increased emphasis in quality measurements creates conflicts among providers about what is "good and right" in healthcare. Increased administrative responsibilities have been shown to impinge on the quality of clinical interactions (Nelson 2005; Willging 2005; Waitzkin 2003; Horton et al. 2014). While policy makers outline the structure of reform, its adaptation on the grown level varies (Nelson 2005). Mulligan’s (2007) work in Puerto Rico explores how gaps in *La Reforma* policies and on-the-ground practices create conflicts when providers have to choose between health care the profession and healthcare the business.

The business model approach that emphasizes the use of quantifiable components of healthcare to monitor health and decrease costs has been critiqued
for it use of population based data and criteria to inform individual clinical
encounters (Horton 2006; Farmer, Ryklo-Beaur 2002). In Puerto Rico, Mulligan
(2007) asserts that this approach fails to account for differences in how these
actors in the system (policy makers, MCOs, providers, and patients) define quality.
In Puerto Rico, similar to the mainland, differences between the policy level and
the day-to-day provision of care transform the initial focus of reform policies from
improving clinical practices to increasing revenue and compiling with regulations
(Mulligan 2007; Lamphere 2005). This gap between policy creation and
implementation not only creates but also exacerbates healthcare problems in the
et al. 2014).

*La Reforma’s* rapid implementation period did not permit a plan for
evaluation. In 2005, 12 years after its implementation, Governor Aníbal Acevedo
Vilà created a committee to review the system. The report findings support many of
the aforementioned critiques. The report noted that the system’s capitations and
performance management protocols limited and controlled the type and quality of
care that physicians provided. This in turn created prejudice and discrimination
against patients. *La Reforma* recipients received inferior care when compared to
other forms of healthcare recipients. The recipients of *La Reforma* have also noted
that it has taken away the person-to-person interaction that defined the Island’s
previous healthcare systems. Irrespective of its deficiencies, *La Reforma’s*
provision of insurance to the poor has become an expected part of the Island’s
healthcare system (Mulligan 2007).
Medicare ran concurrently with the La Reforma plan. In February 2004, La Reforma covered 1.6 million people. Of this number, 236,217 were also on Medicare. In 2003, after the Bush administration passed the Medicare Modernization Act (MMA), the role of Medicare recipients changed from welfare beneficiaries to healthcare consumers. Under the MMA, private organizations contracted through Medicare Advantage entered into a contract with the Medicare program. MMA expanded prescription drug coverage under Medicare. When MMA was implemented in Puerto Rico, there were no directives to explain how it would be applied on the Island. This lack of instructions created complications in the Island’s Medicare program (Mulligan 2007; Commonwealth of Puerto Rico 2011).

Under La Reforma, a Puerto Rican resident was able to access Medicare benefits in two ways: fee for services (the original pathway) or enrollment in a Medicare Management Plan. In the former, the individual encountered limited restrictions but experienced increased out-of-pocket cost due to annual deductibles and or co-payments. In the latter, an individual enrolled in a MMO that facilitated enrollees’ access to physicians (Mulligan 2007). After the first Medicare Management plan was introduced to the Island, it experienced a rapid increase in use; by 2007, more than half (329,240) of eligible Medicare beneficiaries (620,287) were enrolled in an MMO (Mulligan 2010). In 2007, approximately one half of the Island’s residents received government funded health insurance through private programs.

2010 – 2013: Mi Salud

La Reforma was presented as a solution to Puerto Rico’s increasing cost in healthcare and its uninsured. The reform failed to efficiently address these
problems and thus new ones have been created. In March 2010, the Obama administration’s Affordable Care Act was passed initiating another reform of the Island’s healthcare system (CMS 2013). The Patient Protection and Affordable Care Act introduces six changes in health care: 1) lowered healthcare cost and coverage for all Americans, 2) increased access to care (physicians and specialists), 3) improved preventive care and prescription benefits, 4) guaranteed insurance to most Americans, 5) an increase in the age limit (26) for young adults covered by their parents’ insurance, and 6) coverage for individuals with pre-existing conditions (CMS 2013). In October 2010, Governor Luis Fortuño and the New Progressive Party of Puerto Rico (PNP) implemented the Mi Salud program. Between 2010 and 2011, ASES (the government) held two bidding or application processes and finally identified the MCO that would receive the government contract to provide healthcare services to the Island’s indigent population. In 2011, the Mi Salud contract was granted to Triple S, BlueCross BlueShield of Puerto Rico. According to CMS, this MCO is also being used to implement the Affordable Care Act on the Island (2012; Mi Salud 2013). In addition to MCOs, ASES (the government) also contracts with a Managed Health Behavior Organization (MHBO) and two Pharmacy Benefit Management (PBP) programs (CMS 2012).

Since its implementation in 2010, Mi Salud has encountered various problems. One of the first reported problems occurred during the program’s launch month of October when approximately 70 million enrollees failed to receive their cards (Hernandez Burgos 2010). Other problems were linked to inefficient communication between the government and providers. The information offered to
providers was not clear, which prompted some physicians’ decisions to not participate in the program (Hernandez Burgos 2010). Low physician participation in *Mi Salud* affected the program’s ability to provide quality healthcare. Infrastructure problems, particularly with technology, created gaps in the sharing of patients’ medical records (Hernandez Burgos 2010).

### 2014: Mi Salud or La Reforma

Today, a market-based model continues to play a pivotal role in the Puerto Rican healthcare system. Private organizations, MCOs, regulate access and use of the healthcare services and physicians’ ability to provide those services. In mid-2014 ASES began another bidding process to identify the *Mi Salud* MCO. Approximately thirty-five MCOs attended the *Mi Salud* pre-bid meeting; twenty-two MCOs inquired about the application, but only six qualified (Crescioni 2014). In early 2014, there were approximately thirty MCOs in Puerto Rico. The Island’s MCOs can be divided into two groups: private and public or government insurers (Table 2-3). Under the public sector, the government contracts with MCOs (private organizations) to provide Medicaid (*Mi Salud*) and Medicare services to Puerto Ricans. Under the private sector, MCOs regulate access and use of healthcare services to Puerto Ricans for an established deductible. Similar to *La Reforma*, *Mi Salud* continues to receive critiques about their patients’ access to care when compared to their privately insured counterparts.

*La Reforma* changed how most Puerto Ricans accessed healthcare (Rigau-Perez 2000). The current healthcare system on the Island began as a model healthcare system for developing countries. After years of reform, a market-based approach was adopted in efforts to address increases in healthcare cost. Political
and economic changes, on the local and global level, required that the Island reformed, how it provided care to its populace. This reform transformed the Puerto Rican healthcare system from a regionalized system to a managed-care system. The government was no longer the sole provider of care to the poor, and the poor became consumers. Politicians on the Island and mainland influenced Puerto Rico’s adoption of managed-care; today, MCOs use their power to influence elections on the Island (Mulligan 2007).

Today, providers and municipalities (an artifact of healthcare under the Spanish) assume extra responsibilities in an attempt to buffer the gaps that exist in the Island’s healthcare system. This current system has driven a new wave of migration off the Island. Unlike the migrations of low-wage workers in the 1940s to 60’s, today the Island experiences increased migration of its healthcare professionals, a brain drain of its primary care and specialized physicians. This trend has and will continue to affect the system’s ability to successfully provide care to its population (Coto 2013). Puerto Rico’s local government’s dependence on U.S. federal funds links its political policies and healthcare approaches to U.S. agendas. This connection prevents the Island’s healthcare system from critically assessing its healthcare problems and making population-specific changes. This pattern perpetuates the continual cycles of reform that only maintains the status quo and hides under the illusion of change (Briggs 2002). This critique has stimulated research in Puerto Rico, such as this discussion, that examines how U.S. ideologies continue to affect the Island’s political economy, healthcare reforms, and health in Puerto Rico.
Cancer and Puerto Rico

Puerto Rico’s current healthcare system serves a population that experiences increased rates of chronic diseases. Even though it is a Commonwealth of the United States, the Island shares health indicators with other Caribbean countries (Ferlay et al. 2010; Samuels et al. 2012). The Caribbean is recognized as the region with the highest rates of non-communicable diseases (NCDs) related to morbidity and mortality in the Americas (Samuels et al. 2012; Huerta et al. 2007). Despite the region’s diversity in language and ethnicity, a shared history of colonization and rapid economic development has increased sedentary lifestyles and obesity. This lifestyle change increases the region’s inhabitants’ susceptibility to NCDs (Samuels et al. 2012; Huerta et al. 2007).

Puerto Rico has one of the highest income per capita in Latin American and the Caribbean (LAC) region. Nevertheless, it experiences increased inequality in income and increased rates of poverty and unemployment. When compared to Puerto Ricans on the mainland, Puerto Ricans on the Island experience increased rates of NCDs such as obesity and diabetes (Ho et al. 2006).

In 2007, NCDs accounted for eight of the ten leading causes of death on the Island (Samuels et al. 2012). Today, cancer is the second cause of death among Puerto Ricans (Figure 2-2). Breast cancer is the number one cause of death among women on the Island (Figures 2-3, 2-4 and 2-5). This rate mirrors global breast cancer rates (Ferlay et al. 2008; GLOBOCAN 2012; Manderson 2011).

Since the 1960s, the Island has experienced a steady increase in cancer morbidity (Robles, Galanis 2002) (Figures 2-1 and 2-2). Economic development on the Island has increased women’s breast cancer risk and their awareness. Increased
awareness has resulted in increased demand for appropriate preventive and curative services (Robles, Galanis 2002). Similar to other developed countries, breast cancer screening methods available on the Island include: mammography, clinical breast examination, and breast self-examination. Breast cancer treatment options in Puerto Rico include radiation, chemotherapy, and surgery (U.S. Preventive Services Task Force 2009). Currently, the 1998 Women’s Health and Cancer Rights Act protects breast cancer patients who elect to receive mastectomies. The Act mandates that insurers cover reconstructive breast surgery for breast cancer patients who received mastectomies (American Cancer Society 2014). While it is recommended that screening protocol be assessed on an individual basis, mammograms continue to be the most efficient and cost-effective preventive method for breast cancer, specifically for women ages 50-74 (U.S. Preventive Services Task Force 2009).

**Breast Cancer and Puerto Rico**

Financial and political agendas in health reform have overshadowed the need for equitable care, particularly in women’s health initiatives (Franco-Giraldo, Palma et al. 2006; Langer, Nigenda et al., 2000). The new reform program’s, *Mi Salud*, focus on the provision of preventive care attempts to address this issue. Under *Mi Salud*, prevention services include breast cancer biannual screening. Similar to the public sector, private sector insurance companies pay for and provide screening reminders to providers and patients of the appropriate age for biannual breast cancer screenings.

The breast cancer screening recommendations remain a contested topic in the U.S. and Puerto Rico (Sanchez-Ayendez 2000). In 1997, the National Institutes
of Health announced recommendations that required mammography screening for women ages 40 to 49 and 50 to 56 (Sanchez-Ayendez 2000). In 2009, the U.S. Preventive Services Task Forces released requirements that recommend biannual screening mammography for women between ages 50 and 74 years old (U.S. Preventive Services Task Force 2009). In 1997, five years after the implementation of La Reforma, the National Institute of Health (NIH) funded a three-year research project that assessed physicians’ compliance with its new breast cancer screening recommendations and mammogram compliance among low-income middle-age women in Puerto Rico (Sanchez-Ayendez 2000; Lauver 2003). The study aimed to address access barriers that affect Latina’s underutilization of breast cancer screening. Physicians were included in the study because research has identified physician’s referrals as facilitators to women's use of mammograms (O'Mahony 2009; Wallace, MacKenzie et al. 2006).

Similar to cancer research on the mainland, the study found that while cancer knowledge was important (Chavez et al. 2001; Lannin et al. 1998; Sanchez-Ayendez 2000), socioeconomic factors also influenced women’s mammogram use. It also connected physicians’ concerns with their ability to provide effective care to contradictions between MCO ideologies of care and that of the medical profession (Sanchez-Ayendez 2000). Steven Coughlin’s and Robert Uhler’s (2002) work that compared breast cancer screening behavior among Puerto Ricans on the Island and the mainland supports Sanchez-Ayendez findings. The study used Behavioral Risk Factor Surveillance System (BRFSS) data to explore factors associated with Hispanic women’s underuse of breast cancer
screening services. Underutilization of breast cancer screening service is associated with increased rates of late stage breast cancer diagnosis (Zambrana et al. 1999). The study found that 68.2% of women 40 and older reported having a mammogram in the past two years. These women were more likely to have insurance and have seen a physician in the past year. Not having a mammogram was associated with lower income, less education, no health insurance, lack of transportation, and limited breast cancer knowledge (Coughlin 2002).

2010 signified a notable change in cancer trends on the Island. Today breast cancer is the leading cause of death among women, exceeding coronary heart diseases the leading cause of death on the Island for the past three decades (Figure 2-2) (Puerto Rico’s Department of Health 2014).

Market-based ideologies interact with historical and political contexts to create variations in the application of policies in healthcare. Healthcare research in Puerto Rico and the U.S. has shown how a market-based reform in Medicaid and Medicare has caused similar problems (increased barriers in healthcare and labeling of the poor) on the Island and mainland. Ethnographic methods have also been used to explore how the reactions of actors (MCO, physicians, and patients) in Puerto Rico’s healthcare system have produced idiosyncrasies in its market-based healthcare system (Bates et al. 1997; Mulligan 2007).

Despite changes in Puerto Rico’s economy and family structure over the years, personalismo (a value of the person over the institution), allocentrism (an emphasis of the collective need over that of the individual) and familismo (strong attachment to family) have retained their importance in Puerto Rican social
interactions (Canino and Canino 1993; Bates et al. 1997; Zayas, Palleja 1988; Angueira 2001). Maryann Bates and colleagues (1997) assert that this shared valued of the family and person result in differences in how the patient role is defined in doctor-patient interactions in Puerto Rico and the United States. Familismo has also been linked to social support, a buffer to healthcare barriers (Bates et al. 1997). It is posited that this belief creates a dedication to support family members during hardships (Rogler, Cooney 1984; Gracia-Preto 2005; Zayas, Palleja 1988). At the same time, Puerto Rican values such as machismo (when men are regarded as the sole breadwinner and protector of the family) have been barriers to women help-seeking behaviors on the Island (Sanchez-Ayendez 1988; Canino, Canino 1993).

Today, Puerto Rico’s continued efforts to reform its healthcare system continue to be tied to its current economic and political climate. The Island’s recent call for a negotiated moratorium in order to pay its $73 billion debt supports apprehension about its ability to adequately fund its healthcare system and provide quality care to its populace (Walsh 2015). Puerto Rico’s unique historical and current relationship with the U.S., its current economic and health profile, and uncertain healthcare future makes it an optimal location to explore how these factors impact physicians’ and women’s breast cancer experiences.
Figure 2-1. Top 10 causes of death in Puerto Rico: 1945-1960 (Source: Informe Annual de Estadísticas Vitales de Puerto Rico, 1960 Department de Salud, Secretaría Auxiliar de Planificación y Desarrollo, San Juan, Puerto Rico)
Figure 2-2. Top 5 causes of cancer deaths in Puerto Rico: 2004-2012 (Source: Departamento de Salud. (2014). Resumen General de la Salud en Puerto Rico. San Juan, Puerto Rico)
The most frequent incident of cancer for females
2005-2009
N= 28,234

Breast 30.3
Colon and Rectum 13.9
Thyroid 8.0
Corpus and Uterus, NOS 7.1
Lung and Bronchus 4.3
Cervix Uteri 3.8
Non-Hodgkin Lymphoma 3.8
Stomach 2.6
Ovary 2.6
Leukemia 2.0
Other Sites 7.8

Figure 2-3. The most frequent Incident of cancer in females (Source: Departamento de Salud. (2014). Resumen General de la Salud en Puerto Rico. San Juan, Puerto Rico)
Figure 2-4. Age-adjusted female breast cancer incidence rates by municipality in Puerto Rico, 2005-2009 (Source: Departamento de Salud. (2014). Resumen General de la Salud en Puerto Rico. San Juan, Puerto Rico)
Figure 2-5. Age-adjusted female breast cancer mortality rates by municipality in Puerto Rico, 2004-2008 (Source: Departamento de Salud. (2014). Resumen General de la Salud en Puerto Rico. San Juan, Puerto Rico)
Table 2-1 Selected Vital Statistics Puerto Rico: 1940-2005

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<tr>
<td></td>
<td></td>
<td>1,878,000</td>
<td>2,218,000</td>
<td>2,360,000</td>
<td>2,716,000</td>
<td>3,199,300</td>
<td>3,527,796</td>
<td>3,816,901</td>
<td>3,912,054</td>
</tr>
<tr>
<td>Life expectancy at birth</td>
<td>46.01</td>
<td>60.9</td>
<td>69.4</td>
<td>71.9</td>
<td>73.1</td>
<td>74.05</td>
<td>76</td>
<td>77.65</td>
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<tr>
<td>Birth rate*</td>
<td>38.5</td>
<td>38.5</td>
<td>32.2</td>
<td>24.8</td>
<td>22.8</td>
<td>18.9</td>
<td>15.6</td>
<td>13</td>
<td></td>
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<tr>
<td>Mortality rate (crude)*</td>
<td>18.4</td>
<td>9.9</td>
<td>6.7</td>
<td>6.7</td>
<td>6.4</td>
<td>7.4</td>
<td>7.5</td>
<td>7.6</td>
<td></td>
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<tr>
<td>Infant mortality**</td>
<td>113.4</td>
<td>68.3</td>
<td>43.7</td>
<td>28.6</td>
<td>18.5</td>
<td>13.4</td>
<td>9.9</td>
<td>9.3</td>
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<tr>
<td>Cancer mortality***</td>
<td>51.7</td>
<td>58.8</td>
<td>83.7</td>
<td>97.9</td>
<td>102.7</td>
<td>116.4</td>
<td>123</td>
<td>111</td>
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</tr>
</tbody>
</table>

* Rate per 1000 inhabitants. ** Rate per 1000 live births. *** Rate per 100 000 inhabitants. (Source: Informe Annual de Estadísticas Vitales de Puerto Rico, 1960-2006 Department de Salud, Secretaría Auxiliar de Planificación y Desarrollo, San Juan, Puerto Rico)
<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
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<tbody>
<tr>
<td>1890</td>
<td>Board of Health</td>
</tr>
<tr>
<td>1911</td>
<td>Puerto Rico's first local and independent healthcare system</td>
</tr>
<tr>
<td>1917</td>
<td>Puerto Rico's Department of Health</td>
</tr>
<tr>
<td>1919</td>
<td>Rockefeller Foundation Hookworm Study</td>
</tr>
<tr>
<td>1924</td>
<td>System-wide reorganization of the Island's healthcare system (Rockefeller Foundation funded)</td>
</tr>
<tr>
<td>1933</td>
<td>Puerto Rican Reconstruction Administration (PRERA)</td>
</tr>
<tr>
<td>1934</td>
<td>U.S. Public Health Service epidemiological survey by Joseph Mountin</td>
</tr>
<tr>
<td>1938</td>
<td>Implementation of Mountin recommendations</td>
</tr>
<tr>
<td>1947</td>
<td>Hill Burton Act passed</td>
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<tr>
<td>1953</td>
<td>Bayamón Project Survey Phase (1st reformed based evaluation study)</td>
</tr>
<tr>
<td>1957</td>
<td>Bayamón Project Implementation Phase (Rockefeller Foundation funded)</td>
</tr>
<tr>
<td>1960</td>
<td>Arbona and Trussell Study (2nd reformed based evaluation study)</td>
</tr>
<tr>
<td>1967</td>
<td>Medicare and Medicaid implemented</td>
</tr>
<tr>
<td>1970</td>
<td>The University of Puerto Rico’s Graduate School of Planning Study (3rd reformed based evaluation study)</td>
</tr>
<tr>
<td>1972</td>
<td>The Dean of the School of Public Health of Puerto Rico, Nine Curt Study (4th reformed based evaluation study)</td>
</tr>
<tr>
<td>1973</td>
<td>The Commission for Universal Health Insurance</td>
</tr>
<tr>
<td>1972</td>
<td>Law 72 (La Reforma) passed</td>
</tr>
<tr>
<td>2010</td>
<td>Mi Salud (Affordable Care Act on the Island)</td>
</tr>
</tbody>
</table>
Table 2-3 Health insurance providers in Puerto Rico, 2014

<table>
<thead>
<tr>
<th>Public</th>
<th>Private</th>
</tr>
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<tbody>
<tr>
<td>Triple S*</td>
<td>Triple S Servicios de Salud de Bella Vista</td>
</tr>
<tr>
<td>Humana Medicare**</td>
<td>Humana Insurance</td>
</tr>
<tr>
<td>Firs Plus**</td>
<td>First Medical</td>
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<tr>
<td>Medical Plus System (MCS) Classicare**</td>
<td>Medical Card System</td>
</tr>
<tr>
<td>Medicare Original**</td>
<td>Tricare</td>
</tr>
<tr>
<td>Medicare y Mucho Mas (MMM)/ Preferred Medicare Choice (PMC)**</td>
<td>Champ</td>
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CHAPER 3
CULTURE AND SOCIAL CONTEXT IN CANCER RESEARCH

Increased attention to health disparities has fostered an increased use of culture in cancer research. This trend in cancer research is promising because culture theory has been used to explore the relationship between variation in individuals' and groups' cancer meanings and cancer experiences (Csordas 1989; Balshem 1991; DiGiacomo 1999; Hunt 1998; McMullin, Weiner 2009; Chavez et al. 1995). Culture has enabled researchers to identify factors that perpetuate cancer disparities. Yet, when the construct is not appropriately defined and operationalized it can result in research that neglects other important social determinants (Drew, Schoenberg 2011; Powe 1995; Powe, Finnie 2003). Some researchers have cautioned that cancer research that only focuses on culture fails to account for other factors (e.g., social-structural factors) that contribute to variation in cancer experiences (Hunt 1998; Balshem 1991; Chavez 2009; Jain 2007a).

This critique has resulted in the development of frameworks and methods that enable researchers to explore how cultural and social-structural factors interact within specific contexts to influence individuals' and groups' cancer experiences (Chavez et al. 2001; Dressler, Bindon 2000; Gravlee et al. 2005; Reyes-Garcia et al. 2010). Guided by this two-part focus on culture and social-structural factors this chapter 1) reviews the role of culture and social context in cancer research and 2) discusses how culture and social context have been linked in cancer research.
Culture in Cancer Research

Anthropologists have used different definitions (ecological, ideological, or symbolic) of culture to describe health experiences (Goodenough 1999; Sahlin 1976; Geertz 1973; Keesing 1974). The question, how does variation in context and knowledge (within and between groups) influence human sickness experiences, remains an important inquiry in anthropology today (Dressler 2001; Gravlee 2005; Manderson 2011; Weller 2012; Dressler, Balieiro et al. 2015).

Anthropologists’ first attempts at answering this question focused specifically on how the concept of sickness and healing related to individuals’ structural environment. E. E. Evans-Pritchard’s (1937) interwove healing and illness into his exploration of the supernatural amongst the Azande. Victor Turner’s (1967) linked health behaviors to a symbolic system within Ndembu society.

Analogous to Evans-Pritchard and Turner, Charles Frake identifies the importance of individuals’ context in understanding their health experiences. He posits that individuals’ health experiences are dependent on cognitive processes that help them understand their environment (1961). In accordance with Frake, cognitive anthropologists such as Roy D’Andrade (1981) and Ward Goodenough (1999) have defined culture as a shared and learned pool of information that informs individuals’ performance of acceptable behaviors in society. According to this approach, individuals use stored information- culture- to produce and interpret their social environments made up of rules, signals, and institutions (D’Andrade 1981; Goodenough 1999). This definition locates culture at both the aggregate and individual level because it acknowledges that individuals’ stored information, use to navigate their world, are learned and systematically distributed throughout a group.
These distribution patterns correspond with an individual’s context (e.g., birth cohort or location in social hierarchies such as gender or social class) (Frake 1961). This approach to culture has been used to explore associations between variation in individuals’ illness knowledge and their illness experiences (e.g., hypertension, diabetes, and cancer) (Pelt, Pelto 1975; Good 1998; Chavez et al. 1995, 2009; Weller et al. 2012; Dressler 2004).

Anthropologists and public health researchers have recognized the importance of culture in human health (Chavez et al. 1995; Pasick, Burke 2008; Drew, Schoenberg 2011). Yet, its definition and operationalization varies across fields. Some health researchers have cautioned that the dominant approaches to culture in cancer research continue to undermine culture’s importance in understanding and addressing cancer health disparities (Drew, Schoenberg 2011; Powe 1995; Powe, Finnie 2003; Kagawa-Singer, Dressler et al. 2015). These critiques warn that cancer research that regards culture as a static concept and operationalize it as dichotomized variables (e.g., racial or ethnic categories) force researchers to regard minority and underserved populations as homogenous (Lake, Lopez, et al. 2006; Pasick, Burke 2008; Kagawa-Singer, Dadia et al. 2010). When the operationalization of culture is weakened by low construct validity, researchers’ ability to measure the concept and explore culture’s contribution to health disparities is reduced. This approach to culture produces recommendations and interventions that overemphasize genetic or social-structural factors over efforts to address cancer disparities (Chavez et al. 1995).
This appraisal of culture in cancer research has engendered discourse that 1) caution against the conflation of culture and ethnicity or race, and 2) the use of fatalism (the belief that cancer is inevitable) to explain cancer disparities (Dein 2004; Drew, Schoenberg 2011; Lannin et al. 1998). The use of fatalism in cancer research has been attributed to gaps in current health behavior theories (Pasick, Burke 2008). These gaps enable researchers to reduce cultural beliefs into minority group membership (Powe 1995; Powe, Finnie 2003; Luquis, Villanueva Cruz, 2006; Chavez et al. 1995; Spurlock, Cullins, 2006).

Drew and Schoenberg (2011) posit that fatalism’s possible association with the material constraints of poverty makes it relevant to cancer research. Their work demonstrates how poor individuals’ heightened exposure to increased late stage cancer diagnosis and mortality impacts their cancer knowledge by linking cancer screening with death, thus perpetuating fatalistic beliefs (Balshem 1991; Drew, Schoenberg 2011). These fatalistic beliefs when regarded as “cultural idioms”, speak to an interdependent relationship between individuals’ cognition and their environment (Balshem 1991). When expressed, these beliefs represent an individual’s or groups’ distress response that aims to create social and cultural meaning of past and present traumatic experiences (e.g., social marginalization or powerlessness) (Nichter 2010:405; Balshem 1991). This culture theory approach to fatalism cautions that minority populations’ cancer beliefs that contradict dominant definitions should not be disregarded as irrational, but as a call for cancer research that acknowledges that both micro- and macro-level factors influence individuals’ cancer experiences (Drew, Schoenberg 2011).
Social Context in Cancer Research

Researchers take various approaches to the study of social context influences on health. A common but limited approach is to approximate individuals’ position in social hierarchies using the construct of socioeconomic status (SES), commonly measured as a combination of education, occupation, and income (Braveman et al. 2005; Duncan et al. 2002). Duncan and colleagues identified strong links between economic measurements of SES and mortality (2002). Alternatively, some researchers conceptualize social context as external forces that hinder or facilitate health behavior (Dressler, Oths et al. 2005; Zambrana et al. 1999; Monnat 2014). Dressler and colleagues demonstrate how individuals’ discordance with their social and structural context can negatively impact their health (e.g., high blood pressure and low birth weight) (2005). Shannon Monnant’s (2014) work further illustrates the relationship between individuals’ structural context and their health. He shows that increased income and education does not always result in increased cancer screening among American women. Unlike their African and Asian counterparts, White American women’s SES was positively associated with their breast and cervical cancer screening rates (Monnant 2014).

Macro structures such as the healthcare system can also influence individuals’ health by hindering or facilitating their access to and quality of cancer care (Meissner et al. 2006; Kiviniemi et al. 2009; Torres, Erwin et al. 2012). In the U.S. health is a commodity and healthcare insurance mediates individuals’ access to cancer care (Selvin, Brett 2003; Chen, Kessler 2012; Sabik, Tarazi 2015). Scholars have demonstrated associations between insurance status and access and quality of cancer care (e.g., screening and treatment) (Yabroff, Washington et
al. 2003; Chen, Kessler et al. 2012; Mahal, Aizer et al. 2014). Variation in insurance status has been shown to increase cancer disparities (Shi, Lebrun 2011; Bernard, Howe 2012; Wang, Shi 2013; Hamman, Kapinos 2015). Today, as cancer morbidity and mortality decreases disparities among Americans remain (Stimpson, Pagan et al. 2012; Siegel, Naishadham et al. 2012; Wang, Shi et al. 2013). The CDC (2014) notes racial and ethnic minorities are less likely to access screening because they are less likely to have health insurance and a regular physician (2014). Insurance status becomes even more important when care requires timely diagnosis and treatment (e.g., breast cancer) (Bastani, Yabroff et al. 2004; Bernard, Howe et al. 2012).

Researchers have also explored how individuals’ demographics (e.g. age, income, and insurance status) and structural factors (e.g., healthcare system and healthcare reform) interact to influence individuals’ health (Yabroff, Washington et al. 2003; Farmer 2001; Kingfisher, Masovosky 2008; Dressler 2004; Mulligan 2007, 2010). Some scholars have critiqued market-based healthcare systems’ labeling of cancer patients as rational decision makers (Bibeau 1997; Chavez 2009; McMullin, Weiner 2009; Garro 1998; Jain 2013). Market-based approaches to healthcare are presented as vehicles of free choice because they provide patients with quality information that can be used to select optimal care. Critics have argued that this belief assumes a model of human behavior rooted in rational choice theory or a concept of the “universal economic man” (Garro 1998; Young 1980, Sahlins 1976). This model of human behavior ignores the social-structural
constraints on health seeking behavior and ultimately maintains cancer health inequalities (Chavez 2009; Farmer 2001 2005).

