

COLORECTAL CANCER SCREENING AMONG CHAMORU ON GUAHAN:
BARRIERS AND ACCESS TO CARE

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DEDICATION

To my dad, Carlos de la Concepcion Diaz, who is always with me and continues to guide me in my life, and to my lola, Josefina de la Concepcion Diaz, who exemplifies love, intelligence, and light. Thank you for teaching me how important it is to care for others and to work hard. I am forever grateful to you both.

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ABSTRACT

Colorectal cancer (CRC) is the second most common cause of cancer death on Guahan (Guam). Chamoru, the Indigenous peoples of Guahan, have the highest mortality rates in CRC on island, which implicates the need for earlier detection. Limited research has been conducted on CRC screening behavior among Chamoru. To address the gap, this study seeks to understand, explore, and predict factors associated with CRC screening among Chamoru, and to address the research questions: (1) How does access to care impact colorectal cancer screening among Chamoru on Guam; and (2) What are barriers to colorectal cancer screening among Chamoru on Guam? Guided by Andersen's Behavioral Model of Health Service Utilization, individual predictors were categorized as predisposing, enabling, and need factors that facilitate or hinder CRC screening. A mixed quantitative and qualitative methods approach was utilized. First, screening data from the 2010 Guam Behavioral Risk Factor Surveillance System were used to model the association between CRC screening and predisposing, enabling, and need factors. Second, semi-structured in-depth interviews with Chamoru men and women were conducted on why they opted for or against CRC screening. Purposive and snowball sampling was implemented to recruit participants due to the potentially sensitive and stigmatizing subject of colon/rectum screening processes. Binary logistic regression was used in quantitative analysis to determine significant predictors of CRC screening utilization. Qualitative analysis implemented Grounded Theory to determine relevant themes and key findings. Quantitative results show that having an annual check-up and educational attainment of high school or greater significantly predicted CRC screening. Qualitative analysis points to five themes in CRC screening decision-making: (1) being proactive in one's healthcare; (2) intergenerational consciousness of cancer diagnosis and related screening behaviors; (3) social stigma associated with colonoscopies; (4) "If I'm

gonna die, I'm gonna die"; and (5) negative perceptions of the medical system. Findings provide insight toward cultural and health beliefs as facilitators and barriers to CRC screening with broader implications for political status as a determinant of health. Further research toward culturally tailored screening interventions is recommended to address cancer disparities in the context of healthcare access and health equity for Chamoru.

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LIST OF ACRONYMS

ACS	American Cancer Society
BMHSU	Behavioral Model of Health Service Use
BRFSS	Behavioral Risk Factor Surveillance System
CBPR	Community-Based Participatory Research
CDC	Center for Disease Control and Prevention
CHIP	Children's Health Insurance Program
CNMI	Commonwealth of the Northern Mariana Islands
FMAP	Federal Medical Assistance Percentage
FOBT	Fecal Occult Blood Test
GCCCC	Guam Cancer Control Coalition
GCR	Guam Cancer Registry
GDPHSS	Guam Department of Public Health and Social Services
GMHA	Guam Memorial Hospital Authority
GOPA	Guam Office of Public Accountability
GRMC	Guam Regional Medical City
HSR	Human Studies Research

IPS	Information Privacy Security
KAB	Knowledge, Attitudes, and Beliefs
MBTSSW	Myron B. Thompson School of Social Work
MIP	Medically Indigent Program
MSW	Master of Social Work
NASW	National Association of Social Workers
NCCR	National Colorectal Cancer Roundtable
NCHS	National Center for Health Statistics
NIH	National Institute of Health
NPCR	National Program of Cancer Registries
PI	Principal Investigator
SECAP	Survey of Endoscopic Capacity
UN	United Nations
USPSTF	U.S. Preventive Services Task Force

CHAPTER 1

Every year on Guahan, the American Cancer Society holds its annual Relay for Life event at a small high school track and field in the central village of Mangilao. Over ten thousand residents attend the event, lining the track with canopies, barbecue grills, and fiesta food. A resurrected monument of decorated paper bags, each containing a small light and bearing the name of a survivor or loved one lost to cancer, sits at the center of the field. Small crowds take turns walking the worn track throughout the night, often in bright matching t-shirts in remembrance of a loved one. The event nets over \$400,000 a year in donations (American Cancer Society [ACS], 2014). In many ways it is both a testament to the burden of cancer on island and a celebration for those who have survived the disease.