Cancer researchers who focus on the relationship between structural factors and cancer experiences have also linked cancer knowledge production to a business model approach that perpetuates inequalities in the distribution of cancer knowledge and resources (Chavez 2009, Jain 2013). It is argued that this dominant business model approach to cancer perpetuates health disparities in cancer. Leo Chavez’s (2009) exploration of Mexican immigrants’ perception of cervical cancer risk shows that market-based ideas of the poor labels them as consumers in need of intervention or strict monitoring which maintains cancer disparities in the United States. Similar to other scholar Chavez (2009) asserts that a market-based approach to cancer care attempt to fix women and ignore the social and political factors that also influence health experiences (Boehm 2005; Lopez 2005; Nelson 2005; Maskovsky 2000; Mulligan 2007, 2010; Briggs 2002).

**Culture and Social Context Together in Cancer Research**

Scholars have established the importance of both culture and social context in cancer research by 1) using culture theory in cancer research to identify variation in cancer experiences and 2) illustrating how those experiences influence and are influenced by individuals’ context. The recognition that both culture and social context matters to individual health experiences has engendered frameworks that explore the two concepts jointly. Structural-constructivism is an emerging theoretical framework in medical anthropology which builds on advancements in cognitive anthropology theory and methods (Dressler 2001, 2007; Dressler, Oths et al. 2005). The framework provides a platform for
researchers to simultaneously explore culture variation and social context while giving a multi-voiced account (dominant and lay) of individuals’ illness experiences, ultimately addressing critics’ assertion that the dominant cancer discourse creates unequal distribution of power that devalues individuals’ cancer experiences (Jain 2013; Wooodell, Hess 1998; Chavez 2009; Perusek 2012; Balsheh 1991; Pasick, Burke 2008; Dein 2004; Farmer 2001). The framework’s focus on social-structural context and individuals’ cultural meanings also responds to critiques of cancer research that only focuses on individuals’ beliefs (e.g., fatalistic beliefs) outside of their social-structural context (Pasick, Burke 2008; Farmer 2001).

Structural-constructivism allows researcher to focus on two important spheres in individuals’ cancer experiences, the individual and their context. Structural constructivist research uses cognitive anthropology appropriate structured elicitation techniques. Structured elicitation techniques include but are not limited to: free-lists, pile sorts, and ranking. These interviewing techniques allow researchers to first obtain individuals’ knowledge of a category or domain. This measurement of understanding is then used as a metric to identify patterns of agreement and variation in cultural knowledge of illness, ultimately accounting for a dynamic definition of culture by avoiding the use of an *a priori* definition of culture (Romney, Weller et al. 1986; Dressler 2004; Gravlee, Dressler et al. 2005; Reyes-Garcia et al. 2010). This approach permits researchers to not only explore the multiple voices of cancer knowledge (care seekers and care providers), but to also use the framework’s dual focus on culture and context to investigate how these two concepts influence individuals’ cancer experience. To further emphasize the
importance of both culture and social context in cancer research, the following
sections examine how scholars link cancer knowledge and social context to
variation cancer experience.

**Cancer Knowledge Production**

In accordance with Kleinman and colleagues (1978), some researchers
have linked variation in individuals' cancer meanings to their roles (e.g., care-
seekers and –providers) within healthcare (Chavez et al. 1995, 2001; Balshem
cancer research that uses the dominant definitions of cancer to evaluate the quality
of lay experiences (Manderson 2011; Chavez et al. 1995; Jain 2013; Balshem

Scholars have identified two groups of cancer knowledge producers: care-
seekers and -providers (Chavez et al. 1995, 2001; Chavez 2009; Weiner 1999;
Kleinman 1978). Some researchers juxtapose physicians’ occupational relationship
with cancer with their patients’ lived experiences to explore how social context
influences the groups’ cancer meaning construction (Chavez et al. 1995;
(1978,1981) work, researchers have argued that physicians’ and patients’ illness
meanings are based on their perception of sickness episodes. Kleinman and
colleagues (1978) contrast individual patients' perceptions of their sickness
experiences with providers’. Patients' episodes are defined as illnesses, socially
disparaged states. In contrast, physicians define sicknecess as diseases, altered
physiological states. These distinct perceptions of sickness influences how these
two groups construct explanatory models (EMs), illness meaning.
EMs consist of people’s beliefs about what a sickness episode is, what causes it, how it affects them, and what can be done to heal it (Kleinman et al. 1978; Kleinman 1981). Explanatory models have been used in cancer research to identify and compare differences in physicians’ and cancer patients’ knowledge about cancer (Dein 2004; Shaw et al. 2008; Balshem 1991). Dein’s (2004) work identifies inter- (geographical and professional) and intra- (among physicians and minorities) group variation in EMs of cancer in an international sample (United States, United Kingdom, Africa, and Australia). He suggests that differences in patients’ and physicians’ EMs, if not identified and addressed, can result in miscommunication, and ultimately poor cancer experiences for patients (Dein 2004).

While some researchers have used EMs to identify differences between clinicians’ and individuals’ cultural knowledge and cancer experiences, others have used them to explore inter- and intra-group variation in cancer knowledge among lay populations (Erwin et al. 1999; Lannin et al. 1998; Mathews 2000, Moore 2001). Majorie Kagawa-Singer and David Wellisch (2002) used an EMs framework to explore the relationship between variation in Euro-, Chinese, and Japanese American breast cancer patients’ EMs and their perceptions of spousal support and its benefits during cancer treatment. The authors noted that Chinese and Japanese American patients were expected to be self-sacrificing and nurturing to their spouse and family during cancer treatment while Euro-American patients were permitted to depend on their spouses (Kagawa-Singer, Wellisch 2002).
Researchers have also used variation in cancer knowledge to critique the grouping of individuals’ into homogenous groups (e.g., ethnic, race, and geography, and health status) within cancer research (Dein 2004; Perusek 1990). Holly Mathews’ (2000) connects differences between cancer patients’ (African American and Euro-American) definition of survivorship with their use of cancer support groups. She notes that African American women attribute their low use of support groups with the resource’s failure to emphasize the important role of religion and spirituality in the healing process (Mathews 2000).

Variation in cancer knowledge have also been linked to variation in cancer experiences. Some scholar argue that cancer knowledge produced by biomedicine, the cultural system, continues to be regarded as “truths”, ultimately devaluing lay personal cancer experience (Gordon 1990; Good 1998; Saillant 1990; Kirmayer 1992).

Biomedicine, the cultural system, consists of distinct discourses and social roles (e.g., students and physicians), and modes of reasoning (Lock, Nguyen 2010; Good 1998). The clinical environment becomes more than just a place of knowledge and treatment; it also forms a cultural system (Leslie 1980). This cultural system approach to biomedicine has enabled the critical assessment of practices that create biomedical knowledge and maintains its hegemonic dominance over the production and dissemination of cancer knowledge (Good 1998, McMullin, Weiner 2009; Jain 2013). Mary-Jo DelVecchio Good’s (1998) work among American physicians demonstrates how biomedical knowledge is created and refined by participants in the system over time.
Anthropologists have also explored the creation of culturally sensitive medical curriculum to demonstrate how participants in the biomedical cultural system socially constructed biomedical knowledge, through continued critique and refinement (Good 1998; Lock, Nguyen 2010; Bullon 2013; Kleinman 1978; Carpenter-Song et al. 2007). Critics have noted that existing approaches to cultural competency education reduces culture to teachable skill sets, which can be mastered through medical curriculums (Hannah, Carpenter-Song 2013; Llerena-Quinn 2013; Willen, Carpenter-Song 2013). This approach to cultural competency regards culture as a static concept, synonymous to race or ethnicity, indirectly blames patients for their illnesses (Shaw et al. 2008; Kirmayer 2013; Carpenter-Song et al. 2007). In response, some anthropologists have collaborated with other social scientists and physicians to work within the cultural system of biomedicine to refine the definition of culture and integrate it into culturally sensitive medical curriculums (Hannah, Carpenter-Song 2013; Kirmayer 2013; Llerena-Quinn 2013; Willen, Carpenter-Song 2013; Bhui, Bhugra 2004).

**Cancer Knowledge within Context**

Cancer knowledge can be divided into four categories: causation/etiology, diagnosis, management, and survivorship.

**Causation/etiology**

According to medical literature, cancer is a physiological change in the cell structure that causes it to reproduce rapidly and spread throughout the body (Aronowitz 2007; Manderson 2011; McMullin, Weiner 2009; Kelly 2005). The exact cause of this change has not been established. Nonetheless, research has associated individuals’ increased susceptibility with various factors: genetics, age,
tobacco, sunlight, hormones, alcohol, obesity, and ionizing radiation (Kelly 2005).
This definition of cancer locates its etiology in a biological space. This definition,
regarded as fact, guides clinical and societal discourse about cancer. Even though
the dominant, medical, definition of cancer is regarded as an objective truth, it is a
cultural construction that continues to be challenged and refined as research
continues (Manderson 2011; Aronowitz 2007).

Some researchers argue that medical knowledge, birth out of the biomedical
cultural system, is unequally distributed within the system (Good 1998; Sontag
2001; Jain 2007a, 2007b). This creates variation in clinicians’ definitions of cancer
causation and etiology (McMullin et al. 1994; Hunt 1998). Juliet McMullin and
colleagues’ (1994) examination of variation in cultural knowledge of breast cancer
demonstrates that physicians' personal experiences and their employment status,
university or private community, can influence the distribution of cancer knowledge
among physicians. Their findings identified links between physicians’ place of
employment and their ability to create and refine medical discourse on cancer
(McMullin 1994). Physicians who were medical researchers represented the
"formal spokesmen", leaders, and models for the medical professional and
physicians who practiced in the private/community setting relied on the former
group for medical knowledge. Mary-Jo Del Vecchino Good’s (1998) work among
oncologists also identified variation in physician’s cancer knowledge. She noted
that individual experiences influenced how oncologists weighed their dual roles as
scientists and healers and structured their approaches to patient care (Mary-Jo
DelVecchino Good 1998).
Differences also exist in lay individuals’ constructions of cancer etiologies. Some scholars have demonstrated the association between individuals’ cancer etiologies and societal issues. Martha Balshem (1991) regards working class community members’ cancer definition as implicit forms of resistance to the power and authority of the biomedical cultural system and forces outside of their community. She also argues that a disconnect between community casual definitions and the medical definition creates barriers in care and can hinder interventions that fail to account for community members’ social context and causal definitions (Balshem 1991).

Some researchers have also demonstrated how different definitions of the mind and body can influence individuals’ cancer etiologies. Thomas Csordas (1989) identified variation in casual explanations of cancer between Navajo Indian and Anglo Americans. Csordas (1989) argues that the Navajo’s causal explanation of cancer was very distinct from the Anglo patients, even after years of assimilation and interaction with the biomedical healthcare system. Both groups listed injury as the underlying cause of cancer but their causal explanations that connected the two were very different. He associated this variation to different cultural understandings about the relationship between the mind and the body (Csordas 1989).

Environmental pollutants have also been identified in individuals’ causal explanations of cancer. Culture-based cancer research critiques of environmental pollutants have connected it to national cancer campaigns and capitalism (Jain 2013, 2007a; Chavez 2009). Sarah Jain (2013) argues that cancer campaigns
promote “sentimental politic” and “righteous anger” against cancer (2007b: 506). Cooperations use this sentiment of anger against cancer to promote awareness campaigns to fund cancer research (Jain 2013). Jain critiques corporations (e.g., BMW) because they also use these campaigns as business ventures to increase revenue for products that create carcinogens (2007b). Her work also links cancer campaigns to market-based ideas that value profit at the expense of individuals’ health (Farmer 2001).

Scholars have also identified similarities among clinicians’ and patients’ concerns with the power inherent in the word “cancer”. Some researchers have noted the belief that the word’s power lies in its ability to cause or worsen cancer suffering if it is uttered by the sick or those around them (McMullin, Weiner 2009; Gordon 1997; Sontag 2001). Sontag (2001) notes that this belief dates back to early civilizations. She goes on to explain that other literary proses (e.g., metaphors), are used to replace the word “cancer” in efforts to avoid calling cancer and it associated suffering into existence. The belief about the power of the word “cancer” has also been identified in patients’, their families’, and physicians’ cancer diagnosis accounts (Gordon, Paci 1997; Sontag 2001).

Risk. Cancer etiology researchers also focus on risks, information about individuals’ behaviors or factors that increase their susceptibility. Risk is an important part of individuals’ cancer experiences. It is created within the biomedical cultural system and is used by clinicians and patients to construct cancer meanings. It also helps individuals define their “self” in relation to cancer.
Cancer researchers have identified variation between physicians’ and their patients’ perception of risks. Chavez and colleagues’ (1995) research focused on both cervical and breast cancer. The researchers observed various patterns of agreement between and within groups when comparing risks listed by physicians and Anglo and Latina women. They noted that variations in cervical cancer risk perception between groups were related to immigration status. Latinas who were considered immigrants and had reduced access to education and income shared similar perceptions of cervical cancer risks. For example, immigrant Latinas (Mexican and Salvadorians) were more likely to identify physical trauma (being hit in the vagina or an abortion) as a risk for cervical cancer. They also identified differences between physicians and non-physician risk perceptions. Non-physicians listed heredity as the number one risk for cervical cancer and physicians listed multiple sexual partners and initiation of sexual intercourse at a young age (Chavez et al. 1995, 2001).

Rebecca Martinez and colleagues’ (1997) work on cancer risk perception among Latinas and physicians demonstrates how variation in risk definitions between the medical definition—the dominant definition—and individuals indirectly propagates moral and political ideals. The authors note that the Latinas’ and physicians’ use of morality to assess cervical cancer risk encourages victim blaming and draws attention away from historical and social-structural factors that also influence women cancer screening behaviors (Martinez et al. 1997).

Diagnosis

Diagnosis is an important juncture in an individual’s illness experiences. According to Paul Stoller (2004) this is the time when an individual enters “the
village of the sick”. Culture-based cancer research has identified variation in individuals’ perceptions of their diagnosis and physicians’ practices of telling the diagnosis (Lind et al. 1989; Engelberg 2006; Gordon, Paci 1997; Jain 2007a; Lackey 2001). Cancer diagnosis studies have focused on differences between clinical practices, individuals’ decision to share their diagnosis with others, and individuals’ reactions (Lind et al. 1989; Stoller 2004; Good et al. 1990).

The “teller” of cancer diagnosis can be physicians and family members (Press et al. 2005; Good et al. 1990). Similar to other scholars, Press and colleagues (2005) have explored the teller’s and recipient’s reactions. Researchers have shown that some physicians prefer not to disclose a cancer diagnosis to the patient and refrain from uttering the word in their presence (Gordon, Paci 1997; Lind et al. 1989). Deborah Gordon and Eugenio Paci’s (1997) work in Italy located this behavior within the historical and the communal support norms of the country. In this setting it is acceptable that physicians refrain from explicitly telling the patient that they have cancer. It is more acceptable to share the patients’ cancer diagnosis with other family members (Gordon, Paci 1997).

Gordon and Paci also depict cancer disclosure as a contested topic in the biomedicine system (1997). They note that the non-disclosure norm in Italy is being challenged in order to protect patient’s rights as new patient protocol require complete disclosure. The benefits of full disclosure have been critiqued. Some scholars have noted that its benefits may be limited to societies that value individual choice, while others have demonstrated the opposite (Gordon, Paci 1997; Engelberg 2006). The push for full disclosure has not been accompanied
with procedural regulations. It is suggested that the lack of regulation about how cancer diagnosis is shared with cancer patients results in more harm than benefit (Lind et al. 1989).

Cancer narratives about patients' diagnosis experiences have identified variation in diagnosis responses. In her comic book cancer narrative, Miriam Engelberg (2006) notes that her emotional response to her diagnosis was exacerbated because she was informed on the phone. Lind and colleagues (1989) measured breast cancer patients' satisfaction with their diagnosis experiences in relationship to the teller and the channel of communication. They found that patients were more likely to rank their diagnosis experiences negatively if they were informed about their diagnosis over the phone or in the recovery room (Lind et al. 1989).

**Treatment management and prognosis**

After diagnosis, individuals' cancer narratives focus on treatment management and their reactions to their prognosis. Culture-based cancer research demonstrates that cancer treatments are no longer limited to one's local community. In our global society, an individual can cross local or international boundaries in search of cancer treatment. The current market-based approach to health, health as a commodity, and the unequal distribution of health resources has created a cancer patient niche in medical tourism (Chavez 2009; Dalstrom 2013). Cancer patients and their families use medical tourism to obtain conventional or alternative cancer treatments and as a respite from the demands of cancer treatments (Hunter-Jones, 2005; Kangas 2010).
**Conventional treatments.** Conventional cancer treatments vary by the cancer’s type and stage. It can include a combination of: surgery, chemotherapy, radiotherapy, and hormone treatments (Orenstein 2013; Salamonsen et al. 2012; Kelly 2005). Conventional medicine aims to remove the tumor and or kill the malignant cells. Researchers have asserted that individuals’ unique life experiences and contexts create different treatment experiences (Gordon 1990, Kagawa-Singer, Wellisch 2002; Moore 2001). The biomedical cultural system depicts cancer treatment as a process that is best experienced with a positive demeanor (Perusek 2012; Jain 2013).

**Complementary or alternative treatments (CAM).** Cancer patients also have access to non-conventional cancer treatments that can be used in place of or alongside conventional treatments. Complementary or alternative treatment is defined as “a broad domain of healing resources that encompasses all health systems, modalities and practices, and their accompanying theories and beliefs, other than those intrinsic to the politically dominant health system of a particular society or culture in a given historical period” (Zollman, Vickers 2009). These healing resources can include: acupuncture, herbal treatments, aromatherapy, or nutritional therapy (Salamonsen et al. 2012; Zollman, Vickers 2009). A treatment’s classification as complementary or alternative is based on how a cancer patient includes it in their treatment itinerary. If a patient uses a non-dominant healing resource in addition to conventional medicine (e.g., chemotherapy or radiotherapy) then it is regarded as complementary. If a patient uses the healing resource
instead of conventional treatment then it is regarded as an alternative treatment (Hunter-Jones 2005; Orenstein 2013, Kangas 2010).

Cancer patients’ use of complementary or alternative treatment is influenced by various factors. Salamonsen and colleagues (2012) identified three themes that guide cancer patients’ use of CAM. First, patients used the “right to one’s body” theme to assert that it was their bodies and that they have the right to select which treatment was best for them. Second, complementary medicine patients used the “body as a gauge” theme to assess whether CAM could enhance the effectiveness of conventional treatments. Third, alternative treatments users evoked the “body as a guide” theme to inform their body’s healing process.

The CAM discourse includes an underlying assertion that personal experience should be valued over or at least in conjunction with medical expertise (Salamonsen 2012). Researchers have also advocated for patient choice through their critiques of the biomedical cultural system’s authoritarian control over cancer knowledge (Jain 2013; Perusek 2012). Patient advocates have argued that there is a lack of scientific research that speaks to the benefits or limitation of complementary and alternative cancer treatments (Wooddell, Hess 1998). They argue that patients should be provided with unbiased information about all treatments and the opportunity to select non-conventional treatments. These choices should be made in a space in which the patient is not labeled as non-compliant by clinicians or their loved ones if they decide to use non-conventional treatments (Wooddell, Hess 1998).
Cancer Survivorship. A reoccurring topic in cancer research is the concept of survivorship, which continues to be criticized (Perusek 2012; Jain 2007a, 2007b). Critics include patients and their family members. Their accounts paint cancer as a complex experience (Lam, Fielding 2003; Pasick, Burke 2008; Jain 2013). This chaotic lens to cancer is contrasted with the linear “clean” lens of the biomedical cultural system and scientific research.

Critics of the cancer survivorship theme have also noted that medical and corporate cancer discourses include three common themes of survivorship: war on cancer, statistical risk, and hope/positivity (Gordon 1990; Mathews 2000; Good et al. 1990). Mary-Jo DelVecchino Good and colleagues’ (1990) suggest that the “war on cancer” theme creates a militaristic approach to cancer survivorship. They go on to connect the “war on cancer” theme to physicians’ use of statistical risk during diagnosis to help patients understand life after diagnosis, their prognosis. Mary-Jo DelVecchino Good and colleagues’ (1990) also posit that statistical risks are used to gauge the progress that science has made in the war on cancer. According to their findings statistics provided occupational motivation for oncologists but it also discourage them when numbers showed limited progress in the war against cancer.

The militaristic approach to cancer survivorship regards patients as part of an attack front whose objective is to kill the invader, cancer. While the provider administers the treatment the patient’s responsibility is to stay positive (Perusek 2012; Saillant 1990). The cancer patients’ personal disposition is regarded as a meditator in their post diagnosis experiences. A biomedical model survivor stays
positive irrespective of the pain, fear, and turmoil that he or she maybe experiencing (Jain 2013). If a patient expresses fear or doubt their emotional response may be regarded as a retreat in the war, and decreases their changes of survival. Instead of doubt a patient should have hope. Hope is an important part of the medical war on cancer. Cancer, the mysterious disease, is equated to a slow and painful death that requires individuals to rely and hold on to hope (McMullin, Weiner 2009, Good et al. 1990; Sontag 2001). However, hope has both negative and positive effects on an individual’s cancer experience. Hope can support non-disclosure practices or it can be used to devalue the experience of patients (Gordon, Paci 2007; Jain 2013; Wooddell, Hess 1998).

Critics argue that the medical literature’s “clean” account of cancer survivorship does not map onto individuals’ accounts of their cancer experiences (Stoller 2004; Engelberg 2006; Jain 2013; Wooddell, Hess 1998). Patients’ narratives demonstrate a need for an equal evaluation of cancer patients’ lived experiences and the biomedical system’s definitions of cancer in order to effectively improve cancer services and individual cancer experiences.

Researchers have shown that part of the complexity of cancer patients’ narratives lies in their focus on the body and how it is used as a filter for their experiences. This approach generates discourse impregnated with fear, doubt, humor, hopelessness, guilt, and anger (Perusek 2012; Pasick, Burke, 2008). These accounts, when situated against dominant cancer knowledge, can provide in-depth glimpses into the post diagnosis world of cancer patients (Stoller 2004; Engelberg 2006). Patients’ post-diagnosis accounts provide critiques that reject the
war on cancer discourse as harmful because it does not consider their cancer experiences (Mathews 2001; Saillant 1990). Some have even suggested that the term “survivor” contributes to cancer patients’ emotional turmoil (Perusek 2012; Jain 2013). Others critique the concept of the model survivor in the medical war on cancer. These critics propose a model cancer patient who is allowed to express fear and doubt. They argue that a failure to acknowledge the storm of emotions that define the cancer experience ostracizes those who choose to express their feelings (Drew, Schoenberg 2011; Moore 2001; Salamonsen, et al. 2012). These critiques has produced advocacy work influenced by culture theory which supports cancer discourses that acknowledge diverse cancer experiences that do not fit into the clean medical mold of the model cancer patient (Woordell, Hess 1998; Jain 2013).

A dual focus on culture and social context permits cancer discourse that accounts for the complexity and messiness of cancer experiences, ultimately addressing critics’ assertion that the biomedical cultural system’s hegemonic control of cancer discourse creates unequal distribution of power that devalues individuals’ cancer experiences (Jain 2013; Woordell, Hess 1998; Chavez 2009; Perusek 2012; Balshem 1991; Pasick, Burke 2008; Dein 2004; Farmer 2001). The two-part focus on variation in meaning construction and social-structural context gives equal voice to the procedures and users of cancer knowledge, while accounting for the social and structural factors that influence their different experiences.
This emphasis on social context and its interaction with individuals’ cultural meanings also responds to critiques of cancer research that only focuses on individuals’ beliefs (e.g., fatalistic beliefs) outside of their social-structural context (Pasick, Burke 2008; Farmer 2001). This dual approach can be used to provide important contributions to cancer research because it allows researchers to examine two important spheres in individuals’ cancer experiences, the individual and their context. This two-part focus advances the discipline of anthropology and cancer research. It represents another step in anthropologists’ attempt to understand the relationship between culture and behavior and moves cancer research closer to deciphering the mysteries of cancer.

This dissertation synthesizes this approach with existing methods in cancer research (e.g., explanatory models, narratives, and participant observation) to produce in-depth descriptions of intra-cultural variation among care-seekers’ (women) and –providers’ (physicians) cultural knowledge of breast cancer and their breast cancer experiences in Mayaguez, Puerto Rico.
This chapter uses a combination of traditional ethnographic methods (participant observation and semi-structured interviews) and content analysis to locate a multi-voiced discussion of breast cancer experiences in Puerto Rico’s current healthcare system. It equally weighs the voices of two prominent players in breast cancer discourse -- physicians (care-providers) and women (care-seekers) - to 1) describe Puerto Rico’s healthcare system from the lens of its care seekers and providers and 2) explore how the Island’s predominantly Medicaid-funded public insurance structure influences women’s access and use of available breast cancer resources on the Island.

Results

Sample Characteristics

The majority of the women were between the ages of 39 and 59 (Table 4-1). Thirty-four percent received a grade school education, 39 held a college degree, and 27 percent held graduate degrees. Thirty-four percent of the women’s annual family income was under $15,999, 42 percent was between $16,000 and $49,999, and 19 percent was $50,000 or greater (Table 4-1). Ninety-eight percent of the women had medical coverage at the time of the study (Table 4-2). A majority (76 percent) of the women had visited a physician in the past 30 days. When asked whether they had ever had a mammogram, 95 percent of the women reported having a mammogram. Similarly, when asked if they perform breast self-examinations, 86 percent of the women reported performing breast self-exams. However, only 85 percent had a mammogram in the past two years.
Most of the women had never been diagnosed with breast cancer and did not have a family history of breast cancer. However, 69 percent reported having a friend, neighbor, or coworker who was diagnosed with breast cancer. When asked about genetic testing, the majority of the women reported hearing about genetic testing for cancer, but had never had a breast cancer genetic exam (Table 4-2).

Of the 20 physicians, the majority were males between the ages of 40 and 64 (Table 4-3). The physicians’ specializations included general medicine, internal medicine, gynecology and obstetrics, general surgery, plastic surgery, oncology, and family medicine. The physicians’ years of specialization ranged from fewer than five years to more than 31 years. However, the majority of physicians had practiced their specialization for more than 21 years. The majority of the physicians were internal medicine physicians, and gynecologists and obstetricians, half of whom had received their training off the Island. All of the physicians owned private practices. The majority of private practices consisted of one to five physicians. The majority of the physicians were never diagnosed with cancer and did not have a family history of breast cancer.

**Puerto Rico’s Healthcare System**

When asked to explain how the Puerto Rican healthcare system functioned, women and physicians drew organizational charts, faces, and summaries to illustrate their knowledge. The 59 women’s photographic narratives consist predominantly of short summaries (Figures 4-1). In the following sections women are divided by insurance type to explore the relationship between insurance and women’s experience within Puerto Rico’s healthcare system. Of the 59 women, 35 were privately insured, 10 were publicly insured, 13 were Medicare insured, and
one was uninsured. A majority of the physicians’ 20 narratives explained the system’s function through organizational charts (Figure 4-2).

Together the women’s and physicians’ graphic and text summaries of the Island’s healthcare system depict a two-part system divided by insurance funders: public (Puerto Rico’s Department of Health and Medicaid) and private (employers and patients) (Figure 4-3). The Island’s Department of Health is located at the top of the system. Directly under the Department of Health is the Health Insurance Administration (ASES), which is responsible for regulating the provision of public and private health services. Under the public sector, the ASES contracts with a Managed Care Organization (MCO) to manage patient care.

Under the current public MCO, Triple S, is the Independent Physician Association (IPA). The association includes small physician groups dispersed throughout the Island by assigned districts. Each group consists of a number of primary care physicians (e.g., general, internal, and family practitioners and gynecologists). Publicly insured patients are then assigned to a primary care physician who becomes their gatekeeper to other resources in the system (e.g., specialists and pharmaceutical). Before the Island’s indigent population can receive medical care they have to qualify for Puerto Rico’s public insurance, based on a threshold of those living at or below 200 percent of the Federal Poverty Line (FDL) (Common Wealth of Puerto Rico 2011; CMS 2012). Qualified Puerto Ricans receive an insurance card, similar to their private counterparts, which grants them access to a physician in their assigned IPA.
Physicians are free to choose to participate in an IPA. IPA physicians are paid by capitation. They are provided a set amount of money per month per patient (e.g., 90 dollars). The 90 dollars cover laboratory exams, medications, and referrals. Publicly insured patients hospital expenses are covered directly by Triple S, the publicly contracted MCO, and not physicians. Physicians are required to see no more than 33 percent of their assigned population. If they see more than 33 percent of their patients or provide too many referrals and their capitation allotment is in the negative at the end of the month, they are not compensated that month for that patient. As this IPA family practitioner explains, if physicians are not able to manage the allotted amount and they continue to have a negative amount at the end of the month they will be asked to leave the IPA and will not be able to participate in the Island’s public sector:

Ok. That fund, I have to control, regardless ... in fact if you see more than 33 percent of your population you won’t get paid. Per month ... I have to see less and less of 33 percent of my people ... they [the IPA] control, to some extent, how many times and how many patients you can see, yes. On the other hand ... if all the time I am giving referrals and make my medical fund negative. That doctor is given a warning, and if you are not a good user you are thrown away, they kick you out. So you have to have good control of your management and good control of your medical fund, so that if the patient is very chronic... well, one of two things [happens], you end up dropping the patient from your clinic or you have to somehow stop these referrals that you are using because it will make your medical fund negative.

Unlike the publicly insured Islanders, privately insured individuals select from available MCOs (e.g., First Plus, Triple S (private), Humana). These individuals or their employers pay a selected MCO a monthly fee to access care. Some individuals are also expected to pay a co-pay amount at the time of their
medical visit. Generally, physicians provide service on a fee for services basis to privately insured patients.

Three central themes appear in the women’s and physicians’ descriptions of the Puerto Rican healthcare system: “public/private structure”, “available breast cancer services”, and “accessing care.”

Public/private structure

Both women (privately, publicly, and Medicare insured) and physicians used the first main theme, “public/private structure” to explain the organization of the system’s components and to describe the flow of services and human resources in the system. According to an obstetric gynecologist, in Puerto Rico, "…there are two systems; there is a public system, [and] there [is a] private system. I work in the private system." Similarly, a privately insured female patient notes:

Our health system is structured; one public and [one] private in which health providers receive their patients under private or government plans. Both groups have access to services by going from a primary physician, specialist and subspecialist, according to the discretion of each physician’s requirement.

Yet, narratives suggest that the Island’s use of MCOs in its private and public sectors makes it a private system. As this surgeon notes, the "...health system is most unfortunate, the private system, practically the public health system was made private."

Another physician, an internal medicine practitioner, explains that the Island’s system is experiencing a reform in how its MCO’s manage care due to the Affordable Care Act:

Ok, for me, in my opinion, all these plans have become so ... what is now happening with ObamaCare. All this for me becomes a glorified
Obamacare reform. Why? Because now in order to prescribe non-generic medication I have to almost go on my knees and write a long justification to the plan and they will not give it to the patient, if it is not medically necessary.

Various physicians linked increased administrative responsibilities, implemented by MCOs, with restrictions on their ability provide quality care to the their patients.

**Available breast cancer services**

The second dominant theme, “available breast cancer services,” can be divided into two subthemes: “available” and “needed.” The groups' narratives identified the breast cancer resources that the system offers to women but it also notes that there were needs that went under or unaddressed by the system. When discussing available resources, the women’s narratives focus on women’s health resources that span a woman’s life cycle. As this privately insured community woman notes:

The health system in Puerto Rico has some family planning centers and then these centers have two areas, right? One is the area of planning such as children, right? And another area is associated with women's health. In the area of women's health, these centers provide clinical planning and information awareness of breast cancer, self-exams, and give treatment information etc. The area of medical plans, they are driven by different guides, right? They have different guidelines and then depending on the guidelines that the health plan follow is [how] the time for mammography, time for sonomammography [is determined] ... and depending on the results of these studies then they direct the patient to your primary care physician, your gynecologist. Or, if I had to do something else, to a surgeon, hema-onco, right? Depending on the treatment or diagnosis that the patient has.

This community member identifies two important sources of breast cancer information and services for women: medical centers and the health insurance plans. She highlights the importance of health insurance on the Island and
suggests that variation in insurance screening guidelines can impact how and when women have access to breast cancer preventive services.

When speaking about available services physicians generally spoke about the breast cancer services that they provided for women. For example this gynecologist walks through the preventive services that he provides for women based on their age:

Well, the doctors, I am GYN, serve. We give annual yearly breast exams to patients if they have risk factors and [are] over 35 years or more we send them to a sonogram based on if they have risk factors and if they have a palpable mass or something but is less than 35 years, it is mandated to do sonogram or mammograms.

When some women address what the system lacks, they generally focus on one section of the system. As one uninsured community woman explains: "I must say ... that mental health is not a priority, but I think about this, not because it is a priority in Puerto Rico." Others, like this privately insured female patient, used a drawing of a face to refer to deficits in the entire system: “The health system should be more accessible to all. It lacks a lot. Indeed, the face symbolizes that, that it requires more accessible health services for everyone. Most of the physicians’ discussion of the medical services did not focus on deficiencies.

**Accessing care**

The “accessing care” theme was evident in both women’s and physicians’ explanations about how resources flow through the system and are accessed by women or provided by physicians. The groups’ discussions of care seeking map out a process that includes consultation with a physician, referrals, examinations,
and treatments. The women’s narratives illustrate the breast cancer care-seeking process in the system. They describe the care seeking process of a diagnosed woman that begins with her primary care provider (internalist, generalists, or gynecologist), followed by a referral for an exam, an oncologists, and/or surgeon. As this publicly insured community woman explains:

The health system in Puerto Rico works well ... you go to your primary care physician, primary doctor may refer you to a specialist, in the case of breast cancer the first thing you see is the gynecologist, the gynecologist goes to the hospital where you usually see an oncologist, which sends you to an oncology hospital for treatment.

Similar to the previous community woman, this privately insured female patient explains the care seeking process, but the role that insurance plays is more prominent in her explanation:

Ok, that would be talking about the patient. So she goes to the doctor, she goes to the labs but then, when you get to the doctor, you need... it depends on the coverage, referral for laboratory studies ...first you do the laboratory then it is consultation, if not then you look for a specialist to consult then you have to find one, [then] search for plan approval. If they give it then you return for treatment. Yes, treatment and if not ...this [return to primary care] again. Again check the insurance. If it is in advanced stage [and treatment is approved] then it will be catastrophic coverage.

The physicians' discuss the care seeking process from the women’s perspective and their descriptions align with the process mapped out by the women. For example, this obstetric gynecologist explains how care is sought under the public sector:

So you have your private... and then you got your public I guess... or your Reforma... Usually for the private you don’t need referrals. You go straight to the mammogram, and if there’s any positive finding then you could get either an ultrasound or you can go to a surgeon to
get a biopsy. But, if you are on the public system you have to go back to your primary physician, who then will give you a referral who will then give you the order for the mammogram, then you have to go back to your primary, who will then give you another referral order to go to the surgeon.

This physician draws distinction between accessing care as a privately verses a publicly insured women. This excerpt illustrates the delay that is introduced to a woman’s care seeking process based on her insurance type.

**Breast Cancer Experiences Within The System**

In addition to using their narratives to describe the structure of the Island’s healthcare system, the two groups also discuss how the structure of the system influences their experience in accessing and providing breast cancer services in the system. Women’s and physicians’ narratives include three dominant themes: “access,” “quality,” and “cost” (Tables 4-4, 4-5, and 4-6). In addition there were two themes that were specific to the women’s narratives: “doctor-patient interactions” and “responsibility to seek care.”

**Shared theme one: “access”**

The groups’ discussions of healthcare access focus on the reduced access to breast cancer services experienced by publicly insured patients. This theme was mentioned by 30 privately insured women, 14 publicly insured women, 8 Medicare insured women, and 18 physicians (Table 4-4). These discussions are dominated by two subthemes: “general reduced access” and “reduced/restricted access caused by referrals.”

Some women, like this privately insured community woman, acknowledge that the public sector increases poor individuals’ access to healthcare services: “
Well, those with fewer resources have more access to health resources, because they will have a free health plan and they will have the medicines. They will have at least one primary doctor, not specialist, to go to for medical service."

However, the majority of women and physician note that the structure of the public sector reduces the number of physicians who participate in the system. This means that not all physicians accept public insurance on the Island. One publicly insured female, previously diagnosed with breast cancer, provides an example of what can occur to a publicly insured patient when seeking care:

Oh an example here. Your health plan? The say to me "Oh here we don't accept that" ... or go to another "here we don't accept that" "here we don't accept that." Most doctors do not accept...the government plan. They don't take it. That's what I say or I know people that "this hurts", "I have a problem with arthritis", so you go to the doctor, then when you call the doctor, "Look, they don't accept Reforma." It is Reforma... well they say Mi Salud but it is Reforma... they don't accept it. I'm like how?... but that's it.

Similarly, a privately insured community woman explains that there is a difference in access between publicly and privately insured patients:

Absolutely, the treatment that they give. For example there are doctors who refuse to take Reforma. So they just do not see those patients. Or if yes, they assign certain days of the week to Reforma patients. So, the Reforma patients do not mix with the actual patients. You know what I'm saying? Or in the assigning of times for visits, you know, if you have Reforma you can wait three to four months to get an appointment.

Differential access to care between public and private patients is also noted by physicians. The following obstetric gynecologist outlines how the structure of the public sector (e.g., restrictions on physicians use of referrals) 1) creates
practices that reduce patients’ access to care, 2) conflicts with physicians’
definition of their job, 3) and results in physicians leaving the public sector.

What happens? ... La Reforma on paper, fantastic. In reality, an abuse. Doctors have false hours of operation. They have office hours Mondays to Friday. They don't follow it. The referrals make it very difficult for patients. I myself left Reforma because in 2000 I found a lady of thirty-one years, a lady forty years, and a lady thirty-six years with breast lumps. They needed a mammogram. I didn't worry I recommended it... the doctor couldn't give the referral. He couldn't! The primary care doctor could block my expertise. A year [later], I thought that the three died... they said doctor now I will do the biopsy. A year after I find a mass! It's because you're a gynecologist ... according to Reforma. So when I began to see that I said, "This is not medicine." Medicine is if I find something or vice versa... if it is good, if not, they give a referral, we'll send her to a surgeon. I found it was unfortunate ... as a doctor in this system I follow my expertise. I have to have someone review this, who doesn't have my expertise. Not the same level. And then I found that patients... died from breast cancer or were at an advanced stage. I don't expect to find advance stage or perhaps a less advanced stage. So I left Reforma.

Both women and physicians’ narratives identified physicians’ being asked to leave or deciding to not participate in the public sector. Their narratives connect the reduction in physicians' participation in the public sector with increased barriers to care and decreased quality of care for publicly insured women.

The second subtheme, “reduced/restricted access caused by referrals,” was continually evident in the group’s narratives that critiqued the public sector’s restriction on referrals and its effects on patients’ access to breast cancer services. As this privately insured community woman notes: "Medical plans are challenging today because they interrupt or delay treatments and procedures. The protocol to seek authorization for all laboratories and/or drugs may be delayed and sometimes are not authorized." Both publicly and privately insured women critique the public sector’s use of referrals. This privately insured female patient expresses gratitude...
that she is blessed to not need public insurance: "They don't give referrals, they
don't send to specialists. They are left to die in the house. How much of them do
not have money to pay for a specialist, because thanks to the Heavenly Father I
have. But those who do not? That depends on the health system."

Physicians also express concerns about the difficulties referrals create in
their attempts to provide breast cancer services. This obstetric gynecologist notes
how the number of required referrals limits women’s access to breast cancer
preventive and treatment services:

Well, it depends on what kind of insurance you have. If you have a
private insurance it’s usually easier to get a referral for either a
surgeon or someone to get any kind of biopsy. But if you are in
Medicaid, it's awful. It's terrible because you have to go to the
primary physician to get a referral for a surgeon who then need
another referral, you need like a thousand referrals in order for the
patient to get some kind of treatment. Even [to] get a mammogram
it's like a hundred referrals. So there's a lot of delay in treatment and
not a lot of physicians take Medicaid, which also limits the patients’
access to treatment.

This surgeon discusses how his ability to treat diagnosed women is obstructed by
referral requirements:

Okay, it depends on... private [the] plan and the other is government
insurance, which is Reforma. Reforma primary physician ... here
usually delay until you reach [the] surgeon ... then ... once the patient
reaches the biopsy surgeon another delay, order [exam], more delay,
treatment biopsy done, finally. Private insurance, surgeon, test
diagnosis, treatment biopsy, very little delay. A biopsy on a patient
with private insurance ... you come today, I do a biopsy, the next
week I can do the [surgery] but a Reforma patient sometimes brings
me a study, the study is incomplete, they have go to their primary
care physician, ask permission, then come to me, I say "I recommend
you do a biopsy," it can take two or three weeks at least to authorize
the biopsy. The patient returns here with permission and then I give a
date for the biopsy, you see? Because I cannot give them a date
because I don't know when their primary will give authorization.
While both women’s and physicians’ discussions note how referral requirements obstruct women’s access to care, one surgeon notes that it is important to understand that IPA physicians are trying their best and it is not them, but the system that they work in:

However, it is important that you know, usually the primary care physicians are quite ... when we are talking in terms of breast [cancer], well they try to alleviate things but sometimes it is the system it is not them. It is not that they are unwillingness to do that [provide referrals]. It is simply the system is forcing them to ask for referrals before so often they cannot give a referral without consulting the manager that is called IPA, that is this Individual Practice Association. That kind of stuff, see? But basically the difference is the ease with which a thing can be done.

Shared theme two: “quality”

The “quality” theme was dominant in both groups’ discussions of their experiences within the Island’s healthcare system. This theme was mentioned by 25 privately insured women, 10 publicly insured women, 10 Medicare insured women, and 13 physicians (Table 4-5). Women’s discussions of their care seeking experiences illuminate how the referral structure of the public sector reduces the quality of breast cancer services that women receive. As this publicly insured female patient -- previously diagnosed with breast cancer -- notes, the differences in quality of care provided to patients is based on the type insurance:

Not a very good health system here. For here, as you can see, I don't know if you have seen yet. Here the insurance plans. If you have Reforma, the government plan, Mi Salud. They don't provide good care. Not that they don't provide good service, they cannot provide the best quality healthcare to patients. I've seen it, I've heard. Health benefits, their patients is one of the things that worries me.
Physicians express their frustration with their dependency on both sectors of the system and demonstrate how the use of MCO’s can comprise their ability to provide quality care. This surgeon explains that physicians are employees of MCOs and to choose not to accept them would be a death sentence:

Physicians we doctors, we are employees of these insurances, those plans. They audit everything we do. They give us rates, they control the rates. If I decide not to accept any health plan, if I decide not to supply any of these health plan I will die of starvation. Because people do not have money to pay the doctors, very few.

Some also connect the use of capitation in the public sector with restrictions on physicians’ ability to provide quality care. This internal medicine practitioner explains:

This [public insurance] constrains, this side is public. This side [is] private. What happens is that they give you ten thousand dollar, the insurance, and from that ten thousand dollars they keep the payment of the doctor and the payment for the patient. If you refer too many patient you will receive less money. The more you work, less you get paid, less you receive in the public. From this side [private], more you work, more you earned.

Other physicians demonstrate how capitation in the public sector negatively impacts their ability to provide timely care to breast cancer patients. This surgeon explains:

All these levels every time you send someone to radiotherapy or chemotherapy you must mediate authorizations with medical plan, they have control. That's bad because during this time, you lose a lot of time. If this doctor that is here is smart [and] knows that the faster you solve the problem, you will have to visit them less and you will have less expenses. But that is not the mentality of many doctors. So many doctors delay following this authorization process because other processes mediate it, economic issues are in the middle. Do you know what is capitation? Primary care physicians have a capitation. And every time that I operate on a patient these guys will
lose money from their capitation, so they do not care about that operation and that's how bad the system is.

Physicians also note that the restrictions on their ability to provide care were not isolated to the public sector. This internal medicine practitioner explains that the authorization requirements of MCOs in general reduces physicians’ ability to provide quality care:

If the health plan, every plan has a treatment “X” formula and if you leave the formula, they penalize you. They come and tell you that they will not approve the drug for the patient because it is an expensive drug and here is where comes the problem that you as a doctor do not have the option of giving the best treatment that the patient needs and this is a problem that we have.

**Shared theme three: “cost”**

“Cost,” the third theme is evident in both groups’ descriptions of their experiences within the system. This theme was mentioned by 5 privately insured women, 2 publicly insured women, 3 Medicare insured women, and 6 physicians (Table 4-6). Women's discussions of cost focus on the high cost of healthcare and their inability to pay for services partially or not covered by their insurances. This privately insured female explains that MCOs' high deductibles can reduce patients’ access to breast cancer services: "The studies that you need for follow up [visits], are not as accessible because health plans do not cover a high percentage of the cost of mammograms, biopsies, CT, [and] MRI."

According to this privately insured community member, a private insurance plan still presents cost issues with expected deductibles and does not always guarantee coverage when one has a chronic illness or comorbidities:
It is that you are paying, for example, I had a medical plan that I had to pay almost two hundred to three hundred dollars a month. If I had to go to a doctor well the deductible was fifty dollars. I mean no, excuse me, 150 to 200 dollars. So, if the visit was three hundred dollars I had to pay the remainder. That is two hundred and something dollars. Do you understand what I mean? So, I do not think that public... works, supposedly that works for the people who cannot pay, it do not work for them. Then, sadly, the people who work for a medical plan it still cannot cover them. My father is a cancer patient, five times. And there was a drug that every pill that he had to take cost two hundred and fifty dollars. He had Triple-S. Triple-S is supposedly a good health plan, and he paid monthly, Then they did not pay for his medication], a cancer patient who pays.

When speaking about cost, physician’s narratives emphasize the insufficient compensation that they receive in the public sector. This obstetric gynecologist walks us through how a gynecologist under the public sector is compensated:

That’s why our health system is completely fucked up...eloquent, but okay. So explaining the capitation... They will assign a population of women. For example OBGYN...If you work for capitation you get assign 3,000 women. And they will give you two dollars and 50 cents for each patient per month. So, ... if I have three thousand patients and they gave me two dollars and 50 cents for each patient. Every month, how much is that? Seven thousand dollars. They will give you seven thousand dollars a month. NO matter if you see them or not. But you have to see for a rule...you have to see at least 30 percent... every month. No. There’s no maximum, there’s a minimum, Thirty percent. If you do surgery that’s included in the 700. So... where do you think the problem is? If I have to do for example, right now I do around 30 to 40 surgeries a month. Okay, about 20 of them are Reforma and each surgery with an average of 400 dollars. Ok. 400 times 20, how much is that? Eight thousand dollars, right? And they are paying me 7,000 dollars in capitation, what does that mean? That’s for the surgeries. What about the visits? In other words, basically, you are working for free.

Additionally, some physicians also explain that their low rate of compensation is related to the Island’s commonwealth relationship with the U.S. As this internal medicine practitioner explains:
What happens is that in Puerto Rico, the premiums are much lower than in the United States. Although Puerto Rico is a US territory, because we are a Commonwealth, we are not a state, premiums for us are very little, and now it’s down more. So what earnings can I have make if they paid me 60 dollars, now they pay me thirty. And here the doctors are very upset with the system.

Women-specific theme 1: “doctor-patient interactions”

There is one theme unique to the women’s discussions “doctor-patient interactions” and one theme “responsibility to seek care” only evident in the privately insured women’s narratives. These group-specific themes provide further insight into the women’s experiences as care-seekers in the system and are used to evaluate the point of service interaction between physicians (care-providers) and themselves. The “doctor-patient interactions” theme was mentioned by 6 privately insured women, 4 publicly insured women, and 4 Medicare insured women. When discussing their interactions with providers, women describe both positive and negative experiences. Women in the former group such as this privately insured patient explains that “the doctor who treats me is a nice person, he explains things well to me, good services in terms of treatment."

Similarly, a privately insured female patient explains her agreeable experience attaining breast cancer services:

My experience with the use of health plans and physicians that I use is good. My doctor has always treated me well and sent me to do the tests and routine laboratories. Every year I get a mammogram and ultrasound screening. So far everything has been negative. I had a left breast biopsy that was negative. Until now I rejoice in fairly good health.

When the women describe their negative interactions with providers they express unhappiness with their physicians’ approach to healthcare. As this
privately insured community woman explains, she was not content with her providers attempt to deliver short-term treatment for symptoms without further investigation into their cause:

My experience with the health system is ... [the] doctor when you're sick typically work with your symptoms and give you medicines for them. They don't go beyond these symptoms and why? They only relieve what is present or in that moment. No prevention. My doctor asked if I've done my routine exams, that is a mammogram, and if I went to the gynecologist, but not much more.

This publicly insured community women notes that she feels under-informed because her physician does not provide sufficient information about cancer:

It is not great because they do not explain to people what they need to know about cancer or diseases. Not very good. Everyone needs to know about their health. Sometimes they explain nothing. Sometimes you ask the doctors something and they do not explain things well either. I have something in my breast but it is not bad, one thing is that they told me, is if you have cancer it does not hurt. That is was what they said to me and that's not true because my cousin had cancer and she had horrible pains.

Another privately insured female patient explains that the structure of the public sector has replaced doctors’ focus on their patients’ to making money:

The health system influences the mortality of people, because some doctors have lost the warmth to patients. Perhaps as a result of healthcare reform that that they give, so it pays doctors and they accumulate a lot of money and they forget about the health of low-income patients. They do not give them referrals and medicine is very cheap to give but they do d not help their patient's health. That's my opinion.

Women-specific theme 2: “responsibility to seek care”

“Responsibility to seek care,” is only evident in privately insured women’s narratives (7 women). It is used to explain that women’s decision to seek care is
just as important in healthcare as the function of the system. Women’s discussions of this theme can be grouped into two subthemes: “personal responsibility” and “external locus of control.” The women who identify care seeking as the women’s personal responsibility explain that the process of seeking care is based on an individual’s personal characteristics. As this privately insured community woman notes, while increased preventive behaviors among women in the middle and upper middle class is related to the groups’ access to information and health insurance, care seeking is based on an individual’s disposition and material constraints (e.g., SES):

What happens is a question of the disposition of people because it is a cumbersome method, looking for referrals. This, and because sometimes people give up. Now the middle class level, what I have seen a lot is that the group of woman of middle class, upper middle class they tend to use more prevention because they have more access to the services and usually have medical plans.

This privately insured breast cancer patient further explains that it is important for the patient to advocate for herself in order to get the care that she needs:

And this was two thousand and twelve ... in San Juan. What's going on? There comes a time when doctors are also so saturated with a lot of patient and is already like, mechanic. They have this...[ I had to say] no a doctor, excuse me that's not me, I do not have that. I have is this. If a patient is not concerned to learn about what condition they have, if it is a positive receptors, if it is a negative receptors. For those things you have to learn because...if you do not defend yourself, if you do not take care of yourself you know, they [doctor] have lots of patients.

Unlike the previous group of women, some narratives suggest that the process of accessing care is dependent on the structure of the system and is outside of women’s control. This privately insured community woman explains:
Okay, in my experience it is a matter of luck. If you get a good doctor and develop a personal relationship with him or her, the system works. But if no, it is like navigating in the dark. If you have health plan [private] they treat you better or they treat you different, better. But the constant is that you have to know about your condition and cannot depend on the medical staff.

Women's and Physicians' Assessment of the System

The shared dominant themes in the women’s and physicians’ photographic narratives were also used to assess how well the Puerto Rican healthcare system provide breast cancer services to women. This assessment, based on the experiences of the system’s participants-- women (care-seekers) and physicians (care-provides)-- reveals a system that is both praised and criticized. The system’s participants praise it for the access that its public sector provides to its indigent population and critique it because of inequities in the provision of care between its private and public sectors. The women and physicians’ assessment of the system’s access and quality with their overall satisfaction can be divided into three rating groups: positive, neutral, and negative (Table 4-7).

Thirty of the group’s seventy-nine narratives positively describe the system’s ability to provide breast cancer services (Table 4-7). Twenty-eight of those narratives are from women, and equal half of the total women participants. Of the 28 women who positively assess the system 13 were privately insured, four were publicly insured, and nine were Medicare insured. The women positive assessments of the system included descriptions of the benefits of available health insurance for the poor, excellent medical professionals and facilities, provision of needed health information, and great doctor-patient interactions. Only two physicians, ten percent of physician participants, provide positive descriptions of
the system. There narratives describe how well the available health plans function in the system.

Thirty-nine of the two groups’ narratives negatively assess the system’s ability to provide breast cancer services (Table 4-7). Women narratives’ account for 25 (36 percent of the women participants) of those narratives. Of the 25 women who negatively assess the system 17 were privately insured, three were publicly insured, and five were Medicare insured. The women’s negative assessments of the system consist of descriptions of unavailable services, reduced quality and access of care experienced by the publicly insured, long wait times, and delay in care due to referrals. A majority (70 percent) of the physician participants negatively rate the system. There negative assessments describe capitation and referrals and how these protocols restrict their ability to provide care.

Finally, thirteen of the women’s and physicians’ narratives are neutral (Table 4-7). These narratives do not explicitly note the participants’ opinion about the system’s ability to provide breast cancer services. Seven of the women narratives (twelve percent of the women participants) are included in this group. Of the seven women who neutrally assess the system five were privately insured, two were publicly insured, and zero were Medicare insured. The women’s neutral descriptions of the system explain the basic function of accessing care in the system. Six (30 percent) of physician participants are neutral in their description of the system. Similar to the women’s neutral assessments the physicians’ neutral assessments provide an outline of how the system function.
Discussion

This chapter’s in-depth exploration of women’s and physicians’ narratives illustrates a two-part healthcare system that strives to provide care to all Puerto Ricans on the Island. Even though their narratives identify barriers in access, delayed care, and disparities in quality of breast cancer treatment, they also suggest potential benefits that Medicaid expansion might have for cancer disparities.

Analogous to the U.S. mainland, the Island’s healthcare system uses federal funds to provide care to its indigent population within a market-based system. Before 1993, the Puerto Rican government was the primary provider of care on the Island. That year, it adopted a market-based system and created the ASES ultimately, changing the government’s role from provider to regulator. As a regulator, the government contracts with one MCO to provide care to its indigent population and oversees the other private MCOs. This market-based approach to healthcare on the Island created a two-part system based on financing: publicly funded by the government (local and federal) and privately funded through an employer-based model. Under the public sector, the government contracted MCO provides care to poor islanders 65 years old and younger.

This structure is very similar to the Medicaid on the mainland before the ACA in which the federal government provided funds to states and each state created their eligibility criteria. However, eligibility is where the Puerto Rico system and the mainland’s diverge. On the mainland, the federal income eligibility criterion was 100 percent (FPL), but it was not enforced nationally. Since states were permitted to create their own eligibility criteria, variations existed across states.
Some states determined eligibility on whether a family had a dependent while others lowered the federal income requirement (Kaiser Family Foundation 2015). This variation ultimately excluded Americans and increased the number of uninsured individuals on the mainland.

Unlike pre-ACA mainland Medicaid, when Puerto Rico reformed its healthcare system to cover its poor in 1993, its eligibility requirement for public insurance was individuals' income below 200 percent of the FDL. The Island's eligibility requirement also included non-disabled individuals without dependents (Common Wealth of Puerto Rico 2011; CMS 2012). Today after the ACA, the Island’s eligibility threshold has been expanded to include individuals at or below 266 percent of the FDL, approximately 65 to 75 percent of the FDL (Portela, Sommers 2015). While the Island’s reform created an uninsured population on the Island for the first time, its high-income eligibility requirement dramatically increased its poor population access to private care. By 2012, 90 percent of Puerto Ricans were insurance compared to 85 percent of Americans (Portela, Sommers 2015).

Today, as the implementation process of the ACA continues, questions still remain about its efforts to increase access through increased insurance status and its impact on health outcomes. Puerto Rico’s 1993 reform, when regarded as an example of the ACA’s proposed Medicaid expansion, permits discussions about 1) how do increased access to government funded insurance affects existing barriers in healthcare and 2) how will Medicaid expansion affect health outcomes in regards to breast cancer prevention and treatment.
The women’s and physicians’ narratives identify referrals and capitation, two important components of Puerto Rico’s and the U.S. market-based system, and describes how they affect access to and quality of breast cancer services in Mayaguez, Puerto Rico. According to the proponents of a managed care healthcare system, referrals from primary care physicians to specialists are important factors in the system’s ability to reduce cost by preventing overutilization of services (Barton 2010). Researchers have noted that the use of private companies to provide public services categorizes the recipients of public services as a homogenous group with hereditary behavior patterns (culture) that predisposes them to being helpless, hungry for quick gratifications, and dependent on public assistance. This definition supports the use of strict market-based approaches to prevent dependency and misuse of services (Nelson 2005; Briggs 2002). The narratives of the women (care-seekers) illustrate how referrals negatively impact the Puerto Rican healthcare system. Their accounts are filled with examples in which referrals delay breast cancer care and create disparities in quality of care received by Puerto Rican women. Analogous to the women, physicians’ (care providers’) descriptions of their experiences show how referrals conflict with their medical responsibilities and hinder their ability to provide care.

Referrals were identified as a barrier by both care-seekers and providers, and linked to reduced access and inequities in quality of care. However, the narratives of care-providers in the system link referral requirements to capitation protocol in the Island public sector. Similar to referrals, capitation is regarded as an important requirement in managed care because it decreases cost by decreasing
overuse or abuse of healthcare services (Barton 2010). However, physicians’ narratives paint a picture in which providers feel trapped within a system that conflicts with their definition of “good medicine.” In this “damned if you do, damned if you don’t” environment, physicians work within the system (e.g., accepting both private and public insurance) because if they do not they would “die of hunger.” Healthcare costs in Puerto Rico equals that of the mainland, but the economic climate on the Island is equal to that of Detroit before it filed for bankruptcy. Thus, relying on Islanders to pay for healthcare expenses out of pocket is not an option for Puerto Rico’s physicians. Rather their narratives illustrate a story in which they navigate a system that provides “conflicting provider incentives” to offer their patients cost efficient care while rationing care to maximize their end-of-month capitation payments (Barton 2010: 203).

Physicians must first decide whether or not to participate in both sectors of the system (private and public system). Many physicians choose not to practice in the public system because of the restrictions imposed on their ability to provide care. With a decreased number of physicians participating in the public system, both care-seekers and -providers narratives provide examples that shows how a reduced number of physicians in the public sector decreases women’s access to breast cancer services. For the providers who choose to participate in the public sector, their narratives identify the management practices that they have adopted to ensure that they do not violate capitation and risk not being compensated and/or removed from the public sector. One of the main management practices adopted by the physicians is the rationing of referrals. The groups’ stories demonstrate how
this practice decreases women’s access to breast cancer services and the quality of care received and provided.

Variation in the women’s and physicians’ assessment of the Island’s healthcare system can be tied to their roles in the system as care-seekers and providers, respectively. Half of the women’s narratives expressed their satisfaction with the Puerto Rico’s two-part system. This could be due to the sample’s increased private insurance status. However, privately insured women participants generally shared stories of family members or friends experiences to demonstrate their knowledge and critique the disparities in access and quality that exist between the system’s two sectors. So insurance status did not decrease women’s awareness about variations in quality and access.

The women’s assessment presents a system that provides Puerto Rican women with access to available breast cancer services. The women’s picture of the Island’s healthcare system is supported by increased insurance status of the study’s and Island’s population (Portela, Sommers 2015). Yet, the other half of the women’s narratives that negatively evaluate the system suggest that the Island’s promise of equal access also varies based on type of insurance, ultimately decreasing the quality of breast cancer care that women receive. This finding challenges the initial supporters of the Island 1993 market-based healthcare reform, La Reforma, who promised that this new approach to healthcare would increase access to private care while decreasing discrimination against the Island’s poor (Rigau-Perez 2000; Alegria et al. 2001).
Stigmatization of federally funded beneficiaries has also been identified on the U.S. mainland (Han, Call et al. 2015). Xinxin Han and colleagues found that uninsured and publicly insured adults in Minnesota, post ACA, were more likely to reported insurance-based discrimination than privately insured adults. The perception of the poor has been linked to the relabeling of service recipients (the poor) as consumers in need of intervention or strict monitoring procedures (Boehm 2005; Lopez 2005; Nelson 2005; Maskovsky 2000; Alegría et al. 2001; Mulligan 2007; 2010; Briggs 2002). Briggs (2002) asserts that the labeling and relabeling of the “poor” in the U.S. and Puerto Rico has been guided by ideologies of race and gender. In her work in Puerto Rico, she demonstrates that healthcare incentives, funded by the U.S. and local government, have regarded Puerto Rican women as welfare mothers who perpetuate poverty (Briggs 2002). This belief has been used to support the application of market-based incentives (i.e., referrals and capitation) that provide patriarchal guidance for women so that they may avoid their aid dependency nature and become independent consumers (Briggs 2002; Nelson 2005).

Unlike the women, physicians’ assessment of the system was predominantly negative. They expressed concerns that the system’s structure creates barriers and conflicts with their professional responsibilities to provide care. These care-providers particularly stressed how referrals requirement and capitation restriction creates delays in breast cancer prevention and treatment for publicly insured women. Some physicians give the example of a woman who has already had her scheduled mammogram, who then finds a lump and needs
another exam, but is then denied this services because her primary care physician is concerned that that the procedure may exceed his capitation amount. The concerns expressed in the providers’ narratives about delays in breast cancer services support existing research that links timely screening and treatment with increased survival and emphasizes the importance of early screening (National Cancer Institute 2015). The providers’ accounts, similar to the women’s, acknowledge that access has improved on the Island since 1993, but variations in quality of care still remain between women based on insurance type.

Physicians also note sentiments of being undervalued and undercompensated. The providers’ stories illustrate how the Island’s history with the U.S. has created an environment in which they receive the same training as mainland providers and have access to the same technologies, but the low federal compensation received creates feelings of under-appreciation. Many of the physicians’ narratives express immense frustration and a call for legislative changes. Medicaid research on the U.S. mainland and on the Island has noted that increased emphasis in quality measurements (e.g., referrals and capitation) creates conflicts among providers about what is “good and right” in healthcare. Increased administrative responsibilities have been shown to impinge on the quality of clinical interactions (Nelson 2005; Willging 2005; Waitzkin 2003; Horton et al. 2014). While policy makers outline the structure of reform, its adaptation on the ground level varies (Nelson 2005). Mulligan’s (2007) supports the chapter’s findings about discordance between physician’s professional responsibility and the healthcare system requirements and its subsequent influence on their ability to
provide quality care. Her work in Puerto Rico demonstrates how gaps in La 
Reforma policies and on-the-ground practices create conflicts when providers have
to choose between healthcare the profession and healthcare the business.
Table 4-1. Women General Characteristics N=59

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<td>50-59</td>
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Table 4-2. Women Health Characteristics N=59

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<td>Mammogram in Past 2 Years</td>
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<td>Breast Self-Exam Status</td>
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<td>Characteristics</td>
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<td>Family Medicine</td>
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<td>Plastic Surgery</td>
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<tr>
<td>&lt; 5 years</td>
<td>10</td>
</tr>
<tr>
<td>6-10 years</td>
<td>5</td>
</tr>
<tr>
<td>11-15 years</td>
<td>20</td>
</tr>
<tr>
<td>16-20</td>
<td>5</td>
</tr>
<tr>
<td>21-25 years</td>
<td>20</td>
</tr>
<tr>
<td>26-30 years</td>
<td>10</td>
</tr>
<tr>
<td>&gt; 31</td>
<td>30</td>
</tr>
<tr>
<td>Place of Medical Training</td>
<td></td>
</tr>
<tr>
<td>Off of the Island</td>
<td>50</td>
</tr>
<tr>
<td>Professional Status*</td>
<td></td>
</tr>
<tr>
<td>Employed by hospital, group or other entity</td>
<td>10</td>
</tr>
<tr>
<td>Practice owner/ partner/ associate</td>
<td>100</td>
</tr>
<tr>
<td>Practice Size*</td>
<td></td>
</tr>
<tr>
<td>Solo</td>
<td>60</td>
</tr>
<tr>
<td>2-5 physicians</td>
<td>40</td>
</tr>
<tr>
<td>100+ physicians</td>
<td>7</td>
</tr>
<tr>
<td>Cancer Diagnosis</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>80</td>
</tr>
<tr>
<td>Family History of Breast Cancer</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>60</td>
</tr>
</tbody>
</table>

*Percentages do not equal 100 because respondents may have listed more than one item.
Figure 4-1. Organizational Chart of Puerto Rico’s Healthcare System
### Table 4-4 Women and Physician Experiences with Healthcare Access Within Puerto Rico’s Healthcare N=79

<table>
<thead>
<tr>
<th>Theme</th>
<th>Privately Insured</th>
<th>Women (N=59)</th>
<th>Medicare Insured</th>
<th>Physicians (N=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(N= 35)</td>
<td>N= 10</td>
<td>N=13</td>
<td>N=20</td>
</tr>
<tr>
<td>Access</td>
<td>Absolutely, the treatment that they give. For example there are doctors who refuse to take Reforma. So they just do not see those patients. Or if yes, they assign certain days of the week to Reforma patients. So, the Reforma patients do not mix with the actual patients. You know what I'm saying? Or in the assigning of times for visits, you know, if you have Reforma you can wait three to four months to get an appointment.</td>
<td>Good luck because it depends on how good your doctor is to have the opportunity to cure you fast. Good luck. Okay, the other is that you are going to wait many hours, so my advice is that you take a book to wait in the doctor's office.</td>
<td>Oh an example here. Your health plan? The say to me &quot;Oh here we don’t accept that&quot; ... or go to another &quot;here we don’t accept that&quot; &quot;here we don’t accept that.&quot; Most doctors do not accept...the government plan. They don't take it. That's what I say or I know people that &quot;this hurts&quot;, &quot;I have a problem with arthritis&quot;, so you go to the doctor, then when you call the doctor, &quot;Look, they don’t accept Reforma.&quot; It is Reforma... well they say Mi Salud but it is Reforma... they don't accept it. I'm like how?... but that's it.</td>
<td>Well, it depends on what kind of insurance you have. If you have a private insurance it’s usually easier to get a referral for either a surgeon or someone to get any kind of biopsy. But if you are in Medicaid, it’s awful. It’s terrible because you have to go to the primary physician to get a referral for a surgeon who then need another referral, you need like a thousand referrals in order for the patient to get some kind of treatment. Even [to] get a mammogram it’s like a hundred referrals. So there’s a lot of delay in treatment and not a lot of physicians take Medicaid, which also limits the patients’ access to treatment.</td>
</tr>
</tbody>
</table>
Table 4-5 Women and Physician Experiences with Healthcare Quality Within Puerto Rico’s Healthcare N=79

<table>
<thead>
<tr>
<th>Theme</th>
<th>Women (N=59)</th>
<th>Physicians (N=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Privately</td>
<td>Publicly</td>
</tr>
<tr>
<td></td>
<td>Insured</td>
<td>Insured</td>
</tr>
<tr>
<td></td>
<td>N= 35</td>
<td>N=10</td>
</tr>
</tbody>
</table>

Quality

...[those] who have suffered from breast cancer they have been treated by the government plan. And I can say that I do think it's very good system because it is inclusive, they paid not only treatment ... from chemotherapies, surgeries if needed, to breast reconstruction of the patient if they wish, even breast reconstruction for patients who do not want to feel mutilation. So if I'm going to talk about the government, well you have to make a smiley face because there are people who I have contact with who have received very good- very good service, really.

La Reforma is a program for those who qualify. I have no bad experience because they have never denied me a service... For me it is excellent. I was cancer patient and they have never refused any referral or my treatments

Not very good health system here. For here, as you can see, you don't know if you have seen. Here the insurance plans. If you have Reform, the government plan, Mi Salud. They don't provide good care. It is not that they don't provide good service, but they not provide the best quality healthcare to patients. I've seen it, I've heard. Health benefits, of their patients is one of the things that worries me.

This [public insurance] constrains, this side is public. This side [is] private. What happens is that they give you ten thousand dollar, the insurance, and from that ten thousand dollars they keep the payment of the doctor and the payment for the patient. If you refer too many patients you will receive less money. The more you work, less you get paid, less you receive in the public. From this side [private], more you work, more you earned.
Table 4-6 Women and Physician Experiences with Healthcare Cost Within Puerto Rico’s Healthcare N=79

<table>
<thead>
<tr>
<th>Theme</th>
<th>Privately Insured</th>
<th>Women (N=59)</th>
<th>Publicly Insured</th>
<th>Medicare Insured</th>
<th>Physicians (N=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost</td>
<td>It is that you are paying, for example, I had a medical plan that I had to pay almost two hundred to three hundred dollars a month. If I had to go to a doctor well the deductible was fifty dollars. I mean no, excuse me, 150 to 200 dollars. So, if the visit was three hundred dollars I had to pay the remainder. That is two hundred and something dollars. Do you understand what I mean? So, I do not think that public… works, supposedly that works for the people who cannot pay, it do not work for them. Then, sadly, the people who work for a medical plan it still cannot cover them. My father is a cancer patient, five times. And there was a drug that every pill that he had to take cost two hundred and fifty dollars. He had Triple-S. Triple-S is supposedly a good health plan, and he paid monthly, Then they did not pay for his medication, a cancer patient who pays.</td>
<td>You know? I know that the drugs are expensive and you know, a patient’s needs are not all the same</td>
<td>In my experience it has been satisfactory because all tests, exams that they have sent me to do, they covered all without any problems. Sometimes I have to pay a deductible but thank God that I do not have to pay for the complete examination. For me, [my health insurance] works well.</td>
<td>What happens is that in Puerto Rico, the premiums are much lower than in the United States. Although Puerto Rico is a US territory, because we are a Commonwealth, we are not a state, premiums for us are very little, and now it's down more. So what earnings can I have make if they paid me 60 dollars, now they pay me thirty. And here the doctors are very upset with the system.</td>
<td></td>
</tr>
</tbody>
</table>
### Table 4-7 Women and Physician Assessment of Puerto Rico’s Healthcare System

**N=79**

<table>
<thead>
<tr>
<th>Level of Satisfaction</th>
<th>Women Quotes</th>
<th>Physicians Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Positive</strong> (51% of women participants)</td>
<td>“...[those] who have suffered from breast cancer they have been treated by the government plan. And I can say that I do think it's a very good system because it is inclusive, they paid not only treatment ... from chemotherapies, surgeries if needed, to breast reconstruction of the patient if they wish. If they don’t want to stay with the mutilation. So if I'm going to talk about the government, well you have to make a smiley face because there is people who I have contact with who had very good service, really.”</td>
<td>“All the plans are good and they are all the same.”</td>
</tr>
<tr>
<td>Neutral (12% of women participant)</td>
<td>“Our health system is structured; one public and [one] private in which health providers receive their patients under private or government plans. Both groups have access to the service by going from a primary physician, specialist and subspecialist, according to the discretion of each physician’s requirement.”</td>
<td>“Ok, that would be talking about the patient. So she goes to the doctor, she goes to the labs but then, when you get to the doctor, you need... it depends on the coverage, referral for laboratory studies...first you do the laboratory then it is consultation, if not then you look for a specialist to consult then you have to find one, [then] search for plan approval. If they give it then you return for treatment. Yes, treatment and if not ...this [return to primary care] again. Again check the insurance. If it is in advanced stage [and treatment is approved] then it will be catastrophic coverage.”</td>
</tr>
<tr>
<td><strong>Negative</strong> (44% of women participants)</td>
<td>“I understand that this area of health plans are sometimes so focused on the economic side. You lose what sometimes one patient would want, because maybe this month I felt nothing and I did a mammogram nothing came out. Then next month I felt something and I want to do it again, then I cannot because I have to financially take responsibility for the payment or really, I have to have the resources so that I can repeat it.”</td>
<td>“Basically that's [Refroma]. It becomes a way to get some people rich. I disagree with that system obviously. I disagree with that system ... So what happens for patients to get a referral from this primary care physician? They do not give it. It is very difficult because these primary care physicians receive money for a group of patients. And the less they refer cases or the more studies that they do or send patients to, that money goes to them. When Reforma came, many of these primary physicians became millionaires, it gave them a large amount of money.”</td>
</tr>
</tbody>
</table>

*Percentages do not equal 100 because percentages refer to the total sample of women or physicians.*
Figure 4-2. Selected Women Photographic Narratives
Figure 4-3. Selected Physicians Photographic Narratives
CHAPTER 5
WOMEN’S AND PHYSICIANS’ CULTURAL KNOWLEDGE OF BREAST CANCER IN MAYAGUEZ, PUERTO RICO

This chapter aims to explore the variation in care seekers (women) and care providers (physicians) breast cancer knowledge. It responds to the call for research that explores the multiple facets of cancer experience by using free list analysis, an approach that uses individuals’ accounts to examine their knowledge. This is a novel approach because it avoids the trap of using an a priori definition of cancer while simultaneously showcasing an individual-based perspective and multi-voiced (care seekers and providers) account of breast cancer knowledge.

Results

Sample Characteristics

The majority of the women were between the ages of 40 and 59 (Table 5-1). Thirty-seven percent received a grade school education, 43 percent held a college degree, and twenty percent held graduate degrees. Forty-five percent of the women’s annual family income was under $16,000, 34 percent was between $16,000 and $49,999, and 20 percent was $50,000 or greater (Table 5-1). Ninety-seven percent of the women had medical coverage at the time of the study (Table 5-2). The majority (73 percent) of the women visited a physician in the past 30 days. Ninety-seven percent of the women reported ever having a mammogram and doing breast self-exams. However, only 80 percent had a mammogram in the past two years.

Most of the women were never diagnosed with breast cancer and did not have a family history of breast cancer. However, 70 percent reported having a friend, neighbor, or coworker who was diagnosed with breast cancer. When asked about genetic testing, the majority of the women reported hearing about genetic testing for
cancer but had never had a breast cancer genetic exam (Table 5-2). Women participants were also asked to identify the sources or persons that provide them with breast cancer and mammography information. Ninety-three percent reported that they received breast cancer information from their doctors compared to 97 percent for mammography information. Television and reading materials were the second and third most noted source for breast cancer and mammography information (Table 5-3).

Of the 15 physicians, the majority were males between the ages of 40 and 64 (Table 5-4). The physicians’ specializations included general medicine, internal medicine, gynecology and obstetrics, general surgery, oncology, and family medicine. The physicians’ years of specialization ranged from less than five years to more than 31 years. However, the majority of physicians practiced their specialization for more than twenty-one years. The majority of the physicians were internal medicine physicians and gynecologists and obstetricians who were trained off the Island. All of the physicians owned private practices. The majority of the private practices consisted of one to five physicians. The majority of the physicians were never diagnosed with cancer and did not have a family history with breast cancer.

**Breast Cancer Knowledge**

**Lists frequency distribution**

Overall, the aggregate women group listed more items (28 to 41 items) than the physicians (28 to 35) for the four subdomains. However, physicians agreed (percent of respondents who listed an item) more about their listed items than women (Figures 5-1, 5-3, 5-5, and 5-7). The aggregate women group was also divided by insurance type (private, public, and Medicare) to explore the relationship between variation in women’s health insurance and their cultural knowledge. Privately insured
women (31 to 19) listed more items than the publicly (28 to 17) and Medicare (14 to 12) insured women (Figures 5-2, 5-4, 5-6, and 5-8). The privately and publicly insured women shared similar agreement levels about their listed items. The Medicare group’s appeared to have higher level of agreement about listed items when compared to the other two groups but this can be attributed to the group’s small sample size (n=4).

**Preventive Measures.** Women listed 41 unique items for their preventive measures breast cancer domain (Figure 5-1). Their lists ranged from one to seven items (median= 2.75 and s.d. = 1.67). Physicians listed less unique preventive measure items than the aggregate women group (35). Their list ranged between two and nine items (median=5.25 and s.d. = 2.06). Privately insured women listed 31 unique items for their preventive measures breast cancer domain (Figure 5-2). Their lists ranged between two and seven (median= 4 and s.d. = 1.3). Publicly and Medicare insured women listed less unique preventive measures items than the privately insured women, respectively 15 and 12. Publicly insured women’s lists ranged between one and six (median= 2 and s.d. = 1.8). Medicare insured women’s lists ranged between one and eight (median= 3.6 and s.d. = 2.5).

**Symptoms.** Women listed 36 unique items for their symptom breast cancer domain (Figure 5-3). Their lists ranged from one to eight items (median= 3 and s.d. = 1.64). Physicians listed less unique symptom items than the aggregate women group (28) and their list ranged between two and eight items (median=6 and s.d. = 2.38). Privately insured women listed 24 unique items for their symptoms breast cancer domain (Figure 5-4). Their lists ranged between one and five (median= 3 and s.d. =
1.37). Publicly and Medicare insured women listed less unique symptoms items than the privately insured women, respectively 19 and 14. Publicly insured women’s lists ranged between one and seven (median= 3 and s.d.= 1.79). Medicare insured women’s lists ranged between three and eight (median= 3 and s.d.= 2.5).

**Risks.** Women listed 43 unique items for their risk breast cancer domain (Figure 5-5). Their lists ranged from one to eight items (median= 2 and s.d.= 1.78). Once again, physicians listed less unique risk items than the aggregate women group (35). Their list ranged between two and seven items (median=5 and s.d.= 1.53). Privately and publicly insured women listed 23 unique items for their risks breast cancer domain (Figure 5-6). Their lists ranged between one and five (median= 2 and s.d.= 1.4) and one and eight (median= 2 and s.d.= 2.2), respectively. Medicare insured women listed less unique risks items (13) than the other two groups. Medicare insured women’s lists ranged between two and eight (median= 4 and s.d.= 2.2).

**Treatments.** Finally, women listed 28 unique items for their treatment breast cancer domain (Figure 5-7). Their lists ranged from one to eight items (median= 3.66 and s.d.= 1.47). Physicians listed less unique treatment items (28) and their list ranged between four and eight items (median=5.66 and s.d.= 1.45). Privately insured women listed women 19 unique items for their treatment breast cancer domain (Figure 5-8). Their lists ranged between one and five (median= 3 and s.d.= 1.2). Publicly and Medicare insured women listed less unique treatment items than the privately insured women, respectively 17 and 13. Publicly insured women’s lists
ranged between two and six (median = 3.7 and s.d. = 1.3). Medicare insured women’s lists ranged between two and eight (median = 4 and s.d. = 2.6).

**Elements of breast cancer knowledge**

This discussion only focuses on the salient (most frequently listed) items for the four domains, identified by a salience cut off of 10 or 20 percent. This percentage takes into consideration women’s and physicians’ average salient cut off number and permits comparison between the groups’ lists. Therefore, items that were mentioned less than 10 percent (women and physicians) and 20 percent (women’s insurance-based groups) of the time are not included in tables 5-5, 5-6, 5-7, 5-8, 5-9, 5-10, 5-11, and 5-12. Again, women were divided by insurance type to explore the relationship between variation in health insurance and cultural knowledge.

**Preventive Measures.** The physicians’ (nine items) shared more salient preventive measures items than the women (six items) (Figure 5-1). The physicians’ top three items were listed more frequently (73 percent, 67 percent, and 40 percent) than the women’s (50 percent, 33 percent, and 30 percent) (Table 5-5). MDS of the women’s and physicians’ preventive measures lists show patterns of tighter clustering among the physicians. There were no clear patterns of clustering among the aggregate women group (Figures 5-9).

The privately insured women’s (seven items) shared more salient preventive measures items than the publicly (four items) and Medicare (two items) insured women (Figure 5-2). The Medicare insured women’s top item was listed more
frequently (75 percent) than the publicly (60 percent) and privately (53 percent)
insured women. The Medicare insured women’s group high level of agreement can
be attributed to the group’s small sample size. However, it should be noted that the
three group’s level of agreement for the top preventive measure items was above 50
percent. Unlike the Medicare group, the publicly and privately insured group shared a
common most salient preventive measures item. The Medicare and publicly insured
women’s second most listed item was mentioned by half of the respondents. Only 47
percent of the women from the privately insured women listed the group’s second
most listed item (Table 5-6). Similar to the aggregate women’s group, the three
insurance-based groups’ preventive measures MDS shows no clear patterns of
clustering (Figures 5-8).

**Symptoms.** The physicians (nine items) shared more salient items than the
women (six items) (Figure 5-3). The groups shared two salient symptom items in their
top three most listed items. The physicians’ top three items were listed more
frequently (seventy-three percent, sixty percent, and fifty-three percent) than the
women’s (thirty percent, twenty-seven percent, and twenty-seven percent) (Table 5-7).
The participants’ symptoms MDS illustrates tighter clustering among the
physicians. There were no clear patterns of clustering among the aggregate women
group (Figures 5-11).

The publicly insured women’s (eight items) shared more salient symptoms
items than the privately (seven items) and Medicare (two items) insured women
(Figure 5-4). The Medicare insured women’s top items were listed more frequently
(75 percent and 50 percent) than the publicly (40 percent and 30 percent) and privately (33 percent (two items) and 27%) insured women (Table 5-7). Similar to the aggregate women’s group, the three insurance-based groups’ symptoms MDS shows no clear patterns of clustering (Figures 5-10).

**Risks.** The physicians (eleven items) shared more salient risk items than the women (seven items) (Figure 5-5). The women’s most listed risk item was listed by a slightly higher percent of women (forty-seven percent) than the physicians’ (thirty-three percent). Overall, the women and physicians demonstrated similar agreement about their listed risk items (Table 5-9). The women’s and physicians’ risks MDS shows clustering among the physicians on the upper half of the image. There were no clear patterns of clustering among the aggregate women group Figure 5-13).

The privately, publicly, and Medicare insured women’s shared the same amount (three items) of salient risks items (Figure 5-6). The privately insured women’s top item was listed more frequently (67 percent) than the Medicare (50 percent) and publicly (20 percent) insured women (Table 5-10). There were no distinct clusters in the three insurance-based group’s risks MDS. However, one cluster made up of all three groups was shown on the left lower side of the women’s insurance-based risks MDS (Figures 5-12).

**Treatments.** The physicians (nine items) shared more salient treatment items than the women (five items) (Figure 5-7). Unlike the other three lists, physicians and women shared a common item for their first and second most salient breast cancer treatments. The physicians’ top three items were listed more frequently (one hundred percent, ninety-three percent, and fifty-three percent) than the women’s (eighty three percent, ninety-three percent, and fifty-three percent)
percent, sixty-three percent, and thirty-three percent) (Table 5-11). Similar to the previous multidimensional scales, there was a clear pattern of clustering among the physicians. However, there were no clear patterns of clustering among the aggregate women group (Figure 5-15).

The publicly insured women’s (six items) shared more salient treatments items than the privately (four items) and Medicare (four items) insured women (Figure 5-8). Unlike the other three lists, the three groups shared a common item for their first and second most salient breast cancer treatments. The privately insured women’s top two items were listed more frequently (87 percent and 73 percent) than the publicly (80 percent and 60 percent) and privately (75 percent and 50 percent) insured women (Table 5-12). Similar to the aggregate women’s group, the three insurance-based groups’ treatments MDS shows no clear patterns of clustering (Figures 5-16).

**Discussion**

The physicians’ and women’s breast cancer preventive measures, symptoms, and treatments lists share more than three common items, demonstrating similarities in their cultural knowledge about these breast cancer subdomains. However, they did not agree about all of the breast cancer subdomains. They share only one salient item between their breast cancer risk lists. Additionally, the MDS of the breast cancer subdomains show clearer clustering among the physicians when compared to the women.

The women insurance-based groups’ breast cancer preventive measures, symptoms, and treatments lists share at least one common item between two of the three groups, demonstrating limited similarities in their cultural knowledge about
these breast cancer subdomains. The Medicare group’s sample size (n=4) increases the groups’ level of agreement. So while the Medicare group appears to have higher levels of agreement about the four subdomains, this is due to the group’s small sample size. The groups’ lists demonstrate average or below average agreement about the items in their preventive measures, symptoms, and risks subdomains. Treatment is the only subdomain where all three groups demonstrate high levels of agreement. The groups’ limited level of agreement about the four subdomains is supported by their MDS, which shows no clear clusters based on insurance type.

Women’s Main Source of Breast Cancer Information

The women’s and physicians’ lists both identified mammograms and breast self-exams as important preventive measures. This pattern is also seen in the publicly and privately insured women’s lists. This shared support can be linked to women’s main sources of breast cancer and mammogram information. When asked where they received breast cancer and mammogram information, women identified their doctors and the media most often (Table 5-3). The groups’ risk lists also support the women’s reliance on the media for their breast cancer information. The women’s identification of “heredity” as the most salient breast cancer risk can be tied to the media, one of their main sources of breast cancer information, and the increased information in the media about genetic testing for breast cancer. This assertion is supported by the sixty-seven percent of women who reported hearing about genetic testing, and the thirty percent of the women who reported Angelina Jolie’s breast cancer experience as a source of their genetic testing knowledge (Table 5-3).
Shared Value of Mammography and Self-Initiated Breast Exams

The groups shared value of mammograms and self-initiated breast exploration is supported by current breast cancer prevention recommendations (U.S. Preventive Services Task Force 2009). It was also identified in preliminary research among clinicians and patients in Merida, Mexico (Carrington, Gravlee, 2015). The respondents’ preventive measures knowledge may also be influenced by the different contexts in which they learn and share knowledge about breast cancer preventive measures. The physicians’ support of recommended breast cancer preventive behaviors could be associated with their training and occupation, their occupational context. The women’s support for such behaviors can be connected to their dependence on physicians for breast cancer information and services, a care seeking or clinical context. For example, when asked about self-breast exams, a patient explained that she does not practice self-breast examinations. She continued to explain that she preferred to come to the doctor and have him perform the manual examination and provide the referral for her annual mammogram. When asked why, she responded that she just doesn’t like to do the exam herself.

Differences in Locus of Control for Breast Cancer Prevention

While the care seeker and provider relationship between the two groups result in agreement about the importance of recommended breast cancer preventive measures, their preventive measures free lists also suggest that women and physicians locate preventive behavior in two different spaces. The women’s second most salient item, “be careful with the food you eat,” suggests that this group may locate women’s ability to prevent cancer within an individual’s locus of control.
This may differ for the physicians, whose third salient item, “go to the doctor,” implies that the heart of breast cancer prevention is embedded in the care seeker and provider relationship in a clinical setting. Yet, one can also argue that the physicians’ salient item requires women to initiate the care seeker and provider interaction by making the decision to go to the doctor, once again locating breast cancer prevention within women’s locus of control. This assertion was supported by a senior internal medicine physicians’ explanation of how prevention works in Puerto Rico. Sitting across from me at his kitchen table he explains that it is important to understand that even if free or affordable insurance is provided and preventive resources are available, what really matters is that women take responsibility to use those resources by first seeking care.

Scholars have critiqued this approach to cancer prevention because it can result in blaming cancer patients for their diagnosis (Pasick, Burke 2008; Perusek 2012; Saillant 1990; Drew, Schoenberg 2011). These critics assert that a focus on the individual disregards other factors (e.g., social structural factors) that may contribute to individual cancer risks and supports victim blaming (Perusek 2012; Saillant 1990).

**Physiological Cause of Breast Cancer**

Even though the women (aggregate and insurance-based group) had overall low level of agreement about their salient risks items, the aggregate and privately insured group most salient item, “heredity,” and two of the physicians’ top three salient items, “maternal history of cancer” and “genetics,” share a common theme about the genetic characteristic of breast cancer risk. Therefore, it can be inferred that both groups locate breast cancer’s origin in women’s physiological composition.
Furthermore, this perception of breast cancer risk is in alignment with breast cancer
research and the discovery of the BRAC1 and BRAC2 genes that identify family
history and genetics as factors that increase women’s susceptibility to cancer (Press
et al. 1997; Vadaparampil 2010; August et al. 2011).

Food and the Environment Matter

Similar to preliminary findings in Merida, Mexico women participants identified
food as an important factor in breast cancer risk. Like the women in Merida, the
aggregate, public, and Medicare women groups in Mayaguez noted concerns about
the processed aspect of food. The two groups’ concern with food and the chemicals
found in them can be attributed to changes in lifestyle and diet in Mexico and Puerto
Rico (Chavarri-Guerra et al. 2012; Samuels et al. 2012; Huerta et al. 2007). The
women’s connection of breast cancer risk with changes in the environment can be
regarded as what Martha Balshem (1991) refers to as implicit forms of resistance to
the power and authority of biomedicine and forces outside of their community. Critics
such as Sarah Jain (2007) have also noted the interaction between cancer risk and
environmental changes by discussing the relationship between environmental
pollutants and capitalism, or market-based ideologies. Jain argues that corporations
(e.g., BMW) use cancer campaigns as business ventures to increase revenue for
products that create carcinogens in the environment (2007b).

Alone, Cultural Knowledge ≠ Behavior

At first glance, the free listed items “a mass” (a late-stage breast cancer
symptom and the most salient item for physicians and the women’s aggregate and
public group) and “pain” (the first, second, and third most salient item on the
Medicare group’s, the aggregate women group’s, and physicians’ lists) suggest that
the groups regard late-stage breast cancer symptoms as very important. This knowledge about breast cancer may lead one to predict delays in breast cancer screening among women and referrals among physicians in Mayaguez. However, when women participants’ high percentage of well-woman visits and mammogram status are considered, this argument loses its luster. This suggests that other factors should be considered when exploring forces that facilitate or hinder women’s preventive breast cancer behavior. While late-stage breast cancer symptoms are important to the groups’ cultural knowledge of breast cancer, the availability of structural factors such as health insurance enable women in Mayaguez to adhere to recommended breast cancer screening behaviors.

It should also be noted that not all structural factors facilitate women’s access to preventive care. One community woman’s account of seeking care identifies factors such employment type and wait time that restricts her ability to access preventive care. She notes that her ability to get her recommended screenings is based on her ability to first get a day off work. Since the wait time, even with an appointment, is long at her doctor’s office she is unable to take a break from work, attend her appointment, and then return to work.

**Insurance and Cultural Knowledge**

The privately insured women identified more items of the four subdomains, all three groups demonstrated average or below average agreement about the items in their lists (Tables 5-6, 5-8, 5-10, 5-12 and Figures 5-8, 5-10, 5-12, and 5-16). The Medicare group’s high level of agreement is an artifact of the group’s small sample size. The insurance-based groups’ limited consensus does not support an association between women’s insurance type and their cultural knowledge of breast cancer.
cancer. This assertion is further supported by the groups’ MDS, which did not identify any distinct clusters based on insurance type.

The robustness of the previous claim is weakened by its sole reliance on insurance type, one of many factors used to operationalize social context (Duncan et al. 2002; Zambrana et al. 1999; Monnat 2014). The lack of support for the relationship between insurance type and cultural knowledge does not dispute the existence of a relationship between cultural knowledge (culture) and an individual’s context. This finding should serve as an example of the complex relationship between culture, social context, and health (Farmer 2001; Kingfisher, Masovosky 2008; Dressler 2004; Mulligan 2007, 2010). A better understanding of the relationship between culture and social context in cancer research requires the inclusion of multiple measures of social context. A sole variable such as insurance type is not sufficient.

**Same Words, Different Meaning**

Unlike the other three lists, physicians, the aggregate women group, and the three insurance-based groups shared a common item for their first (chemo) and second-most (radio) salient breast cancer treatments. This salience pattern was also identified during the preliminary research in Mexico (Carrington, Gravlee 2015). Interestingly, the aggregate women group and the physician third most salient items, “remove the breast” and “surgery,” suggest that while they share common knowledge about breast cancer treatments, they use different words to express their meaning. The physicians’ more clinical terminology, “surgery,” suggests a professional lens in which a surgical procedure is very important in their treatment subdomain of breast cancer. On the other hand, the women’s terminology, “remove the breast,” suggests
a personal lens that identifies the specific body part and objective of the surgical procedure. This variation in how the groups construct meaning about breast cancer treatment may affect the quality of treatment selection counseling (Dein 2004).

**Physicians Demonstrate More Agreement**

The women identified more items for each of the four subdomains, but physicians agreed more about the items on their shorter lists. So based on the culture consensus theory assumption that increased agreement equals increased knowledge, it can be inferred that physicians are more knowledgeable about the subdomains when compared to the women. The physicians had higher levels of consensus among three of the four subdomains (Tables 5-5, 5-7, 5-9 and Figures 5-9, 5-11, 5-13, and 5-15). This higher level of agreement suggests that the physicians have a higher level of shared cultural knowledge about breast cancer. This pattern is further supported by the group’s MDS, in which the physicians showed clearer clusters than the women. The physicians’ increased consensus about breast cancer can be tied to their shared access to medical training and information. While Juliet McMullin and colleagues (1994) have identified variation in physicians’ cultural knowledge (Gordon, Paci 1997; Lauver et al. 2003), Mary-Jo Del Vecchio Good (1998) and others have demonstrated how medical pedagogy creates collective knowledge among providers (Good et al. 1990; Lock, Nichter 2004). Therefore, the physicians’ high level of agreement among the most frequently listed items and tight clustering patterns support the existence of a collective breast cancer cultural knowledge within the group. Chavez and colleagues’ (2005) and Carrington and
Gravlee’s (2015) work on breast cancer among Spanish speaking population also support this high level of agreement among physicians when compared to lay women.
Table 5-1. Women General Characteristics N=30

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td></td>
</tr>
<tr>
<td>39-49</td>
<td>27</td>
</tr>
<tr>
<td>50-59</td>
<td>33</td>
</tr>
<tr>
<td>60-69</td>
<td>40</td>
</tr>
<tr>
<td>70-75</td>
<td>0</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Primary school</td>
<td>7</td>
</tr>
<tr>
<td>High school</td>
<td>30</td>
</tr>
<tr>
<td>Associates</td>
<td>23</td>
</tr>
<tr>
<td>Bachelors</td>
<td>20</td>
</tr>
<tr>
<td>Masters</td>
<td>17</td>
</tr>
<tr>
<td>Doctorate</td>
<td>3</td>
</tr>
<tr>
<td>Annual Household Income (US Dollar)</td>
<td></td>
</tr>
<tr>
<td>Don't know</td>
<td>1</td>
</tr>
<tr>
<td>Less than $5,000</td>
<td>13</td>
</tr>
<tr>
<td>$5,000 - $15,999</td>
<td>30</td>
</tr>
<tr>
<td>$16,000 - $24,999</td>
<td>17</td>
</tr>
<tr>
<td>$25,000 - $49,999</td>
<td>17</td>
</tr>
<tr>
<td>$50,000 and greater</td>
<td>20</td>
</tr>
</tbody>
</table>
Table 5-2. Women Health Characteristics N=30

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insurance Status</td>
<td></td>
</tr>
<tr>
<td>Insured</td>
<td>97</td>
</tr>
<tr>
<td>Medical Visit in the Past 30 Days</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>73</td>
</tr>
<tr>
<td>Ever Had Mammogram</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>97</td>
</tr>
<tr>
<td>Mammogram in Past 2 Years</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>80</td>
</tr>
<tr>
<td>Breast Self-Exam Status</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>97</td>
</tr>
<tr>
<td>Breast Cancer Diagnosis</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>80</td>
</tr>
<tr>
<td>Family History of Breast Cancer</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>60</td>
</tr>
<tr>
<td>Non-Family Experience w/ Breast Cancer Patients</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>70</td>
</tr>
<tr>
<td>Knowledge of Genetic Testing</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>63</td>
</tr>
<tr>
<td>Genetic Testing Status</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>97</td>
</tr>
</tbody>
</table>

Table 5-3. Women Breast Cancer and Mammography Information N=30

<table>
<thead>
<tr>
<th>Breast Cancer Sources*</th>
<th>%</th>
<th>Mammography Sources*</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor</td>
<td>93</td>
<td>Doctor</td>
<td>97</td>
</tr>
<tr>
<td>Television</td>
<td>93</td>
<td>Television</td>
<td>90</td>
</tr>
<tr>
<td>Reading materials (newspapers, magazines, books)</td>
<td>80</td>
<td>Reading materials (newspapers, magazines, books)</td>
<td>77</td>
</tr>
<tr>
<td>Radio</td>
<td>73</td>
<td>Family members</td>
<td>73</td>
</tr>
<tr>
<td>Informative materials in doctors offices or health center</td>
<td>73</td>
<td>Informative materials in doctors offices or health center</td>
<td>73</td>
</tr>
<tr>
<td>Family members</td>
<td>70</td>
<td>Friends or neighbors</td>
<td>63</td>
</tr>
<tr>
<td>Other</td>
<td>60</td>
<td>Radio</td>
<td>60</td>
</tr>
<tr>
<td>Friends or neighbors</td>
<td>53</td>
<td>Nurse</td>
<td>37</td>
</tr>
<tr>
<td>Nurse</td>
<td>37</td>
<td>Health professional</td>
<td>26</td>
</tr>
<tr>
<td>Health professional</td>
<td>23</td>
<td>Other</td>
<td>23</td>
</tr>
</tbody>
</table>

*Percentages do not equal 100 because respondents may have listed more than one item.
Table 5-4. Physicians Characteristics N=15

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
</tr>
<tr>
<td>&lt; 25</td>
<td>0</td>
</tr>
<tr>
<td>26-39</td>
<td>13</td>
</tr>
<tr>
<td>40-64</td>
<td>67</td>
</tr>
<tr>
<td>&gt; 65</td>
<td>20</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>27</td>
</tr>
<tr>
<td>Male</td>
<td>73</td>
</tr>
<tr>
<td><strong>Specialization</strong>*</td>
<td></td>
</tr>
<tr>
<td>General Medicine</td>
<td>7</td>
</tr>
<tr>
<td>Internal Medicine</td>
<td>33</td>
</tr>
<tr>
<td>Gynecology and Obstetrics</td>
<td>26</td>
</tr>
<tr>
<td>General Surgery</td>
<td>20</td>
</tr>
<tr>
<td>Oncology</td>
<td>7</td>
</tr>
<tr>
<td>Family Medicine</td>
<td>7</td>
</tr>
<tr>
<td><strong>Years of Specialization</strong></td>
<td></td>
</tr>
<tr>
<td>&lt; 5 years</td>
<td>13</td>
</tr>
<tr>
<td>6-10 years</td>
<td>7</td>
</tr>
<tr>
<td>11-15 years</td>
<td>20</td>
</tr>
<tr>
<td>16-20</td>
<td>0</td>
</tr>
<tr>
<td>21-25 years</td>
<td>13</td>
</tr>
<tr>
<td>26-30 years</td>
<td>7</td>
</tr>
<tr>
<td>&gt; 31 years</td>
<td>40</td>
</tr>
<tr>
<td><strong>Place of Medical Training</strong></td>
<td></td>
</tr>
<tr>
<td>Off of the Island</td>
<td>53</td>
</tr>
<tr>
<td><strong>Professional Status</strong>*</td>
<td></td>
</tr>
<tr>
<td>Employed by hospital, group or other entity</td>
<td>7</td>
</tr>
<tr>
<td>Practice owner/partner/associate</td>
<td>100</td>
</tr>
<tr>
<td><strong>Practice Size</strong>*</td>
<td></td>
</tr>
<tr>
<td>Solo</td>
<td>47</td>
</tr>
<tr>
<td>2-5 physicians</td>
<td>53</td>
</tr>
<tr>
<td>100+ physicians</td>
<td>7</td>
</tr>
<tr>
<td><strong>Cancer Diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>80</td>
</tr>
<tr>
<td><strong>Family History of Breast Cancer</strong></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>53</td>
</tr>
</tbody>
</table>

*Percentages do not equal 100 because respondents may have listed more than one item.
Figure 5-1. Scree plot of the frequency (% of respondents) of women and physician free listed preventive measures items
Figure 5-2. Scree plot of the frequency (% of respondents) of women (by insurance type) free listed preventive measures items
Figure 5-3. Scree plot of the frequency (% of respondents) of women and physician free listed symptoms items
Figure 5-4. Scree plot of the frequency (% of respondents) of women (by insurance type) free listed symptoms items
Figure 5-5. Scree plot of the frequency (% of respondents) of women and physician free listed risks items
Figure 5-6. Scree plot of the frequency (% of respondents) of women (by insurance type) free listed risks items
Figure 5-7. Scree plot of the frequency (% of respondents) of women and physician free listed treatments items
Figure 5-8. Scree plot of the frequency (% of respondents) of women (by insurance type) free listed treatments items
Table 5-5. Frequency (% of respondents) of most salient breast cancer preventive measures in free lists, by women and physicians

<table>
<thead>
<tr>
<th></th>
<th>Women (N=30)</th>
<th>%</th>
<th>Physicians (N=15)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Get a mammogram</td>
<td>50</td>
<td></td>
<td>Get a mammogram</td>
<td>73</td>
</tr>
<tr>
<td>Be very careful with the food you eat</td>
<td>33</td>
<td></td>
<td>Do breast self-exams</td>
<td>67</td>
</tr>
<tr>
<td>Do breast self-exams</td>
<td>30</td>
<td></td>
<td>Go to the doctor</td>
<td>40</td>
</tr>
<tr>
<td>Check yourself</td>
<td>30</td>
<td></td>
<td>Get a sonomammogram</td>
<td>33</td>
</tr>
<tr>
<td>Go to the doctor</td>
<td>30</td>
<td></td>
<td>There is nothing you can do to prevent it</td>
<td>27</td>
</tr>
<tr>
<td>Exercise</td>
<td>20</td>
<td></td>
<td>Maintain your weight</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Do not smoke</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Maintain a healthy diet</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Screening</td>
<td>20</td>
</tr>
</tbody>
</table>

*Percentages do not equal 100 because respondents may have listed more than one item.

Table 5-6. Frequency (% of respondents) of most salient breast cancer preventive measures in free lists, by women’s insurance type

<table>
<thead>
<tr>
<th></th>
<th>Private (N=15)</th>
<th>%</th>
<th>Public (N=10)</th>
<th>%</th>
<th>Medicare (N=4)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Get a mammogram</td>
<td>53</td>
<td></td>
<td>Get a mammogram</td>
<td>60</td>
<td>Go to the doctor</td>
<td>75</td>
</tr>
<tr>
<td>Do breast self-exams</td>
<td>47</td>
<td></td>
<td>Check yourself</td>
<td>50</td>
<td>Be very careful with the food you eat</td>
<td>50</td>
</tr>
<tr>
<td>Go to the doctor</td>
<td>33</td>
<td></td>
<td>Be very careful with the food you eat</td>
<td>40</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do not smoke</td>
<td>27</td>
<td></td>
<td>Exercise</td>
<td>20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Be very careful with the food you eat</td>
<td>27</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Check yourself</td>
<td>20</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exercise</td>
<td>20</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Percentages do not equal 100 because respondents may have listed more than one item.
Table 5-7. Frequency (% of respondents) of most salient breast cancer symptoms in free lists, by women and physicians

<table>
<thead>
<tr>
<th>症状</th>
<th>女性 (N=30)</th>
<th>%</th>
<th>医生 (N=15)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>一个肿块</td>
<td>30</td>
<td></td>
<td>73</td>
<td></td>
</tr>
<tr>
<td>无症状</td>
<td>27</td>
<td></td>
<td>60</td>
<td></td>
</tr>
<tr>
<td>疼痛</td>
<td>27</td>
<td></td>
<td>53</td>
<td></td>
</tr>
<tr>
<td>一个小球</td>
<td>20</td>
<td></td>
<td>47</td>
<td></td>
</tr>
<tr>
<td>乳头溢液</td>
<td>20</td>
<td></td>
<td>40</td>
<td></td>
</tr>
<tr>
<td>一个结节</td>
<td>20</td>
<td></td>
<td>27</td>
<td></td>
</tr>
<tr>
<td>橙色皮肤</td>
<td>20</td>
<td></td>
<td>27</td>
<td></td>
</tr>
<tr>
<td>乳头溢血</td>
<td>20</td>
<td></td>
<td>27</td>
<td></td>
</tr>
</tbody>
</table>

*百分比不等于100，因为受访者可能列出多个项目。

Table 5-8. Frequency (% of respondents) of most salient breast cancer symptoms in free lists, by women’s insurance type

<table>
<thead>
<tr>
<th>症状</th>
<th>私人 (N=15)</th>
<th>%</th>
<th>公共 (N=10)</th>
<th>%</th>
<th>医疗保险 (N=4)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>一个肿块</td>
<td>33</td>
<td>40</td>
<td>30</td>
<td></td>
<td>20</td>
<td></td>
</tr>
<tr>
<td>一个结节</td>
<td>33</td>
<td>30</td>
<td>27</td>
<td></td>
<td>20</td>
<td></td>
</tr>
<tr>
<td>一个球</td>
<td>27</td>
<td>20</td>
<td>20</td>
<td></td>
<td>20</td>
<td></td>
</tr>
<tr>
<td>乳头溢液</td>
<td>27</td>
<td>20</td>
<td>20</td>
<td></td>
<td>20</td>
<td></td>
</tr>
</tbody>
</table>

*百分比不等于100，因为受访者可能列出多个项目。
Table 5-9. Frequency (% of respondents) of most salient breast cancer risks in free lists, by women and physicians

<table>
<thead>
<tr>
<th></th>
<th>Women (N=30)</th>
<th>Physicians (N=15)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td></td>
</tr>
<tr>
<td>Heredity</td>
<td>47</td>
<td>Obesity</td>
</tr>
<tr>
<td>Food</td>
<td>17</td>
<td>Maternal family history of breast cancer</td>
</tr>
<tr>
<td>Smoking</td>
<td>17</td>
<td>Genetics</td>
</tr>
<tr>
<td>Alcohol</td>
<td>13</td>
<td>Smoking</td>
</tr>
<tr>
<td>Birth control</td>
<td>10</td>
<td>Estrogen</td>
</tr>
<tr>
<td>A hit</td>
<td>10</td>
<td>Family history of breast cancer</td>
</tr>
<tr>
<td>Not getting a mammogram</td>
<td>10</td>
<td>Early Menarche</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Race</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Nulliparous</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Previous history of cancer</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Late menopause</td>
</tr>
</tbody>
</table>

*Percentages do not equal 100 because respondents may have listed more than one item.

Table 5-10. Frequency (% of respondents) of most salient breast cancer risks in free lists, by women’s insurance type

<table>
<thead>
<tr>
<th></th>
<th>Private (N=15)</th>
<th>Public (N=10)</th>
<th>Medicare (N=4)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Heredity</td>
<td>67</td>
<td>20</td>
<td>A hit</td>
</tr>
<tr>
<td>Smoking</td>
<td>27</td>
<td>20</td>
<td>Food</td>
</tr>
<tr>
<td>Alcohol</td>
<td>20</td>
<td>20</td>
<td>Heredity</td>
</tr>
<tr>
<td>Food</td>
<td></td>
<td>20</td>
<td>50</td>
</tr>
<tr>
<td>Don't know</td>
<td></td>
<td>20</td>
<td></td>
</tr>
<tr>
<td>Not getting a mammogram</td>
<td></td>
<td>20</td>
<td></td>
</tr>
</tbody>
</table>

*Percentages do not equal 100 because respondents may have listed more than one item.
Table 5-11. Frequency (% of respondents) of most salient breast cancer treatments in free lists, by women and physicians

<table>
<thead>
<tr>
<th></th>
<th>Women (N=30)</th>
<th>Physicians (N=15)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>83</td>
<td>100</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>63</td>
<td>93</td>
</tr>
<tr>
<td>Remove the breast</td>
<td>37</td>
<td>53</td>
</tr>
<tr>
<td>Pills</td>
<td>27</td>
<td>40</td>
</tr>
<tr>
<td>Surgery</td>
<td>27</td>
<td>33</td>
</tr>
<tr>
<td>Medication</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mastectomy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bilateral mastectomy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radical mastectomy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reconstructive surgery</td>
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</tbody>
</table>

*Percentages do not equal 100 because respondents may have listed more than one item.

Table 5-12. Frequency (% of respondents) of most salient breast cancer treatments in free lists, by women’s insurance type

<table>
<thead>
<tr>
<th></th>
<th>Private (N=15)</th>
<th>Public (N=10)</th>
<th>Medicare (N=4)</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>87</td>
<td>80</td>
<td>75</td>
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<tr>
<td>Radiotherapy</td>
<td>73</td>
<td>60</td>
<td>50</td>
</tr>
<tr>
<td>Remove the breast</td>
<td>40</td>
<td>40</td>
<td>50</td>
</tr>
<tr>
<td>Pils</td>
<td>27</td>
<td>30</td>
<td>50</td>
</tr>
</tbody>
</table>

*Percentages do not equal 100 because respondents may have listed more than one item.
Figure 5-9. MDS of women’s and physicians’ agreement on free listed preventive measures items (excluding WP10). Kruskal Stress= 0.134 (Notes: A respondent was eliminated because her coordinates stretched the visual and made it difficult to identify patterns between the groups.)
Figure 5-10. MDS of women’s (by insurance type) agreement on free listed preventive measures items (excluding WP10). Kruskal Stress= 0.116 (Notes: A respondent was eliminated because her coordinates stretched the visual and made it difficult to identify patterns between the groups.)
Figure 5-11. MDS of women’s and physicians’ agreement on free listed symptoms items. Kruskal Stress = 0.120
Figure 5-12. MDS of women’s (by insurance type) agreement on free listed symptoms items. Kruskal Stress = 0.108
Figure 5-13. MDS of women’s and physicians’ agreement on free listed risk items.  
Kruskal Stress = 0.046
Figure 5-14. MDS of women’s (by insurance type) agreement on free listed risk items. Kruskal Stress = 0.032
Figure 5-15. MDS of women’s and physicians’ agreement on free listed treatment items (excluding WP3-5). Kruskal Stress= 0.173 (Note: Three respondents were eliminated because their coordinates stretched the visual and made it difficult to identify patterns between the groups.)
Figure 5-16. MDS of women’s and physicians’ agreement on free listed treatment items (excluding WP3-5). Kruskal Stress= 0.104 (Note: Three respondents were eliminated because their coordinates stretched the visual and made it difficult to identify patterns between the groups.)
CHAPTER 6
CULTURAL MODELS OF BREAST CANCER IN CONTEXT IN MAYAGUEZ, PUERTO RICO

This chapter uses a dual focus on culture and social context to 1) explore variations in women’s and physician’s cultural knowledge of breast cancer and 2) examine how these levels of variation and social context influence women’s and physicians’ breast cancer experiences. It represents another step in anthropologists’ attempt to understand the relationship between culture and social context and its impact on individuals’ varying experiences of illness such as cancer, a condition whose discourse continues to be shrouded in ambiguity and fear.

Results

Sample Characteristics

The majority of the women were between the ages of thirty-nine and fifty-nine (Table 6-1). Thirty-one percent received a grade school education, thirty-five held a college degree, and thirty-four percent held graduate degrees. Thirty-two percent of the women’s annual family income was under $15,999, fifty-one percent was between $16,000 and $49,999, and seventeen percent was $50,000 or greater (Table 6-1). A hundred percent of the women had medical coverage at the time of the study (Table 6-2). A majority (seventy-nine percent) of the women had visited a physician in the past thirty days. When asked whether they had ever had a mammogram, ninety-seven percent of the women reported having a mammogram. Similarly, when asked if they perform breast self-examinations, ninety-seven percent of the women reported performing breast self-exams. However, only ninety-three percent had a mammogram in the past two years.
Most of the women had never been diagnosed with breast cancer and did not have a family history of breast cancer. However, sixty-six percent reported having a friend, neighbor, or coworker who was diagnosed with breast cancer. When asked about genetic testing, the majority of the women reported hearing about genetic testing for cancer again, the majority had never had a breast cancer genetic exam (Table 6-2). Women participants also were asked to identify the sources or persons that provide them with breast cancer and mammography information. Ninety-three percent reported that they received breast cancer information from the television and from reading materials. Doctors (eighty-six percent) were identified as the third most mentioned source of breast cancer information for women. Ninety-seven percent of women reported that they received mammography information from their doctors. Television and reading materials were the second and third most noted source for mammography information (Table 6-3).

Of the twenty physicians, the majority were males between the ages of forty and sixty-four (Table 6-4). The physicians' specializations included general medicine, internal medicine, gynecology and obstetrics, general surgery, plastic surgery, oncology, and family medicine. The physicians' years of specialization ranged from fewer than five years to more than thirty-one years. However, the majority of physicians practiced their specialization for more than twenty-one years. The majority of the physicians were internal medicine physicians and gynecologists and obstetricians, half of whom had received their training off the island. All of the physicians owned private practices. Majority of the private practices consisted of one
to five physicians. Majority of the physicians were never diagnosed with cancer and did not have a family history of breast cancer.

**Patterns of Agreement**

Overall the groups MDS illustrate distinct clusters of breast cancer items that suggest a cultural model structured around themes of prevention, symptoms, and treatments. Figures 6-1, 6-2, 6-3, and 6-4 show the visual representation of the women’s breast cancer cultural domain. To explore variation between women who were observed seeking care and general community women, the aggregate women group was also divided into two groups subgroups. The two subgroups, community-women and patient women, were based on the place of interview.

Figure 6-1 shows the visual representation of the aggregate women group’s cultural domain of breast cancer. The identified subdomains could also be artifacts of the research design, which combined the free list items of the four subdomains into one pile sort task. A more appropriate approach would have been to collect a pile sort for each of the four subdomains.

This visual suggests that the aggregate has three main clusters that shape their breast cancer domain: prevention, symptoms, and treatment. The prevention cluster, located on the upper left side of the visual includes items such as “go to the doctor”, “get a mammogram”, “there is nothing you can do to prevent it”, and “don’t smoke.” The symptoms cluster is located in the lower center and contains items such as “nipple secretion”, “little ball”, and “discomfort”. The treatment cluster is located on the opposite side of the other two clusters and is defined by items such as “-pills”, “radiotherapy”, and “biopsy.” There is also a loose cluster of items, located to the upper middle section of the visual, which consists of an admixture of risk and
treatment items (e.g., “don’t have a mammogram”, “smoking”, and “birth control”). Additionally, to the lower left there is a loss cluster of three items, “do breast self-exam” “asymptomatic”, and “no pain”, suggesting some relationship between these three items.

Figure 6-2 shows the visual representation of the community-women’s breast cancer cultural domain. The identified subdomains could also be artifacts of the research design, which combined the free list items of the four subdomains into one pile sort task. This visual suggests that the community-women have three main clusters of that shape their breast cancer domain: prevention, symptoms, and treatment. The women’s prevention items clusters to the right. Unlike the other two clusters this group of predominately preventive items (e.g., “do not smoke”, “be careful with you the food you eat”, “there is nothing you can do to prevent it”, and “have a mammogram”) also contains items risk-like items (“food”, “heredity”, and “smoking”). This is interesting, because there is no clear risk cluster; rather, the items are loosely dispersed throughout the domain. The women’s symptoms cluster is located to the upper left section of the visual, opposite the prevention cluster. This cluster includes items such as “pain”, “nipple secretion”, and “a little ball.” The community-women’s third cluster, treatments, is located to the lower left of the visual. It includes items such as “surgery”, “radiotherapy”, and “biopsy.” Treatment options such as “chemotherapy”, “removing the breast”, and “mastectomy” are positioned away from the main treatment cluster to the center of the visual. The items “a lot of pain” and “hit” appears to split the symptoms and treatment clusters. Lastly, similar to the aggregate there is a loose cluster of three items, “do breast self-exams”
“asymptomatic”, and “no pain”, suggesting some relationship between these three items.

Figure 6-3 shows the visual representation of the patient-women’s cultural domain of breast cancer. Once again, the identified subdomains could also be artifacts of the research design, which combined the free list items of the four subdomains into one pile sort task. Similar to the aggregate and the community-women group, the patient-women’s visual illustrates three main clusters that shape their breast cancer domain: prevention, symptoms, and treatment. Despite their clusters’ loose grouping, the patient-women’s MDS shows a more distinct structuring of the breast cancer items. Yet, the loose relationship between “hit”, “pain” and “discomfort” and its close proximity to the symptoms cluster, observed in community-women visual, is also present in the patient-women’s MDS. The group’s prevention cluster is positioned to the center left. Unlike the aggregate and community-women group, this group’s prevention cluster has a noticeable division that creates two smaller prevention groups. The first group includes three items: “having a mammogram”, “exercising”, and “know your family history.” The second cluster, the larger cluster, is located above the previous clusters. It includes items such as “there is nothing you can do to prevent it”, “be careful” and “go to the doctor.” Similar to the community-women’s group there is also a loose clustering of items that is defined by items such as “no pain”, “smoking”, and “birth control.”

Figure 6-4 shows the visual representation of the physicians’ breast cancer cultural domain. Similar to the women’s MDS, the identified subdomains could also be artifacts of the research design, which combined the free list items of the four
subdomains into one pile sort task. Unlike the women’s visuals the physicians’ MDS illustrates four clear cluster themes, prevention, risks, symptoms, treatments. The physicians’ risk items are positioned in the left center, its defined structure, sets it apart from the women’s three risk-like clusters. It consists of items such as “smoking”, “maternal history of breast cancer”, and “obesity.” The group’s prevention cluster is located to the left under the treatment cluster. It consists of items such as “don’t smoke”, “got to the doctor”, and “maintain weight.” The physicians’ symptom cluster is located to the bottom center and is defined by the following items: “asymptomatic”, “bloody nipple secretion”, and “pain.” Finally, the group’s treatment cluster is tightly grouped and is located to the middle right of the visual, opposite the other three clusters. It contains items such as “chemotherapy”, hormone therapy and “bilateral mastectomy”.

**Agreement On The Importance Of Breast Cancer Subdomain Items**

Table 6-5 shows that as an aggregate group, women and physicians share a single cultural model of breast cancer risks (eigenvalue ratio 4:1). It also shows that as individual groups women share a cultural model of breast cancer preventive measures (eigenvalue ratio 3:1) and physicians share a cultural model of breast cancer symptoms (eigenvalue ratio 4:1). The aggregate group’s eigenvalue ratios for preventive measures and symptoms, the women’s ratio for symptoms, and the physicians’ ratio for preventive measures fall below the required 3:1 ratio to support a shared cultural model (Romney, Weller et al. 1986; Weller 2007; Weller, Baer 2002). The following sections will only focused on the three identified shared cultural models: the aggregate group’s shared risks model, women’s shared preventive measures model, and physicians’ symptoms model.
**Shared Cultural Models of Breast Cancer**

**Risk (Women and Physicians).** Figure 6-5 shows the scree plot of eigenvalues from a factor analysis of the aggregate group’s risks ranking task. It illustrates a sharp drop between the first (20) and second factor (5). The first eigenvalue is four times the second, fulfilling the required 3:1 ratio to support a shared cultural model. A standard deviation of 0.4 indicates that respondents’ competency scores are moderately spread out from the mean. A mean competency of 0.52, an average level of agreement, suggests that the group have an average level of consensus about breast cancer risks. The multiple loadings on the second factor suggests that there may be another independent cluster or model (consisting of approximately half of the respondents) in addition to the one associated with the first factor.

Figure 6-8 is a factor loading scatterplot of the aggregate group’s loading on factor one by their loading on factor two. It shows that the aggregate group (women and physicians) is loosely clustered between 0.5 and 1 loading on factor one and -0.5 and 0.5 on factor two. This loose clustering suggests levels of intercultural variation based on how women and physicians ranked the importance of risks items. The scatterplot also demonstrates evidence of a possible second model because some physicians’ plots have high loadings (+/-0.5) on factor two and low loadings on factor one. The visual shows distinct clusters for the individual women group and physicians’ group. The tighter cluster among physicians illustrates their higher level of consensus. The physicians’ (10 to 1) larger eigenvalue ratio when compared to the women’s (5.5:1) supports this observation.
The aggregate women group was also divided by insurance type to further investigate associations between insurance type and intercultural variation among women. Figure 6-9 is a factor loading scatterplot of the women by insurance type loading on factor one by their loading on factor two. It shows that the aggregate women group (private and public) is loosely clustered between -0.2 and 0.8 loading on factor one and -0.5 and 1 on factor two. This loose clustering suggests levels of intercultural variation based on how privately and publicly insured women ranked the importance of risks items. The visual shows a distinct cluster for privately insured women. The tighter cluster among privately illustrates their higher level of consensus. The publicly insured women’s small sample size and the possible limits that it presents when discussing intercultural variation among women should also be noted.

**Preventive Measures (Women).** Figure 6-6 shows the scree plot of eigenvalues from a factor analysis of the women’s preventive measures ranking task. It illustrates a sharp drop between the first (10) and second factor (3). The first eigenvalue is three times the second, fulfilling the required 3:1 ratio to support a shared cultural model. A standard deviation of 0.34 indicates that respondents’ competency scores are moderately spread out from the mean. A mean competency of 0.53, an average level of agreement, suggests that the group has an average level of consensus about breast cancer preventive measures. The multiple moderately high loadings on the second factor suggest that there is systematic intracultural variation that deserves further exploration (e.g., via residual agreement analysis).

Figure 6-10 is a factor loading scatterplot of the women’s loading on factor one by their loading on factor two. It shows that majority of the women are loosely
clustered between 0.0 and 1.0 loading on factor one and -0.5 and 0.5 on factor two. This loose clustering suggests levels of intracultural variation in the women’s ranking of the preventive measures items. The scatterplot also demonstrates evidence of a possible second model because some women’s plots have high loading (+/-0.5) on factor two and low loading on factor one.

**Symptoms (Physicians).** Figure 6-7 shows the scree plot of eigenvalues from a factor analysis of physicians’ symptoms ranking task. It illustrates a sharp drop between the first (8) and second factor (2). The first eigenvalue is four times the second, fulfilling the required 3:1 ratio to support a shared cultural model. A standard deviation of 0.38 indicates that respondents’ competency scores are moderately spread out from the mean. A mean competency of 0.56, a slightly high average level of agreement, suggests that the group have an average level of consensus about breast cancer symptoms. The second factor’s multiple loadings suggest the existence of systematic intracultural variation that deserves further exploration (e.g., via residual agreement analysis).

Figure 6-11 is a factor loading scatterplot of the physicians’ loading on factor one by their loading on factor two. It shows that majority of the physicians are loosely clustered between 0.5 and 1 loading on factor one and -0.5 and 1 on factor two. This loose clustering suggests levels of intracultural variation based on how physicians ranked the importance of the symptoms items. The scatterplot also support the existences a second model because some physicians’ plots have high loading (+/- 0.5) on factor two and low loading on factor one.
Content of models

In addition to identifying the existence of a single shared model, cultural consensus analysis also produced an answer key, “correct answer,” for the identified models. The order of the groups’ aggregate risk model, the women’s preventive measures model, and physicians’ symptoms model demonstrates underlying themes of inter- and intragroup agreement about the importance of the items in these subdomains.

Risk (Women and Physicians). The aggregate groups’ risks rank order can be divided into two themes: genetics and lifestyle choices. Genetic characteristics of breast cancer are the most important component of the women and physicians shared culture model of breast cancer risks. The “genetic” theme of breast cancer risks is defined by the following five items: “family history of breast cancer”, “previous history of cancer”, “family history of cancer”, “heredity”, and “genetics.” The group’s second risks rank order theme is lifestyle choices. This theme includes the following items: “not getting a mammogram”, “estrogen use”, “smoking” and “alcohol.”

Preventive Measures (Women). The groups’ preventive measures ranking order suggests that women identify themselves as the catalyst of breast cancer prevention. The main theme of “internal locus of control” in the preventive measures ranking can be divided into three subthemes: “self-awareness of the body,” “getting recommended screening exams,” and “maintaining a healthy lifestyle.” Items that define the self-awareness subtheme include “do breast-self exams”, “know your family breast cancer history”, and “check yourself every month.” The “getting recommended screening exams” subtheme includes “get a mammogram”, “go to the doctor”, “get a sonomammogram”, “do your medical examinations.” Finally, “the
maintaining a healthy lifestyle” subtheme includes the following items: “maintain a healthy diet”, “do not smoke”, and “do not drink alcohol.” The item “there is nothing you can do to prevent it” was ranked as one of the least important item in the subdomain.

Symptoms (Physicians). The physicians’ symptoms rank order identified the overarching theme of “physiological changes”. This main theme includes two subthemes: “changes in breast structure” and “bodily sensations.” The “changes in breast structure” subtheme includes items such as “a sore”, “nipple retraction”, and “orange skin.” The “sensations” subtheme, though lowly ranked includes items such as “discomfort”, “itching”, and “fatigue.” Physicians also ranked “asymptomatic, “pain”, and “no pain” as some of the least important breast cancer symptoms.

Discussion

The groups’ pile sorts illustrate that women’ and physicians’ cognitive spatial maps are structured around three breast cancer subdomains preventive measures, symptoms, and treatments. However, it can also be argued that due to bias introduced by the research design, the findings demonstrate respondents’ ability to rearrange the items back into the original four domains used in the free list tasks.

According to Kleinman and colleagues (1978) patients’ and physicians’ explanatory models, people’s beliefs about what a sickness episode is, includes information about what causes it, how it affects them, and what can be done to heal it (Kleinman et al. 1978; Kleinman 1981). Women and physicians agree and share a single model about what causes breast cancer (risk). Only women demonstrate sufficient agreement to support the existence of a shared cultural model of what can be done to prevent breast cancer (preventive measures). Unlike women, physicians
high level of consensus about how breast cancer affects the body (symptoms) support a single shared cultural model of breast cancer symptoms.

Even though physicians and women shared a single model of breast cancer risk further exploration of their shared model illustrates inter- and intragroup variation about how the women's (care seekers) and physicians' (care providers) rank the importance's of the risk items in their model. This variation in women's and physicians' understanding of the etiology of breast cancer is supported by existing cancer research that identify variation between physicians' and their patients' perception of risks. Chavez and colleagues' research observed differences between physicians and non-physician breast and cervical cancer risk perceptions (Chavez et al. 1995, 2001). Similarly, Rebecca Martinez and colleagues' (1997) work on cancer risk perception among Latinas and physicians illustrates variation in risk definitions between the medical definition -the dominant definition- and individuals of cancer risk. She uses this finding to suggest that variation in risk definition may negatively impact the quality of cancer care received and provided.

The women and physicians cognitive maps for the breast cancer domain suggest that women (care seekers) and physicians (care providers) generally share an understanding about breast cancer preventive measure and symptoms, and treatments. However, a shared single model between women and physicians, with noted inter- and intragroup variation, was only identified for the risk domain. Consensus analysis findings provide adequate support for inter- and intragroup variation in women's and physicians' cultural models of breast cancer.
Variation in the women’s and physicians’ definition of breast cancer can be linked to their context. As Kleinman and colleagues suggest, patients’ and physicians’ illness experiences are related to their illness definitions (1978). Therefore one can infer that physicians’ shared model of breast cancer symptoms is informed by their shared educational and professional context, which promotes a physiological definition of breast cancer that emphasizes the importance of knowing and identifying breast cancer symptoms. In contrast, the personal and social experiences that inform women’s construction of breast cancer do not result in agreement about the meaning or role of breast cancer symptoms. Martha Balshem (1991) cancer etiology work among the working class locates individuals’ cancer etiology within their social context. She regards individuals’ cancer definition as implicit responses of resistance to dominant definitions and forces outside of their community. Balshem also argues that a disconnect between individual’s casual definitions and the dominant medical definition creates barriers in care and can hinder interventions that fail to account for patients’ social context (Balshem 1991).

Balshem’s (1991) assertion is supported by some women’s explanation about contradictions between the symptoms information received from their physicians and from their personal experiences. One female patient noted that she continues to question the breast cancer information that she receives from her physician. She justified her concern by explaining that a family member was later diagnosed with breast cancer after experiencing pain in her breast and then seeking care. The patient continued to explain that her family member’s experience contradicts her
physician’s continual declaration that breast cancer is asymptomatic and not accompanied by pain.

The women’s shared preventive measures model can also be linked to their social context. As care seekers, the ranking order of the women’s list demonstrate the importance that the group places on the individual and her responsibility to take care of herself and then to seek care. One can suggest that women but not physicians share an internal locus of control approach to breast cancer prevention. While women gather information both from their personal relations and their physicians it is ultimately the woman’s decision to lead a healthy life and to seek care when necessary. Many women readily shared information about their monthly self-breast exams. Even when a community woman noted that she did not consistently perform her self-breast exams she quickly admitted that she knew better and needed to do the exam more often.
Table 6-1. Women General Characteristics N=29

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<td>50-59</td>
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<td>70-75</td>
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<td>Masters</td>
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### Table 6-2. Women Health Characteristics N=29

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<td>Medical Visit in the Past 30 Days</td>
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<td>Ever Had Mammogram</td>
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<td>Yes</td>
<td>93</td>
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<td>Mammogram in Past 2 Years</td>
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<td>Breast Self-Exam Status</td>
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<td>Breast Cancer Diagnosis</td>
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<td>Non-Family Experience w/ Breast Cancer Patients</td>
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<tr>
<td>Knowledge of Genetic Testing</td>
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<td>Genetic Testing Status</td>
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Percentages do not equal 100 because respondents may have listed more than one item.

### Table 6-3. Women Breast Cancer and Mammography Information N=29

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<th>%</th>
<th>Mammography Sources*</th>
<th>%</th>
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</thead>
<tbody>
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<td>Television</td>
<td>93</td>
<td>Doctor</td>
<td>97</td>
</tr>
<tr>
<td>Reading materials (newspapers, magazines, books)</td>
<td>93</td>
<td>Television</td>
<td>90</td>
</tr>
<tr>
<td>Doctor</td>
<td>86</td>
<td>Reading materials (newspapers, magazines, books)</td>
<td>90</td>
</tr>
<tr>
<td>Radio</td>
<td>83</td>
<td>Informative materials in doctors offices or health center</td>
<td>86</td>
</tr>
<tr>
<td>Informative materials in doctors offices or health center</td>
<td>79</td>
<td>Radio</td>
<td>79</td>
</tr>
<tr>
<td>Friends or neighbors</td>
<td>69</td>
<td>Friends or neighbors</td>
<td>62</td>
</tr>
<tr>
<td>Family members</td>
<td>66</td>
<td>Family members</td>
<td>59</td>
</tr>
<tr>
<td>Health professional</td>
<td>28</td>
<td>Health professional</td>
<td>31</td>
</tr>
<tr>
<td>Nurse</td>
<td>24</td>
<td>Nurse</td>
<td>24</td>
</tr>
<tr>
<td>Other</td>
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<td>Other</td>
<td>10</td>
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Percentages do not equal 100 because respondents may have listed more than one item.
<table>
<thead>
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<th>Characteristics</th>
<th>%</th>
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<tbody>
<tr>
<td>Age (years)</td>
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<td>26-39</td>
<td>10</td>
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<tr>
<td>40-64</td>
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<td>&gt; 65</td>
<td>10</td>
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<tr>
<td>Sex</td>
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<tr>
<td>Female</td>
<td>25</td>
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<td>Male</td>
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<td>Specialization*</td>
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<td>General Medicine</td>
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<tr>
<td>General Surgery</td>
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<tr>
<td>Oncology</td>
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</tr>
<tr>
<td>Family Medicine</td>
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<tr>
<td>Plastic Surgery</td>
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</tr>
<tr>
<td>Years of Specialization</td>
<td></td>
</tr>
<tr>
<td>&lt; 5 years</td>
<td>10</td>
</tr>
<tr>
<td>6-10 years</td>
<td>5</td>
</tr>
<tr>
<td>11-15 years</td>
<td>20</td>
</tr>
<tr>
<td>16-20</td>
<td>5</td>
</tr>
<tr>
<td>21-25 years</td>
<td>20</td>
</tr>
<tr>
<td>26-30 years</td>
<td>10</td>
</tr>
<tr>
<td>&gt; 31</td>
<td>30</td>
</tr>
<tr>
<td>Place of Medical Training</td>
<td></td>
</tr>
<tr>
<td>Off of the Island</td>
<td>50</td>
</tr>
<tr>
<td>Professional Status*</td>
<td></td>
</tr>
<tr>
<td>Employed by hospital, group or other entity</td>
<td>10</td>
</tr>
<tr>
<td>Practice owner/ partner/ associate</td>
<td>100</td>
</tr>
<tr>
<td>Practice Size*</td>
<td></td>
</tr>
<tr>
<td>Solo</td>
<td>60</td>
</tr>
<tr>
<td>2-5 physicians</td>
<td>40</td>
</tr>
<tr>
<td>100+ physicians</td>
<td>7</td>
</tr>
<tr>
<td>Cancer Diagnosis</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>80</td>
</tr>
<tr>
<td>Family History of Breast Cancer</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>60</td>
</tr>
</tbody>
</table>

*Percentages do not equal 100 because respondents may have listed more than one item.
Figure 6-1. MDS of women’s pile sorts of breast cancer items. Kruskal Stress= 0.165
Figure 6-2. MDS of community-women's pile sorts of breast cancer items. Kruskal Stress= 0.123
Figure 6-3. MDS of patient-women’s pile sorts of breast cancer items. Kruskal Stress= 0.169
Figure 6-4. MDS of physicians’ pile sorts of breast cancer items Kruskal Stress= 0.092
A 3:1 ratio between the first and second eigenvalues confirms the existence of a shared cultural model (a single factor solution).

Table 6-5. Goodness of Fit Measures of Cultural Consensus Analysis by subdomain and group

<table>
<thead>
<tr>
<th>Breast Cancer Subdomain</th>
<th>Group</th>
<th>1st and 2nd Eigenvalues Ratio</th>
<th>Variance by 1st Factor (%)</th>
<th>Average Knowledge (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preventive Measures</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>3 to 1</td>
<td>42</td>
<td>0.53 (± 0.34)</td>
<td></td>
</tr>
<tr>
<td>Physicians</td>
<td>1.6 to 1</td>
<td>36</td>
<td>0.37 (± 0.4)</td>
<td></td>
</tr>
<tr>
<td>Aggregate</td>
<td>2.5 to 1</td>
<td>39</td>
<td>0.48 (± 0.4)</td>
<td></td>
</tr>
<tr>
<td>Risks</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>5.5 to 1</td>
<td>43</td>
<td>0.56 (± 0.3)</td>
<td></td>
</tr>
<tr>
<td>Physicians</td>
<td>10 to 1</td>
<td>56</td>
<td>0.51 (± 0.5)</td>
<td></td>
</tr>
<tr>
<td>Aggregate</td>
<td>4 to 1</td>
<td>43</td>
<td>0.52 (± 0.4)</td>
<td></td>
</tr>
<tr>
<td>Symptoms</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>1.8 to 1</td>
<td>35</td>
<td>0.47 (± 0.31)</td>
<td></td>
</tr>
<tr>
<td>Physicians</td>
<td>4 to 1</td>
<td>49</td>
<td>0.56 (± 0.56)</td>
<td></td>
</tr>
<tr>
<td>Aggregate</td>
<td>2 to 1</td>
<td>36</td>
<td>0.49 (± 0.33)</td>
<td></td>
</tr>
</tbody>
</table>
Figure 6-5. Eigenvalue scree plot of breast cancer risks ranking by women and physicians
Figure 6-6. Eigenvalue scree plot of breast cancer preventive measures ranking by women
Figure 6-7. Eigenvalue scree plot of breast cancer symptoms ranking by physicians
Figure 6-8. Scree plot of 1\textsuperscript{st} and 2\textsuperscript{nd} of breast cancer risk ranking by women and physicians
Figure 6-9. Scree plot of 1\textsuperscript{st} and 2\textsuperscript{nd} of breast cancer risk ranking by women by insurance type
Figure 6-10. Scree plot of 1st and 2nd of breast cancer preventive measures ranking by women
Figure 6-11. Scree plot of 1\textsuperscript{st} and 2\textsuperscript{nd} of breast cancer symptoms ranking by physicians
Table 6-6. Order of breast cancer risks items in ranking task, by women and physicians

<table>
<thead>
<tr>
<th>Item</th>
<th>Answer Key</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family history of breast cancer</td>
<td>1</td>
</tr>
<tr>
<td>Previous history of cancer</td>
<td>2</td>
</tr>
<tr>
<td>Family history of cancer</td>
<td>3</td>
</tr>
<tr>
<td>Heredity</td>
<td>4</td>
</tr>
<tr>
<td>Genetics</td>
<td>5</td>
</tr>
<tr>
<td>Not getting a mammogram</td>
<td>6</td>
</tr>
<tr>
<td>Estrogen use</td>
<td>7</td>
</tr>
<tr>
<td>Hormones</td>
<td>8</td>
</tr>
<tr>
<td>Early menarche</td>
<td>9</td>
</tr>
<tr>
<td>Birth control</td>
<td>10</td>
</tr>
<tr>
<td>Smoking</td>
<td>11</td>
</tr>
<tr>
<td>Food</td>
<td>12</td>
</tr>
<tr>
<td>Age</td>
<td>13</td>
</tr>
<tr>
<td>Late menopause</td>
<td>14</td>
</tr>
<tr>
<td>Having the first child after age 35</td>
<td>15</td>
</tr>
<tr>
<td>Obesity</td>
<td>16</td>
</tr>
<tr>
<td>Not having any children</td>
<td>17</td>
</tr>
<tr>
<td>Not breastfeeding</td>
<td>18</td>
</tr>
<tr>
<td>Alcohol</td>
<td>19</td>
</tr>
<tr>
<td>A hit</td>
<td>20</td>
</tr>
<tr>
<td>Race</td>
<td>21</td>
</tr>
<tr>
<td>The environment</td>
<td>22</td>
</tr>
<tr>
<td>Depression</td>
<td>23</td>
</tr>
<tr>
<td>Using creams to grow the breast</td>
<td>24</td>
</tr>
<tr>
<td>Deodorant</td>
<td>25</td>
</tr>
<tr>
<td>Abuse</td>
<td>26</td>
</tr>
<tr>
<td>Cellphones</td>
<td>27</td>
</tr>
<tr>
<td>Lifting heavy things</td>
<td>28</td>
</tr>
<tr>
<td>Not wearing a bra</td>
<td>29</td>
</tr>
</tbody>
</table>
Table 6-7. Order of breast cancer preventive measures items in ranking task, by women

<table>
<thead>
<tr>
<th>Item</th>
<th>Answer Key</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do breast self-exams</td>
<td>1</td>
</tr>
<tr>
<td>Know your family breast cancer history</td>
<td>2</td>
</tr>
<tr>
<td>Go to the doctor</td>
<td>3</td>
</tr>
<tr>
<td>Get a mammogram</td>
<td>4</td>
</tr>
<tr>
<td>Get a sonomammogram</td>
<td>5</td>
</tr>
<tr>
<td>Check yourself every month</td>
<td>6</td>
</tr>
<tr>
<td>Do your medical examinations</td>
<td>7</td>
</tr>
<tr>
<td>Be careful</td>
<td>8</td>
</tr>
<tr>
<td>Check yourself</td>
<td>9</td>
</tr>
<tr>
<td>Screening</td>
<td>10</td>
</tr>
<tr>
<td>Follow your doctor's instructions</td>
<td>11</td>
</tr>
<tr>
<td>Maintain a healthy diet</td>
<td>12</td>
</tr>
<tr>
<td>Be very careful with the food you eat</td>
<td>13</td>
</tr>
<tr>
<td>Do not smoke</td>
<td>14</td>
</tr>
<tr>
<td>Get a genetic test</td>
<td>15</td>
</tr>
<tr>
<td>Exercise</td>
<td>16</td>
</tr>
<tr>
<td>Change your lifestyle</td>
<td>17</td>
</tr>
<tr>
<td>Maintain your weight</td>
<td>18</td>
</tr>
<tr>
<td>Do not drink alcohol</td>
<td>19</td>
</tr>
<tr>
<td>Breastfeed your children</td>
<td>20</td>
</tr>
<tr>
<td>Avoid hormone replacement</td>
<td>21</td>
</tr>
<tr>
<td>Avoid exposure to radiation</td>
<td>22</td>
</tr>
<tr>
<td>There is nothing you can do to prevent it</td>
<td>23</td>
</tr>
<tr>
<td>Do not use deodorant</td>
<td>24</td>
</tr>
<tr>
<td>Avoid microwaves</td>
<td>25</td>
</tr>
</tbody>
</table>
Table 6-8. Order of breast cancer symptoms items in ranking task, by physicians

<table>
<thead>
<tr>
<th>Item</th>
<th>Answer Key</th>
</tr>
</thead>
<tbody>
<tr>
<td>A sore</td>
<td>1</td>
</tr>
<tr>
<td>Nipple retraction</td>
<td>2</td>
</tr>
<tr>
<td>Orange skin</td>
<td>3</td>
</tr>
<tr>
<td>Bloody nipple discharge</td>
<td>4</td>
</tr>
<tr>
<td>A mass</td>
<td>5</td>
</tr>
<tr>
<td>Hardening of the breast</td>
<td>6</td>
</tr>
<tr>
<td>A little ball</td>
<td>7</td>
</tr>
<tr>
<td>Sinking in part of the breast</td>
<td>8</td>
</tr>
<tr>
<td>Breast deformity</td>
<td>9</td>
</tr>
<tr>
<td>A nodule</td>
<td>10</td>
</tr>
<tr>
<td>A little lump</td>
<td>11</td>
</tr>
<tr>
<td>Redness of the nipple</td>
<td>12</td>
</tr>
<tr>
<td>Discoloration of the skin</td>
<td>13</td>
</tr>
<tr>
<td>Nipple discharge</td>
<td>14</td>
</tr>
<tr>
<td>Redness of the breast</td>
<td>15</td>
</tr>
<tr>
<td>A bulge</td>
<td>16</td>
</tr>
<tr>
<td>Areola growth</td>
<td>17</td>
</tr>
<tr>
<td>A bruise on the breast</td>
<td>18</td>
</tr>
<tr>
<td>No pain</td>
<td>19</td>
</tr>
<tr>
<td>Pain</td>
<td>20</td>
</tr>
<tr>
<td>Discomfort</td>
<td>21</td>
</tr>
<tr>
<td>Asymptomatic</td>
<td>22</td>
</tr>
<tr>
<td>Itching</td>
<td>23</td>
</tr>
<tr>
<td>Fatigue</td>
<td>24</td>
</tr>
</tbody>
</table>
CHAPTER 7
CONCLUSION

Who are the voices of cancer and how does their context impact their cancer experiences? This question shares a similar focus with anthropologists’ continued efforts to understand the relationship between culture and health experiences. Today cancer disparities continue to increase alongside increased cancer incidence and prevalence. This trend has created 1) increasing critiques that argue that cancer and individuals' understanding and experiences of the illness is a complex phenomena that does not easily map unto the dominant cancer discourse and 2) a call for research that explores the factors that create variation in cancer experiences.

The demand for research that focuses on variation in cancer experiences aligns with the National Institutes of Health (NIH) call for studies that include appropriate measures of culture that can demonstrate if and how the construct contribute to variation in health outcomes. Earlier this year the organization published a culture framework guide that provides an inter-disciplinary discussion of culture, its importance, and guidelines to help researchers define and operationalize the construct (Kagawa-Singer, Dressler et al. 2015).

The continued anthropological inquiry about culture and health experiences and the NIH's call for comprehensive uses of culture in health research makes it an opportune time to use recent developments in culture theory and methods to explore how variations in individual's cancer experiences are influenced by the relationship between their culture (cancer knowledge) and social context. This dissertation used a dual focus on culture and social context to showcase two important voices in breast cancer discourse, care seekers (women) and care providers (physicians), and
illustrate the importance of locating their voices within their specific social context to understand their breast cancer meaning. It argues that both culture (cultural knowledge) and social context influence women’s and physicians’ breast cancer experiences. This work addressed two specific objectives:

3. To explore how women’s and physicians’ breast cancer experiences vary based on their locations within Puerto Rico’s healthcare system

4. To describe and compare women’s and physicians’ cultural knowledge of breast cancer and its relationship to their social context

The study’s use of culture theory and appropriate methods responds to the NIH’s call for health research that incorporates comprehensive definitions and measures of culture. It contributes to a growing body of research in medical anthropology that aims to understand the relationship between social context and cultural meaning and their impact on health experiences (Dressler and Bindon, 2000; Gravlee, Dressler, and Bernard, 2005; Reyes-Garcia et al., 2010). It is only the second study (and the first in Puerto Rico) to use this approach to operationalize culture and explore the influence of cultural knowledge and social context on cancer experiences.

**Breast Cancer Experiences in Puerto Rico’s Healthcare System**

The dissertation first addressed objective one by equally showcasing the voices of two prominent players in breast cancer discourse -- physicians (care-providers) and women (care-seekers) -- to 1) describe Puerto Rico’s healthcare system from the lens of its care seekers and providers and 2) explore how the Island’s predominantly Medicaid-funded public insurance structure influences women’s access and use of available breast cancer resources on the Island.
The care-providers’ and care-seekers’ narratives suggest that the Island’s Medicaid reform granted all Puerto Rican women access to private healthcare, particularly for those with low income. This finding supports existing Medicaid expansion research on the mainland which identifies association between friendlier Medicaid qualification requirements and increased access to care among low-income individuals (Sommers, Baicker et al. 2012; Dickman, Himmelstein et al. 2015).

Mulligan’s (2007; 2010) work in Puerto Rico illustrates how the privatization of the Island’s healthcare system transformed its populace into consumers of healthcare. Similar to Mulligan’s findings, this dissertation illustrates the political and economic ties between the development of the Island’s healthcare system and its adoption of a market-based approach to healthcare. Mulligan also notes that the market-based structure of Puerto Rico’s 1993 healthcare reform, though presented as the best approach to deliver high quality care to its indigent population, introduced disparities in quality and access of care (2010).

While Mulligan’s work, explores the Island’s healthcare system from the lens of the insurer and insured this work uses the lens of the care-seeker and care-provider (Mulligan 2007; 2010). It shows that administrative requirements imposed by MCOs to improve efficiency of services continue to create disparities in women’s access to care, such as specialized care important for breast cancer diagnosis and treatment. When we look at breast cancer services, the groups’ narratives suggest that variation in access creates disparities in the quality of breast cancer care that women on the Island receive.
In Puerto Rico’s case, Medicaid expansion increased access, which may be related to improved breast cancer prevention indicators on the Island. Today, Puerto Rico has an 85 percent mammogram rate compared to 81 percent in the US (Portela, Sommers 2015). However, this study’s in-depth discussion of the Island’s care-seekers and -providers experiences within the system illustrates a system, despite its Medicaid expansion, that shares systemic barriers to care with the U.S. mainland system before ACA. So, from a policy viewpoint, while Medicaid expansion increases access, and access may improve breast cancer outcomes, it is not the panacea to cancer disparities in Puerto Rico. Nonetheless, it should be regarded as one step in the right direction, albeit within the context of a market-based healthcare system.

**Cultural Knowledge of Breast Cancer in Puerto Rico**

The dissertation addressed objective two in two stages. First free list analysis, an approach that uses individuals’ accounts, was used to explore the variation in care-seekers and care-providers breast cancer knowledge. This novel approach avoids the trap of using an a priori definition of culture (cultural knowledge). Second, a dual focus on culture and social context was used to examine how identified levels of variation in cultural knowledge and social context influence women’s and physicians’ breast cancer experiences.

In the first stage, the study’s findings identified similarities and differences in women’s and physicians’ knowledge of breast cancer. The similarities suggest a shared understanding of some aspects of breast cancer (preventive measures, symptoms, and treatments) between the groups. However, differences in the women’s and physicians’ understanding of breast cancer coexist along with those shared ideas. This variation in knowledge, when located within the groups’ specific
contexts, implies that context (e.g., medical training, the media) influences how the groups create breast cancer meaning and their experience of the concept. The lack of consensus among the insurance-based women’s groups suggests that the relationship between culture and context cannot be easily reduced to simple measures of social-structural factors such as insurance type.

The study’s use of methods that focus on the respondent’s perception of cancer responds to the call for cancer research that explores variation in cancer experiences by incorporating lay voices in cancer discourse (Lam, Fielding 2003; Pasick, Burke 2008; Jain 2013; Wooddell, Hess 1998; Engelberg 2006). However, it is only the first step in exploring the multiple facets of cancer experiences. This study, like others, demonstrates a need for more research that examines how variations in lay and recommended medical knowledge of breast cancer interact with other factors to influence individuals’ cancer experiences and care-seeking behaviors (Pasick, Burke 2008; Wooddell, Hess 1998; Jain 2013). Research that builds on this exploration of variation in cancer knowledge and examines its interaction with context and material constraints can provide in-depth descriptions of women’s and physicians’ breast cancer experiences, which can, in turn, provide more informed accounts of the many dimensions of cancer experiences.

In the second stage, the study’s findings once again suggest that the women’s and physicians’ definition of breast cancer are linked to their context. Care-seekers and care-providers agree about what causes breast cancer but they also demonstrate distinct cultural models about what can be done to prevent breast cancer and how the condition affects the body. Physicians and women’s shared
clinical interactions along with physicians shared educational and professional context may facilitate their shared cultural model of breast cancer risk. In contrast, women’s personal and social experiences and physicians’ professional experience with breast cancer encourages distinct construction of breast cancer meaning, particularly what can be done to prevent the condition and its effect on the body.

Similar to existing research this study defined and operationalized culture and its construction as a dynamic process in order to illustrate links between variation in group’s cancer knowledge, social context, and their cancer experiences (Balshem 1991, 1993; Chavez 1995; Manderson 2011; Moore 2001; Mathews 2000). The work’s exploration of the relationship between the groups’ context and the construction of their three shared breast cancer cultural models contribute to ongoing discussions about the important role that culture and social context holds in understanding cancer (Weiner 1999; Hunter-Jones 2005; Kangas 2010; Salamonsen, et al. 2012). Finally, these findings align with existing research that advocates bringing patients’ cancer experiences both positive and negative to the forefront of cancer care (Jain 2013; Perusek 2012). The identified aggregate and group-specific shared models also have implications for doctor-patient interactions. For example, recommendations for medical training that acknowledge that like patients, physicians’ context influences how they provide care can enhance patient-center care approaches and improve breast cancer services.

Limitations

There are three main limitations to the study’s findings. First, the study’s focus on the Island’s healthcare system illustrated variation in access and quality of care between publicly and privately insured women. While the sample size for women was
appropriate for the selected analyses, a more representative sample of women based on insurance type may have aided a more systematic exploration into the relationship between insurance type and breast cancer experiences.

Second, the study’s discussion of Puerto Rico’s healthcare system only focused on two major voices, care-seekers and -providers. It did not incorporate other important voices of the Island’s healthcare system such government officials and MCO personnel. Including these additional voices could have provided a more comprehensive description of the system, its functions, and explorations into how disparities in quality and access are created and maintained.

Third, one of the study’s purposes was to describe variation in the structure of women’s and physician’s domains of breast cancer. However, the pile sort task design introduced bias because it combined the four subdomains into one pile sort task. This means that the task measured the respondents’ ability to recreate the original four subdomains rather than provide appropriate information about the structure or organization of the groups’ breast cancer subdomains.

**Future Research**

This dissertation used a combination of participant observation, semi-structured ethnographic interviewing, and structured elicitation tasks suitable for cultural consensus analysis to emphasize the importance of culture and social context in discussions about individuals’ breast cancer experiences. The subsequent step would be to test how these two constructs interact and measure the amount of variance that cultural knowledge and specific social factors explain in breast cancer outcomes. This next step would continue anthropological and public health efforts to understand the unequal distribution of cancer suffering. It would also respond to the
NIH’s call for research designs that 1) includes a dynamic definition of culture and 2) produces statistically significant measures of culture that explains if and how much variance the concept contributes to health outcomes.
APPENDIX A
CONSENT FORMS FOR INTERVIEWS

Protocol Title: Women and Physicians Cultural Knowledge of Breast Cancer and Use of Preventive Services (English)

Please read this consent document carefully before you decide to participate in this study.

Purpose of the research study:
The purpose of this study is to understand how cultural knowledge about breast cancer influences women’s participation in breast cancer screening in Mayaguez, Puerto Rico.

What you will be asked to do in the study:
You will be asked a series of questions about your basic demographic information and your perceptions of breast cancer. I would like to learn your point of view and will encourage you to suggest and discuss what you think is important to the conversation.

Time required:
Approximately one hour.

Risks and Benefits:
I do not anticipate that you will experience any immediate risks or benefits from participating in the research.

Compensation:
There is no cost or compensation to you for participation in this research.

Confidentiality:
Your identity will be kept confidential as proved by law. Your information will be assigned a code number. Your name will not be used in any report of publication.

Voluntary participation:
Your participation in this study is completely voluntary. There is no penalty for not participating. You do not have to answer any question you do not wish to answer.

Right to withdraw from the study:
You have the right to withdraw from the study at anytime without consequence.

Audio recording:
Everything you have to say is important. We would like to audio-record the interview to capture what is said. This audio recording will be available to the project researcher only.
☐ I consent to audio recording.
☐ I do not consent to audio recording.

Initials: ____________ Date: __________
Whom to contact if you have questions about the study:
Principal Investigator: June Carrington, Graduate Student, Department of Anthropology, University of Florida, P.O. Box 117305 University of Florida, Gainesville, FL 32611-7305, (XXX) XXX-XXXX, Xxxxxxxxxx@ufl.edu

Faculty Supervisor: Clarence Gravlee, PhD, Associate Professor; P.O. Box 117305 University of Florida, Gainesville, FL 32611-7305 phone (XXX) XXX-XXXX; Xxxxxxxxxx@ufl.edu

Whom to contact about your rights as a research participant in the study:
IRB02 Office, Box 112250, University of Florida, Gainesville, FL 32611-2250; phone 392-0433.

Agreement:
I have read the explanation provided to me. I have had all of my questions answered to my satisfaction, and I voluntarily agree to participate in this study. I HAVE BEEN GIVEN A COPY OF THIS CONSENT FORM.
Participant: ___________________________ D ate: __________
Principal Investigator: ___________________________ D ate: __________
Título del Protocolo: Creencias culturales de las mujeres y los médicos respecto al cáncer de mama y los hábitos de salud de la mujer en Mayagüez, Puerto Rico (Spanish)

Por favor, lea atentamente este documento de consentimiento antes de decidirse a participar en este estudio.

**Objetivo del estudio:**
El objetivo de este estudio es examinar cómo las creencias culturales sobre el cáncer de mama influyen en los hábitos de salud de la mujer, en Mayagüez, Puerto Rico.

**¿Qué se le pedirá hacer en el estudio?:**
Se le pedirá una serie de preguntas sobre información demográfica básica y sus percepciones sobre el cáncer de mama. Me gustaría conocer su punto de vista y animarle a proponer y discutir lo que usted piensa; es importante para la conversación.

**Tiempo:**
Aproximadamente una hora.

**Riesgos y beneficios:**
No anticipó que va a experimentar ningún riesgo inmediato o beneficios de participar en la investigación.

**Compensación:**
No hay ningún costo o compensación en participar en esta investigación.

**Confidencialidad:**
Su identidad se mantendrá confidencial, como lo demuestra la ley. A su información se le asignará un número de código. Su nombre no será utilizado en ningún informe de la publicación.

**Participación voluntaria:**
Su participación en este estudio es completamente voluntaria. No hay sanción por no participar. Usted no tiene que contestar ninguna pregunta que no desea responder.

**Derecho a retirarse del estudio:**
Usted tiene el derecho de retirarse del estudio en cualquier momento sin consecuencias.

**Grabación de audio:**
Todo lo que tengo que decir es importante. Nos gustaría tener grabaciones de audio de la entrevista para captar lo que se dice. Estas grabaciones de audio estarán disponibles solamente para el investigador responsable del proyecto.

☐ Yo **consiento** a la grabación de audio.
☐ Yo **no consiento** a la grabación de audio.

Iniciales: ___________ Fecha: ___________
¿A quién puedo contactar si tengo preguntas sobre el estudio?:
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¿A quién se debe contactar acerca de mis derechos como participante en este estudio?:
IRB Office Box 112250
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Teléfono (352) 392-0433.

Acuerdo:
He leído la explicación ofrecida a mí. He tenido todas las respuestas a mis preguntas a mi satisfacción, y estoy de acuerdo en participar voluntariamente en este estudio. He recibido una copia de este formulario de consentimiento.

Participante: ___________________________ Fecha: __________
Investigador Principal: ___________________________ Fecha: __________
APPENDIX B
INTERVIEW SCHEDULE

PHASE 1: FREE LIST

Subject ID: ______________________

Women Interview Guide (English)

BREAST CANCER FREE-LIST Now I will ask you some questions about breast cancer. I am only interested in learning more about how people in Mayaguez think about breast cancer. I would like to learn more about how you think about breast cancer and about your experiences with breast cancer. Please remember that there are no right or wrong answers.

1. Please list all the symptoms of breast cancer.
   (Probe: You said that _____ and _____ are symptoms of breast cancer, what are some other symptoms of breast cancer?)

2. Please list all the risks for breast cancer.
   (Probe: You said that _____ and _____ are risk for breast cancer, what are some other risks of breast cancer?)

3. Please list all of the things that a women can do to prevent breast cancer.
   (Probe: You said that _____ and _____ are some ways to prevent breast cancer, what are some other preventive measures of breast cancer?)

4. Please list all of the treatments for breast cancer.
   (Probe: You said that _____ and _____ are treatments for breast cancer, what are some other treatments of breast cancer?)

5. If you had to draw a picture of the health care system in Puerto Rico to explain how it works, what would you draw? [Give respondent a paper and pencil]

CANCER HISTORY Now I would like to ask you some questions about your cancer experiences.

1. Has anyone told you that you have cancer, any type of cancer?
   No (00) [Skip to Q #5]
   Yes (01)
   Don’t Know (03) [Skip to Q #5]

2. What type of cancer were you diagnosed with?
   Other type of cancer (00)
   Breast cancer (01)

3. When were you diagnosed with cancer? (DD/MM/YYYY) ____________________________
   [Skip to Q #4 if respondent does not know date]

4. How old were you when you were diagnosed with breast cancer?

Now I would like to ask you some questions about your family’s cancer experiences.

1. Has anyone in your family ever been diagnosed with breast cancer?
   No (00) [Skip to next section]
   Yes (02)
   Don’t Know (03)
1. **Which family member was it?** [For every family member mention, ask if they were on the mother or father side of the family]

2. **Do you have any friends, neighbors or colleagues from work who have been diagnosed with breast cancer or who have died from breast cancer?**
   - No (00) [Skip to next section]
   - Yes (02)
   - Don't know (03) [Skip to next section]

3. **What is or was this person's relationship to you?**

**HEALTHCARE ACCESS AND FAMILY HEALTH** Now I would like to ask you some questions about your health and your family’s health.

1. **Do you have medical insurance?**
   - No (00) [Skip to Q #2]
   - Yes (01) [Ask respondent: What is the name of your medical insurance? ________________________]
   - Don’t know (03)

2. **Have you seen a physician in past 30 (thirty) days?**
   - No (00)
   - Yes (01)
   - Don’t know (03)

3. **Have you ever had a mammogram (breast x-ray)?**
   - No (00)
   - Yes (01)
   - Don’t know (03)

4. **Have you had a mammogram in the past two-months?**
   - No (00)
   - Yes (01)
   - Don’t know (03)

5. **Do you know of any places where mammograms (breast x-rays) are done?**
   - No (00) [Skip to Q # 7]
   - Yes (01) [Ask respondent to name place ________________________]
   - Don’t know (03)

6. **Do you know of any places where you can go to have a mammogram (breast x-ray)?**
   - No (00)
   - Yes (01) [Ask respondent to name place ________________________]
   - Don’t know (03)
1. Do you examine your breasts (touch your breasts to look for or find masses, lumps or changes in the skin). This is also referred to as a self-exam.
   No (00) [Skip to next section]
   Yes (01)
   Don’t know (03)

2. How often did you examine your breast? (__________ times monthly or _________ times yearly)

**SOCIAL SUPPORT**

Now I would like to ask you some questions about social support.

1. The majority of the time, what transportation do you use to get to your medical appointments?
   Own car (00)
   Public transportation (bus or public van) (01)
   Family member’s car (02)
   Neighbor or friend’s car (03)
   I pay someone to take me (04)
   Municipality or government transportation (05)
   Walk (06)
   Other means of transportation Specify (07)

2. The majority of the time, who goes with you to the doctor’s office when you have an appointment?
   (Select all that applies)
   No one (00)
   Spouse/Partner (01)
   Daughter(s) (02)
   Son(s) (03)
   Daughter-in-law or son-in-law (04)
   Sister(s) or brother(s)
   Another family member Specify (06)
   Friend(s) or neighbor(s) (07)
   Another person Specify (08)

3. Do you take care of small children, grandchildren or another person?
   No (00) [Skip to Q #8]
   Yes (02)
   Don’t Know (03)

4. Who do you take care of? ______________________

5. Do you have any problems finding someone to take care of her/him/them when you have a doctor’s appointment?
   Never (00) [Skip to Q #7]
   Sometimes (01)
   Almost always (03)
   Always (04)

6. If you cannot find someone to take care of her/him/them how does this impact ability to attend your doctor’s appointments? ______________________
1. Who normally helps to take care of her/him/them when you have a doctor’s appointment?

2. **Where or from whom have you received information about breast cancer?** (Select all that applies)
   - Doctor (00)
   - Nurse (01)
   - Health professional (02)
   - Radio (03)
   - Television (04)
   - Reading materials (newspapers, magazines, books) (05)
   - Family members (06)
   - Friends or Neighbors (07)
   - Informative material in doctors office or health center (08)
   - Other source _____ Specify _____ (09)

3. **Where or from whom did you receive information about mammograms (breast x-rays)?** (Select all that applies)
   - Doctor (00)
   - Nurse (01)
   - Health professional (02)
   - Radio (03)
   - Television (04)
   - Reading materials (newspapers, magazines, books) (05)
   - Family members (06)
   - Friends or Neighbors (07)
   - Informative material in doctors office or health center (08)
   - Other source _____ Specify _____ (09)

**GENETIC TESTING AWARENESS** The following questions refer to genetic testing for cancer risk. That is, testing your blood to see if you carry genes which may predict a greater chance of developing cancer at some point in your life. This does NOT include tests to determine if you have cancer.

1. **Have you ever heard of genetic testing to determine if a person is at greater risk of developing cancer?**
   - No (00)
   - Yes (01)
   - Don’t Know (03)
   - Refused (04)

2. **Have you ever discussed the possibility of getting a genetic test for cancer risk with a doctor or other health professional?**
   - No (00) [Go to Q#4]
   - Yes (01)
   - Don’t Know (03) [Go to Q#4]
   - Refused (04) [Go to Q#4]
1. **Did the doctor or other health professional advice you to have such a test?**
   - No (00)
   - Yes (01)
   - Don’t Know (03)
   - Refused (04)

2. **Have you ever had a genetic test to determine if you are at greater risk of developing cancer in the future? (This does not include any test to see whether you had cancer in the past or have cancer now).**
   - No (00) [Go to the next section]
   - Yes (01)
   - Don’t Know (03) [Go to the next section]
   - Refused (04) [Go to the next section]

3. **Please think about your most recent genetic test for cancer. Which kinds of cancer was it for?**
   - Breast (00)
   - Ovarian (01)
   - Colon or rectal (02)
   - Another cancer (03)

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**SOCIODEMOGRAPHIC INFORMATION**  *Finally, the following questions refer to demographic information.*

1. **What is your birthdate? (DD/MM/YYYY) __________________________**
   [Skip to Q #2 if respondent does not know birthdate]
   [Skip to Q #3 if birthdate is not known]

2. **What is your age?________**

3. **What grade did you finish school?**
   - I did not attend school (00)
   - Primary school (01)
   - High school (02)
   - Technical school (03)
   - Associates (04)
   - Bachelors (05)
   - Masters (06)
   - Doctoral (07)
   - Other studies Specify(08)

4. **What is your marital status?**
   - Single (00)
   - Widowed (01)
   - Married (02)
   - Living with a partner (03)
   - Separated (04)
   - Divorced (05)
1. How many children do you have?
   Never had children (00) [Skip to Q #10]
   One (01)
   Two (02)
   Three (03)
   Four (04)
   Five (05)
   More than six (06)

2. What is the birthdate of your child? (DD/MM/YYYY) ________________
   [Skip to Q #10 if respondent has/had only one child]
   [Skip to Q #8 if she has/had more than one child]
   [Go to Q #7 if she does not know the birthdate]

3. What is the age of your first child? ________________

4. What is the birthdate of your last child? (DD/MM/YYYY) ________________
   [Skip to Q #9 if respondent does not know birthdate]
   [Skip to Q #10 if birthdate is not known]

5. What is the age of your last child? ________________

6. Are you employed?
   No (00) [Skip to Q #11]
   Yes (01) [Skip to Q #13]

7. Have you worked outside of your home in the past?
   No (00) [Skip to Q #15]
   Yes (01)

8. What was your occupation? ________________

9. What is your occupation? ________________

10. Are you employed part-time or full-time?
    Part-time (00)
    Full-time (01)

11. Including yourself, how many people live in your household? __________
1. **Who do you live with?** *(Select all that applies)*
   - Spouse/Partner (00)
   - Daughter(s) (01)
   - Son(s) (02)
   - Grandchild (grandchildren) (03)
   - Sister(s) (04)
   - Brother(s) (05)
   - Other family members (06)
   - Friend(s) (07)
   - Other person _______ (08)

2. **How many of these individuals are adults (18 and older)?** _________

3. **How many bedrooms are in your home?** _________

4. **How many bathrooms are in your home?** _________

5. **What is your annual family income?**
   - Don't Know (00)
   - Less than $5,000 (01)
   - $5,000 - $11,999 (02)
   - $12,000 - $15,999 (03)
   - $16,000 - $24,999 (04)
   - $25,000 - $49,000 (05)
   - $50,000 and greater (06)

**CASE HISTORY RECRUITMENT**

Thank you for taking the time out today to speak with me about your breast cancer experience. I would like to learn a little more about your experience with breast cancer and with the health care system in Puerto Rico. **Can I contact you at a later date to ask you some more questions?**
Women Interview Guide (Spanish)

CÁNCER DE SENO FREE-LIST Ahora le preguntaré algunas preguntas sobre el cáncer de seno. Estoy interesada en aprender más acerca de cómo las personas en Mayagüez piensan sobre el cáncer de seno. Me gustaría saber más sobre cómo usted piensa sobre el cáncer de seno y sobre sus experiencias con el cáncer de seno. Por favor, recuerde que no hay respuestas correctas o incorrectas.

1. Por favor, puede enumerar todos los síntomas del cáncer de seno.
   (Pregunte: Usted dijo que ____ y ____ son síntomas de tener cáncer de seno, ¿Cuáles son algunos otros síntomas de cáncer de seno?)

2. Por favor, podría enumerar cuales son todos los riesgos del cáncer de seno.
   (Pregunte: Usted dijo que ____ y ____ son riesgos de tener cáncer de seno, ¿Cuáles son algunos otros riesgos de cáncer de seno?)

3. Por favor, puede enumerar todas las cosas que una mujer puede hacer para evitar tener cáncer de seno.
   (Pregunte: Usted dijo que ____ y ____ son cosas que una mujer puede hacer para evitar tener cáncer de seno, ¿Cuáles son algunas otras cosas que una mujer puede hacer para evitar tener cáncer de seno?)

4. Por favor, enumere de todos los tratamientos para el cáncer de seno.
   (Pregunte: Usted dijo que ____ y ____ son tratamientos de cáncer de seno, ¿Cuáles son algunos otros tratamientos de cáncer de seno?)

5. Si usted tuviera que hacer un dibujo del sistema de salud en Puerto Rico para explicar cómo funciona, ¿Qué haría usted dibujar? [Dale entrevistado un papel y un lápiz]

HISTORIA DEL CÁNCER
Ahora le haré algunas preguntas sobre sus experiencias con el cáncer.

1. ¿Alguien le ha informado usted que tenía cáncer, cualquier tipo de cáncer?
   No (00) [Ir a P#5]
   Sí (01)
   No Sabe (03) [Ir a P#5]

2. ¿Con qué tipo de cáncer fue diagnosticada?
   Otro tipo de cáncer (00)
   Cáncer de mama (01)

3. ¿Cuándo le diagnosticó un cáncer? (DD/MM/AAAA) ________________
   [Ir a P#4 si se no conoce la fecha]

4. ¿Qué edad tenía usted cuando fue diagnosticada con cáncer de seno? ________________

Ahora le haré algunas preguntas sobre su familia experiencias con el cáncer.

1. ¿Alguien en su familia ha sido diagnosticada/o con cáncer de seno?
   No (00) [Ir a la sección siguiente]
   Sí (02)
   No sabe (03)
1. ¿Miembro de la familia fue diagnosticado/a con cáncer? [Por cada miembro de la familia que mencione, pregunte si estaban relacionados/as por el lado materno o el lado paterno de la familia.]

2. ¿Tiene amistades, vecinos/as o compañeros/as de trabajo que han sido diagnosticada con cáncer de seno o que han muerto a causa de cáncer de seno?
   No (00) [Ir a la sección siguiente]
   Sí (02)
   No sabe (03) [Ir a la sección siguiente]

3. ¿Cuál es o fue la relación de esta persona con usted? 

SALUD ACCESO Y SALUD FAMILIAR Ahora le haré algunas preguntas sobre su salud y la salud de su familia.

1. ¿Tiene seguro médico?
   No (00) [Ir a P# 2]
   Sí (01) [Pregunta: ¿Cuál es el nombre de su seguro médico?]
   No sabe (03)

2. ¿Ha ido a un médico en los últimos 30 (treinta) días? 

3. ¿Alguna vez se ha hecho una mamografía (radiografía de la mama)? 

4. ¿Se ha hecho una mamografía en los últimos dos meses o sesenta días? 

5. ¿Conoce los lugares donde se realizan las mamografías (radiografía de la mama)?
   No (00) [Ir a P# 7]
   Sí (01) [Pregunta: ¿Cuál es el nombre de lugar o lugares?] 
   No sabe (03)

6. ¿Conoce los lugares donde se puede ir a hacerse una mamografía (radiografía del mama)?
   No (00)
   Sí (01) [Pregunta: ¿Cuál es el nombre de lugar o lugares?]
   No sabe (03)

7. ¿Se examina las mamas (toca sus senos para buscar o encontrar masas, bolitas o cambios en la piel)?
   Esto también se conoce como un auto-examen.
   No (00) [Ir a la sección siguiente]
   Sí (01)
   No sabe (03)

8. ¿Con qué frecuencia se hace un auto-examen? (________ veces mensualmente o ________ veces anual)
1. **Dónde o de quién recibió información sobre el cáncer de mama?** (Seleccione todas las que corresponda)
- Médico (00)
- Enfermera (01)
- Profesional de la salud (02)
- Radio (03)
- Televisión (04)
- Materiales de lectura (periódicos, revistas, libros) (05)
- Miembros de la familia (06)
- Amigos o vecinos (07)
- Material informativo en la oficina de médicos o centro de salud (08)
- Otra fuente ______ Especifique ______ (09)

2. **¿De dónde o de quién recibió la información sobre las mamografías (radiografías de mama)?**
   (Seleccione todas las que corresponda)
- Médico (00)
- Enfermera (01)
- Profesional de la salud (02)
- Radio (03)
- Televisión (04)
- Materiales de lectura (periódicos, revistas, libros) (05)
- Miembros de la familia (06)
- Amigos o vecinos (07)
- Material informativo en la oficina de médicos o centro de salud (08)
- Otra fuente ______ Especifique ______ (09)

**CONCIENCIA DE PRUEBA GENÉTICA** Las preguntas siguientes se refieren a las pruebas genéticas para el riesgo de cáncer. Es decir, el análisis de sangre para ver si usted tiene los genes que pueden predecir una mayor probabilidad de desarrollar cáncer en algún momento de su vida. Esto NO incluye pruebas para determinar si tiene cáncer.

1. **¿Alguna vez ha oído las pruebas genéticas para determinar si una persona está en mayor riesgo de desarrollar cáncer?**
   - No (00)
   - Sí (01)
   - No sabe (03)
   - Rehusó contestar (04)

2. **¿Alguna vez a consultado un médico u otro profesional de la salud sobre la posibilidad de tomar una prueba genética para conocer el riesgo de cáncer?**
   - No (00) [Ir a P#4]
   - Sí (01)
   - No sabe (03) [Ir a P#4]
   - Rehusó contestar (04) [Ir a P#4]

3. **¿El médico u otro profesional de la salud le sugirió que usted se hiciera una prueba genética?**
   - No (00)
   - Sí (01)
   - No sabe (03)
   - Rehusó contestar (04)
1. ¿Alguna vez se ha hecho una prueba genética para determinar si usted está en mayor riesgo de desarrollar cáncer en el futuro? ( Esto no incluye ninguna prueba para ver si usted tenía cáncer en el pasado o tiene cáncer ahora.).
   No (00) [Ir a la sección siguiente]
   Sí (01)
   No sabe (03) [Ir a la sección siguiente]
   Rehusó contestar (04) [Ir a la sección siguiente]

2. Por favor, piense acerca de su prueba genética para el cáncer más reciente. ¿Para cuál tipo de cáncer era?
   De mama (00)
   De ovario (01)
   De colon o rectal (02)
   Otro tipo de cancer (03)

INFORMACIÓN SOCIODEMOGRÁFICA
Por último, las preguntas siguientes se refieren a la información demográfica.

1. ¿Cuál es su fecha de nacimiento? (DD/MM/AAAA)
   [Ir a P#2 si el entrevistado no conoce la fecha de nacimiento]
   [Ir a P#3 si no se conoce la fecha de nacimiento]

2. ¿Cuál es su edad? __________________________

3. ¿Hasta que año estudió?
   Yo no asistí a la escuela (00)
   Primaria (hasta sexto grado) (01)
   Secundaria (hasta escupa superior) (02)
   La escuela técnica (escuela vocacional) (03)
   Grado Asociado (04)
   Bachillerato (05)
   Maestría (06)
   Doctorado (07)
   Otros estudios _____ Especifique _____(09)

4. ¿Cuál es su estado civil?
   Soltera (00)
   Viuda (01)
   Casada (02)
   Vive con pareja sin casarse (03)
   Separada (04)
   Divorciada (05)

5. ¿Cuántos hijos/as tiene usted?
   Nunca tuvo hijos (00) [Ir a P #10]
   Uno (01)
   Dos (02)
   Tres (03)
   Cuatro (04)
   Cinco (05)
   Seis o más (06)
1. ¿Cuál es la fecha de nacimiento de su (primer) hijo? (DD/MM/AAAA) 
   [Ir a P#10 si el entrevistado ha / tenía un solo hijo]
   [Ir a P#8 si ha / tenido más de un hijo]
   [Ir a P#7 si ella no sabe la fecha de nacimiento]

2. ¿Cuál es la edad de su primer hijo? 

3. ¿Cuál es la fecha de nacimiento de su último hijo? (DD/MM/AAAA) 
   [Ir a P#9 si el entrevistado no conoce la fecha de nacimiento]
   [Ir a P #10 si se no conoce la fecha de nacimiento]

4. ¿Cuál es la edad de su último hijo? 

5. ¿Usted está trabajando actualmente? 
   No (00) [Ir a P#11]
   Sí (01) [Ir a P#13]

6. ¿Has trabajado fuera de su hogar en el pasado? 
   No (00) [Ir a P#15]
   Sí (01)

7. ¿Cuál era su ocupación? 

8. ¿Cuál es su ocupación? 

9. ¿Está empleada a tiempo parcial o a tiempo completo? 
   Tiempo parcial (00)
   Tiempo completo (01)

10. Incluyéndole a usted, ¿cuántas personas viven en su casa? 

11. ¿Con quién vive usted? (Selezione todas las que corresponda) 
   Esposo/Pareja (00)
   Hija(s) (01)
   Hijo(s) (02)
   Nieto (Nietos) (03)
   Hermana(s) (04)
   Hermano(s) (05)
   Otros miembros de la familia (06)
   Amigo (s) (07)
   Otra persona ______ (08)

12. ¿Cuántas de estas personas son adultos (18 años o más)? 

13. ¿Cuántos habitaciones se encuentran en su hogar? 

14. ¿Cuántos baños se encuentran en su hogar?
1. ¿Cuál es su ingreso familiar anual?
   No sabe (00)
   Menos de $5,000 (01)
   $5,000 - $11,999 (02)
   $12,000 - $15,999 (03)
   $16,000 - $24,999 (04)
   $25,000 - $49,000 (05)
   Más de $50,000 (06)

HISTORIA DE RECLUTAMIENTO DE CASO
Gracias por tomarse el tiempo hoy para hablar conmigo acerca de su experiencia con el cáncer de seno. Me gustaría conocer un poco más acerca de su experiencia con el cáncer de seno y con el sistema de salud en Puerto Rico. ¿Puedo contactar con usted en una fecha posterior a hacerle algunas preguntas más?
Physicians Interview Guide (English)

BREAST CANCER FREE-LIST Now I will ask you some questions about breast cancer. I am only interested in learning more about how people in Mayaguez think about breast cancer. I would like to learn more about how you think about breast cancer and about your experiences with breast cancer. Please remember that there are no right or wrong answers.

1. Please list all the symptoms of breast cancer.
   (Probe: You said that _____ and _____ are symptoms of breast cancer, what are some other symptoms of breast cancer?)

2. Please list all the risks for breast cancer.
   (Probe: You said that _____ and _____ are risk for breast cancer, what are some other risks of breast cancer?)

3. Please list all of the things that a women can do to prevent breast cancer.
   (Probe: You said that _____ and _____ are some ways to prevent breast cancer, what are some other preventive measures of breast cancer?)

4. Please list all of the treatments for breast cancer.
   (Probe: You said that _____ and _____ are treatments for breast cancer, what are some other treatments of breast cancer?)

5. If you had to draw a picture of the health care system in Puerto Rico to explain how it works, what would you draw? [Give respondent a paper and pencil]

CANCER HISTORY Now I would like to ask you some questions about your cancer experiences.

1. Has anyone told you that you have cancer, any type of cancer?
   No (00) [Skip to Q #5]
   Yes (01)
   Don’t Know (03) [Skip to Q #5]

2. What type of cancer were you diagnosed with?
   Other type of cancer (00)
   Breast cancer (01)

3. When were you diagnosed with cancer? (DD/MM/YYYY) ________________
   [Skip to Q #4 if respondent does not know date]

4. How old were you when you were diagnosed with breast cancer? ________________

Now I would like to ask you some questions about your family’s cancer experiences.
1. Has anyone in your family ever been diagnosed with breast cancer?
   No (00) [Skip to next section]
   Yes (02)
   Don’t Know (03)

2. Which family member was it? [For every family member mention, ask if they were on the mother or father side of the family]

3. Do you have any friends, neighbors or colleagues from work who have been diagnosed with breast cancer or who have died from breast cancer?
   No (00) [Skip to next section]
   Yes (02)
   Don’t know (03) [Skip to next section]

4. What is or was this person's relationship to you? ____________________________

SOCIODEMOGRAPHIC INFORMATION The following questions refer to demographic information.

1. What is your birthdate? (DD/MM/YYYY) ____________________________
   [Skip to Q #2 if respondent does not know birthdate]
   [Skip to Q #3 if birthdate is not known]

2. What is your age? _________________

3. What is your gender [Do not ask, just record gender]
   Male (01)
   Female (02)

4. What is your marital status?
   Never been married (00)
   Widowed (01)
   Married (02)
   Living with a partner (03)
   Separated (04)
   Divorced (05)

5. What is your current occupation? ____________________________

6. What is your current professional status? (Select all that applies)
   Employed by hospital, group or other entity (01)
   Practice owner/partner/associate (02) [Skip to Q#6]
   Other (03)

7. What is the size of your practice?
   Solo (00)
   2-5 physicians (01)
   5-10 physicians (02)
   11-30 physicians (03)
   31-10 physicians (04)
   100+ physicians (05)
1. What is your specialty?

2. How many years have you practiced this specialization?

3. Where did you attend medical school?

4. Where did you complete your residency?

5. In what area did you do your residency?

CASE HISTORY RECRUITMENT
Thank you for taking the time to speak with me about your breast cancer experience. I would like to learn a little more about your experience with breast cancer and with the health care system in Puerto Rico. Can I contact you at a later date to ask you some more questions?
Physicians Interview Guide (Spanish)

CÁNCER DE MAMA FREE-LIST Ahora le preguntaré algunas preguntas sobre el cáncer de mama. Sólo estoy interesada en aprender más acerca de cómo las personas en Mayagüez piensan sobre el cáncer de mama. Me gustaría saber más sobre cómo usted piensa acerca del cáncer de mama y sobre sus experiencias con el cáncer de mama. Por favor, recuerde que no hay respuestas correctas o incorrectas.

1. Por favor, puede enumerar todos los síntomas del cáncer de seno.
   (Pregunta: Usted dijo que _____ y _____ son síntomas de tener cáncer de seno. ¿Cuáles son algunos otros síntomas de cáncer de seno?)

2. Por favor, podría enumerar cuales son todos los riesgos del cáncer de seno.
   (Pregunta: Usted dijo que _____ y _____ son riesgos de tener cáncer de seno. ¿Cuáles son algunos otros riesgos de cáncer de seno?)

3. Por favor, puede enumerar todas las cosas que una mujer puede hacer para evitar tener cáncer de seno.
   (Pregunta: Usted dijo que _____ y _____ son cosas que una mujer puede hacer para evitar tener cáncer de seno. ¿Cuáles son algunas otras cosas que una mujer puede hacer para evitar tener cáncer de seno?)

4. Por favor, enumere de todos los tratamientos para el cáncer de seno.
   (Pregunta: Usted dijo que _____ y _____ son tratamientos de cáncer de seno. ¿Cuáles son algunos otros tratamientos de cáncer de seno?)

5. Si usted tuviera que hacer un dibujo del sistema de salud en Puerto Rico para explicar cómo funciona, ¿qué haría usted dibujar? [Dale entrevistado un papel y un lápiz]

HISTORIA DEL CÁNCER
Ahora le haré algunas preguntas sobre sus experiencias con el cáncer.

1. ¿Alguien le ha informado usted que tenía cáncer, cualquier tipo de cáncer?
   No (00) [Ir a P#5]
   Sí (01)
   No Sabe (03) [Ir a P#5]

2. ¿Con qué tipo de cáncer fue diagnosticada?
   Otro tipo de cáncer (00)
   Cáncer de mama (01)

3. ¿Cuándo se le diagnosticó un cáncer? (DD/MM/AAAA) ________________________________
   [Ir a P#4 si se no conoce la fecha]

4. ¿Qué edad tenía usted cuando fue diagnosticada con cáncer de seno? __________________
Ahora le haré algunas preguntas sobre su familia experiencias con el cáncer.

1. ¿Alguien en su familia ha sido diagnosticada/o con cáncer de seno?
   No (00) [Ir a la sección siguiente]
   Sí (02)
   No sabe (03)

2. ¿Miembro de la familia fue diagnosticado/a con cáncer? [Por cada miembro de la familia que mencione, pregunte si estaban relacionados/as por el lado materno o el lado paterno de la familia.]

3. ¿Tiene amistades, vecinos/as o compañeros/as de trabajo que han sido diagnosticada con cáncer de seno o que han muerto a causa de cáncer de seno?
   No (00) [Ir a la sección siguiente]
   Sí (02)
   No sabe (03) [Ir a la sección siguiente]

4. ¿Cuál es o fue la relación de esta persona con usted? ______________________________________

INFORMACIÓN SOCIODEMOGRÁFICA Las siguientes preguntas se refieren a la información demográfica.

1. ¿Cuál es su fecha de nacimiento? (DD/MM/AAAA)
   [Ir a P#2 si el entrevistado no conoce la fecha de nacimiento]
   [Ir a P#3 si se no conoce la fecha de nacimiento]

2. ¿Cuál es su edad? ______________________________________

3. ¿Cuál es su sexo? [No pregunte, simplemente grabe sexo]
   Hombre (01)
   Mujer (02)

4. ¿Cuál es su estado civil?
   Soltera (00)
   Viuda (01)
   Casada (02)
   Acompañada (03)
   Separada (04)
   Divorciada (05)

5. ¿Cuál es su ocupación actual? ____________________________

6. ¿Cuál es su situación profesional actual? (Seleccione todas las que corresponda)
   Empleado por hospital, grupo u otra entidad (01)
   Medicina privada /socio (02) [Ir a P#6]
   Otro (03)
1. ¿Cuál es el tamaño de su práctica?
   Solo (00)
   2-5 médicos (01)
   5-10 médicos (02)
   11-30 médicos (03)
   31-10 médicos (04)
   100+ médicos (05)

2. ¿Cuál es su especialidad? ________________

3. ¿Cuántos años hace que practica esta especialización? ________________

4. ¿En cuál escuela de medicina estudio usted? ________________

5. ¿Dónde terminó su residencia? ________________

6. ¿En qué área de especialidad hizo su residencia? ________________

HISTORIA DE RECLUTAMIENTO DE CASO
Gracias por tomarse el tiempo hoy para hablar conmigo acerca de su experiencia con el cáncer de mama usted. Me gustaría conocer un poco más acerca de su experiencia con el cáncer de mama y con el sistema de salud en Puerto Rico. ¿Puedo contactar con usted en una fecha posterior a hacerle algunas preguntas más?
PHASE 2: PILE SORT AND RANK ORDER

Subject ID: __________________________

Women Interview Guide (Spanish)

CÁNCER DE SENO PILESORT Y RANK ORDER Ahora le preguntaré algunas preguntas sobre el cáncer de seno. Estoy interesada en aprender más acerca de cómo las personas en Mayagüez piensan sobre el cáncer de seno. Me gustaría saber más sobre cómo usted piensa sobre el cáncer de seno y sobre sus experiencias con el cáncer de seno. Por favor, recuerde que no hay respuestas correctas o incorrectas.

SECCIÓN I: PILE SORT

Pilesort Direcciones:
• Tengo un grupo de trajetas con palabras o frases.
• Primero me gustaría que usted lea cada tarjeta.
• Por favor, use las palabras o frases para crear grupos de las cosas que son similares.
• Cuando haya terminado por favor hágamelo saber.

[DESPUÉS PARTICIPANTE TERMINA PILESORT]

Pilesort Preguntas:
• Por qué puso estas palabras o frases juntas?
• ¿Qué es lo que hace a estas cosas similares?
• ¿Qué es lo que hace a estas cosas diferentes el uno del otro?

SECCIÓN II: RANKING

Rank Order Direcciones:
• Tengo un grupo de trajetas con palabras o frases.
• Primero me gustaría que usted lea cada tarjeta.
• Por favor, ponga las palabras en el orden de más importante/ grave a menos importante/grave.
• Cuando haya terminado por favor hágamelo saber.
[DESPUÉS PARTICIPANTE TERMINA PILESORT]

Ranking Preguntas:

I. Prevención
- Por qué puso estas palabras o frases en este orden?
- ¿Lo que hace que ______ más importante que ________?
- ¿Lo que hace que ______ menos importante que ________?

II. Los Riesgos
- Por qué puso estas palabras o frases en este orden?
- ¿Lo que hace que ______ más importante que ________?
- ¿Lo que hace que ______ menos importante que ________?

III. Los Síntomas
- Por qué puso estas palabras o frases en este orden?
- ¿Lo que hace que ______ más importante que ________?
- ¿Lo que hace que ______ menos importante que ________?

SECCIÓN III: EL SISTEMA DE SALUD

EL SISTEMA DE SALUD EN PUERTO RICO

Por favor, ¿puedes hacer un dibujo para explicar cómo funciona el sistema de salud en Puerto Rico? [Dale entrevistado un papel y un lápiz]

SECCIÓN IV: SOCIODEM PREGUNTAS

HISTORIA DEL CÁNCER
Ahora le haré algunas preguntas sobre sus experiencias con el cáncer.

1. ¿Ha sido diagnosticado con cáncer, cualquier tipo de cáncer?
   No (00) [Ir a la sección siguiente]
   Sí (01)
   No Sabe (03) [Ir a la sección siguiente]

2. ¿Con qué tipo de cáncer fue diagnosticada?
   Otro tipo de cáncer (00)
   Cáncer de mama (01)

3. ¿Cuándo se le diagnosticó un cáncer? (DD/MM/AAAA) ____________
   [Ir a P#4 si se no conoce la fecha]
1. ¿Qué edad tenía usted cuando fue diagnosticada con cáncer de seno? ____________

Ahora le haré algunas preguntas sobre las experiencias de cáncer en su familia.

1. ¿Alguien en su familia ha sido diagnosticado/o con cáncer de seno?
   No (00) [Ir a la sección siguiente]
   Sí (02)
   No sabe (03)

2. ¿Cuál miembro de la familia fue diagnosticado/a con cáncer? [Por cada miembro de la familia que mencione, pregunte si estaban relacionados/as por el lado materno o el lado paterno de la familia.]

3. ¿Tiene amistades, vecinos/as o compañeros/as de trabajo que han sido diagnosticada con cáncer de seno o que han muerto a causa de cáncer de seno?
   No (00) [Ir a la sección siguiente]
   Sí (02)
   No sabe (03) [Ir a la sección siguiente]

4. ¿Cuál es o fue la relación de esta persona con usted? ________________

SALUD ACCESO Y SALUD FAMILIAR Ahora le haré algunas preguntas sobre su salud y la salud de su familia.

1. ¿Tiene seguro médico?
   No (00) [Ir a P# 2]
   Sí (01) [Pregunta: ¿Cuál es el nombre de su seguro médico?]
   No sabe (03)

2. ¿Ha ido a un médico en los últimos 30 (treinta) días? ________________ [¿Por qué, si no?]

3. ¿Alguna vez se ha hecho una mamografía (radiografía de la mama)? __________ [¿Por qué, si no?]

4. ¿Se ha hecho una mamografía en los últimos dos meses o sesenta días? __________ [¿Por qué, si no?]

5. ¿Conoce los lugares donde se realizan las mamografías (radiografía de la mama)?
   No (00) [Ir a P# 7]
   Sí (01) [Pregunta: ¿Cuál es el nombre de lugar o lugares?] ________________
   No sabe (03)

6. ¿Conoce los lugares donde se puede ir a hacerse una mamografía (radiografía del mama)?
   No (00)
   Sí (01) [Pregunta: ¿Cuál es el nombre de lugar o lugares?] ________________
   No sabe (03)

7. ¿Se examina las mamas (toca sus senos para buscar o encontrar masas, bolitas o cambios en la piel)?
   Esto también se conoce como un auto-examen.
   No (00) [Ir a la sección siguiente]
   Sí (01)
   No sabe (03)
1. ¿Con qué frecuencia se hace un auto-examen? (_________ veces mensualmente o ________ veces annual)

APOYO SOCIAL Ahora le preguntaré sobre el apoyo social.

1. ¿Qué tipo de transportación utiliza la mayoría de las veces para llegar a sus citas médicas?
   - Carro propio (00)
   - El transporte público (guagua o carro público) (01)
   - El carro de un miembro de la familia (02)
   - El carro de un/a vecino/a o amigo/a (03)
   - Le paga a alguien para que la lleve (04)
   - Transporte de la municipalidad o el transporte del gobierno (05)
   - Camina (06)
   - Otros medios de transporte ___ Especifique ________________ (07)

2. ¿La mayoría de las veces quien va con usted a la oficina del médico cuando tiene una cita?
   - Nadie (00)
   - Esposo / Pareja (01)
   - Hija(s) (02)
   - Hijo(s) (03)
   - Nueva o Yerno (04)
   - Hermana(s) or Hermano(s) (05)
   - Otro miembro de la familia ___ Especifique ________________ (06)
   - Amigo(s) o Vecino(s) (07)
   - Otra persona ___ Especifique ________________ (08)

3. ¿Cuida usted niños/as menores, nietos/as, alguna otra persona?
   - No (00) [Ir a P#8]
   - Sí (02)
   - No sabe (03)

4. ¿A quién cuida? ________________________________

5. ¿Tiene problemas para encontrar a alguien para cuidar de él / ella / ellos/as cuando tienes una cita con el médico?
   - Nunca (00) [Ir a P#7]
   - A veces (01)
   - Casi siempre (03)
   - Siempre (04)

6. Si usted no puede encontrar a alguien para cuidar de él / ella / ellos/as, ¿cómo esto impacta su capacidad a atender sus citas médicas? ________________________________

7. ¿Quién normalmente le ayuda a cuidar de ella / él / ellos/as, cuando tiene una cita con el médico?
1. ¿Dónde o de quién recibió información sobre el cáncer de mama? (Seleccione todas las que corresponda)
   Médico (00)
   Enfermera (01)
   Profesional de la salud (02)
   Radio (03)
   Televisión (04)
   Materiales de lectura (periódicos, revistas, libros) (05)
   Miembros de la familia (06)
   Amigos o vecinos (07)
   Material informativo en la oficina de médicos o centro de salud (08)
   Otra fuente ______ Especifique (09)

2. ¿De dónde o de quién recibió la información sobre las mamografías (radiografías de mama)?
   (Seleccione todas las que corresponda)
   Médico (00)
   Enfermera (01)
   Profesional de la salud (02)
   Radio (03)
   Televisión (04)
   Materiales de lectura (periódicos, revistas, libros) (05)
   Miembros de la familia (06)
   Amigos o vecinos (07)
   Material informativo en la oficina de médicos o centro de salud (08)
   Otra fuente ______ Especifique (09)

**CONCIENCIA DE PRUEBA GENÉTICA** Las preguntas siguientes se refieren a las pruebas genéticas para el riesgo de cáncer. Es decir, el análisis de sangre para ver si usted tiene los genes que pueden predecir una mayor probabilidad de desarrollar cáncer en algún momento de su vida. Esto NO incluye pruebas para determinar si tiene cancer.

1. ¿Alguna vez ha oído las pruebas genéticas para determinar si una persona está en mayor riesgo de desarrollar cáncer?
   No (00)
   Sí (01)
   No sabe (03)
   Rehusó contestar (04)

2. ¿Alguna vez a consultado un médico u otro profesional de la salud sobre la posibilidad de tomar una prueba genética para conocer el riesgo de cáncer?
   No (00) [Ir a P#4]
   Sí (01)
   No sabe (03) [Ir a P#4]
   Rehusó contestar (04) [Ir a P#4]

3. ¿El médico u otro profesional de la salud le sugirió que usted se hiciera una prueba genética?
   No (00)
   Sí (01)
   No sabe (03)
   Rehusó contestar (04)
1. ¿Alguna vez se ha hecho una prueba genética para determinar si usted está en mayor riesgo de desarrollar cáncer en el futuro? (Esto no incluye ninguna prueba para ver si usted tenía cáncer en el pasado o tiene cáncer ahora.).
   No (00) [Ir a la sección siguiente]
   Sí (01)
   No sabe (03) [Ir a la sección siguiente]
   Rehusó contestar (04) [Ir a la sección siguiente]

2. Por favor, piense acerca de su prueba genética para el cáncer más reciente. ¿Para cuál tipo de cáncer era?
   De mama (00)
   De ovario (01)
   De colon o rectal (02)
   Otro tipo de cáncer (03)

INFORMACIÓN SOCIODEMOGRÁFICA
Por último, las preguntas siguientes se refieren a la información demográfica.

1. ¿Cuál es su fecha de nacimiento? (DD/MM/AAAA)
   [Ir a P#2 si el entrevistado no conoce la fecha de nacimiento]
   [Ir a P#3 si se no conoce la fecha de nacimiento]

2. ¿Cuál es su edad? ____________________________

3. ¿Hasta que año estudió?
   Yo no asistí a la escuela (00)
   Primaria (hasta sexto grado) (01)
   Secundaria (hasta escuadra superior) (02)
   La escuela técnica (escuela vocacional) (03)
   Grado Asociado (04)
   Bachillerato (05)
   Maestría (06)
   Doctorado (07)
   Otros estudios ___ Especifique ___ (09)

4. ¿Cuál es su estado civil?
   Soltera (00)
   Viuda (01)
   Casada (02)
   Vive con pareja sin casarse (03)
   Separada (04)
   Divorciada (05)

5. ¿Cuántos hijos(as) tiene usted?
   Nunca tuvo hijos (00) [Ir a P #10]
   Uno (01)
   Dos (02)
   Tres (03)
   Cuatro (04)
   Cinco (05)
   Seis o más (06)
1. ¿Cuál es la fecha de nacimiento de su (primer) hijo? (DD/MM/AAAA) ____________________________
   [Ir a P#10 si el entrevistado ha / tenía un solo hijo]
   [Ir a P#8 si ha / tenido más de un hijo]
   [Ir a P#7 si ella no sabe la fecha de nacimiento]

2. ¿Cuál es la edad de su primer hijo? ____________________________

3. ¿Cuál es la fecha de nacimiento de su último hijo? (DD/MM/AAAA) ____________________________
   [Ir a P #9 si el entrevistado no conoce la fecha de nacimiento]
   [Ir a P #10 si se no conoce la fecha de nacimiento]

4. ¿Cuál es la edad de su último hijo? ____________________________

5. ¿Usted está trabajando actualmente?
   No (00) [Ir a P#11]
   Sí (01) [Ir a P#13]

6. ¿Has trabajado fuera de su hogar en el pasado?
   No (00) [Ir a P#15]
   Sí (01)

7. ¿Cuál era su ocupación? ____________________________

8. ¿Cuál es su ocupación? ____________________________

9. ¿Está empleada a tiempo parcial o a tiempo completo?
   Tiempo parcial (00)
   Tiempo completo (01)

10. Incluyéndole a usted, ¿cuántas personas viven en su casa? ____________________________

11. ¿Con quién vive usted? (Seleccione todas las que corresponda)
   Espeso/Pareja (00)
   Hija(s) (01)
   Hijo(s) (02)
   Nieto (Nietos) (03)
   Hermana(s) (04)
   Hermano(s) (05)
   Otros miembros de la familia (06)
   Amigo (s) (07)
   Otra persona ________ (08)

12. ¿Cuántas de estas personas son adultos (18 años o más)? ____________________________

13. ¿Cuántos habitaciones se encuentran en su hogar? ____________________________

14. ¿Cuántos baños se encuentran en su hogar? ____________________________
1. ¿Cuál es su ingreso familiar anual?
   No sabe (00)
   Menos de $5,000 (01)
   $5,000 - $11,999 (02)
   $12,000 - $15,999 (03)
   $16,000 - $24,999 (04)
   $25,000 - $49,000 (05)
   Más de $50,000 (06)

HISTORIA DE RECLUTAMIENTO DE CASO
Gracias por tomarse el tiempo hoy para hablar conmigo acerca de su experiencia con el cáncer de seno. Me gustaría conocer un poco más acerca de su experiencia con el cáncer de seno y con el sistema de salud en Puerto Rico. ¿Puedo contactar con usted en una fecha posterior para hacerle algunas preguntas más?
Physicians Interview Guide (Spanish)

CÁNCER DE MAMA PILE SORT Y RANK ORDER. Ahora le preguntaré algunas preguntas sobre el cáncer de seno. Estoy interesada en aprender más acerca de cómo las personas en Mayagüez piensan sobre el cáncer de seno. Me gustaría saber más sobre cómo usted piensa sobre el cáncer de seno y sobre sus experiencias con el cáncer de seno. Por favor, recuerde que no hay respuestas correctas o incorrectas.

SECCIÓN I: PILE SORT

Pile Sort Direcciones:
• Tengo un grupo de tarjetas con palabras o frases.
• Primero me gustaría que usted lea cada tarjeta.
• Por favor, use las palabras o frases para crear grupos de las cosas que son similares.
• Cuando haya terminado por favor hágamelo saber.

[DESPUÉS PARTICIPANTE TERMINA PILE SORT]

Pile Sort Preguntas:
• Por qué puso estas palabras o frases juntas?
• ¿Qué es lo que hace a estas cosas similares?
• ¿Qué es lo que hace a estas cosas diferentes al uno del otro?

SECCIÓN II: RANKING

Rank Order Direcciones:
• Tengo un grupo de tarjetas con palabras o frases.
• Primero me gustaría que usted lea cada tarjeta.
• Por favor, ponga las palabras en el orden de más importante/grave a menos importante/grave.
• Cuando haya terminado por favor hágamelo saber.
[DESPUÉS PARTICIPANTE TERMINA PILESORT]

**Ranking Preguntas:**

**I. Prevención**
- Por qué puso estas palabras o frases en este orden?
- ¿Lo que hace que ______ más importante que ________?
- ¿Lo que hace que ______ menos importante que ________?

**II. Los Riesgos**
- Por qué puso estas palabras o frases en este orden?
- ¿Lo que hace que ______ más importante que ________?
- ¿Lo que hace que ______ menos importante que ________?

**III. Los Síntomas**
- Por qué puso estas palabras o frases en este orden?
- ¿Lo que hace que ______ más importante que ________?
- ¿Lo que hace que ______ menos importante que ________?

*PREGUNTE SÓLO SI, ESTA PRIMERA ENTREVISTA DEL MÉDICO*

**SECCIÓN III: EL SISTEMA DE SALUD**

**EL SISTEMA DE SALUD EN PUERTO RICO**

Por favor, ¿puedes hacer un dibujo para explicar cómo funciona el sistema de salud en Puerto Rico? [Dale entrevistado un papel y un lápiz]

**SECCIÓN IV: SOCIODEM PREGUNTAS**

**HISTORIA DEL CÁNCER**

Ahora le haré algunas preguntas sobre sus experiencias con el cáncer.

1. **¿Ha sido diagnosticado con cáncer, cualquier tipo de cáncer?**
   - No (00) [Ir a la sección siguiente]
   - Sí (01)
   - No Sabe (03) [Ir a la sección siguiente]
1. ¿Con qué tipo de cáncer fue diagnosticada?
   Otro tipo de cáncer (00)
   Cáncer de mama (01)

2. ¿Cuándo se le diagnosticó un cáncer? (DD/MM/AAAA) ____________________________
   a. [Ir a P#4 si se no conoce la fecha]

3. ¿Qué edad tenía usted cuando fue diagnosticada con cáncer de seno? _______________

Ahora le haré algunas preguntas sobre las experiencias de cáncer en su familia.

1. ¿Alguien en su familia ha sido diagnosticada/o con cáncer de seno?
   No (00) [Ir a la sección siguiente]
   Sí (02)
   No sabe (03)

2. ¿Cuál miembro de la familia fue diagnosticado/a con cáncer? [Por cada miembro de la familia que mencione, pregunte si estaban relacionados/as por el lado materno o el lado paterno de la familia.]
   ____________________________

3. ¿Tiene amistades, vecinos/as o compañeros/as de trabajo que han sido diagnosticada con cáncer de seno o que han muerto a causa de cáncer de seno?
   No (00) [Ir a la sección siguiente]
   Sí (02)
   No sabe (03) [Ir a la sección siguiente]

4. ¿Cuál es o fue la relación de esta persona con usted? ____________________________

INFORMACIÓN SOCIODEMOGRÁFICA Las siguientes preguntas se refieren a la información demográfica.

1. ¿Cuál es su fecha de nacimiento? (DD/MM/AAAA) ____________________________
   [Ir a P#2 si el entrevistado no conoce la fecha de nacimiento]
   [Ir a P#3 si se no conoce la fecha de nacimiento]

2. ¿Cuál es su edad? ____________________________

3. ¿Cuál es su sexo? [No pregunte, simplemente grabe sexo]
   Hombre (01)
   Mujer (02)

4. ¿Cuál es su estado civil?
   Soltera (00)
   Viuda (01)
   Casada (02)
   Acompañada (03)
   Separada (04)
   Divorciada (05)

5. ¿Cuál es su ocupación actual? ____________________________
1. ¿Cuál es su situación profesional actual? (Seleccione todas las que corresponda)
   Empleado por hospital, grupo u otra entidad (01)
   Medicina privada/socio (02) [Ir a P#7]
   Otro (03)

2. ¿Cuál es el tamaño de su práctica?
   Solo (00)
   2-5 médicos (01)
   5-10 médicos (02)
   11-30 médicos (03)
   31-10 médicos (04)
   100+ médicos (05)

3. ¿Cuál es su especialidad? ______________________

4. ¿Cuántos años hace que practica esta especialización? ______________________

5. ¿En cuál escuela de medicina estuvo usted? ______________________

6. ¿Dónde terminó su residencia? ______________________

7. ¿En qué área de especialidad hizo su residencia? ______________________

HISTORIA DE RECLUTAMIENTO DE CASO
Gracias por tomarse el tiempo hoy para hablar conmigo acerca de su experiencia con el cáncer de seno. Me gustaría conocer un poco más acerca de su experiencia con el cáncer de seno y con el sistema de salud en Puerto Rico. ¿Puedo contactar con usted en una fecha posterior para hacerle algunas preguntas más?
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June Omadela Carrington was born in Georgetown, Guyana South America. She migrated to Brooklyn, New York with her family in 1993. In 2003 she graduated from Martin Luther King Jr. High School (New York, New York). She earned a Bachelor of Arts in Anthropology with highest honors from CUNY Herbert Lehman College in 2007. She spent the next two years in Buffalo, New York where she earned a Master of Arts in medical anthropology from SUNY University at Buffalo in 2009. In the same year she was awarded the prestigious McKnight Doctoral Fellowship from the Florida Education Fund and the Ronald E. McNair Fellowship from the University of Florida’s Graduate School. She enrolled in the University of Florida Anthropology Department’s Doctoral Program during the summer of 2009. In 2010 she also enrolled in the University of Florida Master of Public Health Program. Two years later she earned her Master of Public Health with a concentration in Social Behavioral Sciences. June Omadela Carrington received her Ph.D. from the University of Florida in the fall of 2015. In the same semester she began a research postdoctoral position at the University of Miami School of Nursing and Health Studies’ Center of Excellence for Health Disparities Research: El Centro.