Statement of the Problem

Cancer is the second leading cause of death and accounts for every 1 in 5 deaths on Guahan. The Chamorro or Chamoru, the Indigenous peoples of Guahan, are disproportionately affected by the disease. Although they comprise approximately 37 percent of the island population (U.S. Census Bureau, 2010), Chamoru make up more than half of those newly diagnosed with cancer and more than half of those who die from cancer each year (Guam Department of Public Health and Social Services [GDPHSS], 2009). Contrary to trending declines in U.S. cancer rates, from 1998 to 2002 Chamoru on Guahan had the highest overall age-adjusted cancer mortality rate at 247.2 cases per 100,000, more than 25 percent higher than the US rate (Haddock, Talon, & Whippy, 2006).

This study aims to explore the significant area of cancer screening disparities among Chamoru with a fixed emphasis on colorectal cancer. Limited research has been conducted on colorectal cancer despite its rank as the second most common cause of cancer death and the

fourth highest in cancer incidence (new cases per year) on Guahan (GDPHSS, 2015).¹ The following information reflects data collected from 2008 to 2012 (GDPHSS, 2015). Colorectal cancer ranks third and fourth in cancer incidence for males and females respectively, following prostate and lung cancers for males and breast, cervix, and lung cancers for females. It is the third leading cause of cancer death for both sexes. By ethnicity, Chamoru have the highest age-adjusted incidence and mortality rates in colorectal cancer. Data indicate that colorectal cancer incidence among Chamoru is 39.4 per 100,000 compared to the U.S. rate of 42.8. The next highest incidence rates by ethnicity are Whites at 30.3 and Filipinos and Asians at 27.8. While incidence for Chamoru is lower than the U.S. average, the mortality rate for colorectal cancer among Chamoru is 20.75 per 100,000, above the U.S. rate of 15.7.² Second to the Chamoru in colorectal cancer mortality rates are Filipinos at 10.84 per 100,000 (GDPHSS, 2015).

For the purposes of this study, exploration of positive and negative influences on access to care for Chamoru on colorectal cancer screening will be pursued. This first chapter gives a brief background on Guahan's political and colonial history, the impact of colonization on Chamoru health and wellness, an overview of cancer services on Guahan, and colorectal cancer participation on Guahan. Chapter 2 provides a literature review on cancer screening among Chamoru and Andersen's Behavioral Model of Health Service Utilization as a theoretical framework. Chapter 3 explicates the mixed methodological approaches and data analyses utilized in the study. Chapter 4 discusses results from the secondary data analysis, qualitative in-depth interviews, and mixed methods combined. Chapter 5 concludes the dissertation with a discussion of the findings and implications for colorectal cancer screening education, social welfare, and future research. A glossary of acronyms is provided in Appendix A.

¹ Colorectal cancer mortality is based on aggregate rates from 2002-2007 and 2008-2012.

² Cancer rates for the U.S. are based on 2010 national data as reported by GDPHSS.

Background on Political and Colonial History of Guahan

Guahan is the largest island in the region of Micronesia and is the southernmost island of the Mariana Island chain. Although part of the Mariana Islands, Guahan holds a separate political status and is distinguished from the Northern Mariana Islands (known as the Commonwealth of the Northern Mariana Islands [CNMI]) due to its political and colonial history. It is located below the equator, approximately 3700 miles west-southwest of Hawai`i, 1550 miles south of Japan, and 1500 miles east of the Philippines. The island is 32 miles in length and 9 miles at its widest point. The population on Guahan is estimated at 160,000 persons (U.S. Census Bureau, 2010). The Chamoru comprise the largest percent of the population at 37 percent followed by Filipinos who make up approximately 26 percent. The two next largest groups are Chuukese and White that each constitute approximately 7 percent of the population (U.S. Census Bureau, 2010). Other ethnic groups include other Asians (e.g., Korean, Chinese, Japanese, Vietnamese) and other Micronesians (e.g., Palauan, Pohnpeian, Yapese). The military population and their dependents on island are not necessarily accounted for by Guahan's U.S. Census count. Those living in group quarters on base or on military vessels are counted in the Military or Shipboard census reports (Wyn, Reyes, & Caldwell, 2012). Outside of those exceptions, military personnel might fill out the census on island if they report that they live and sleep most of the time at the Guahan address on the form (U.S. Census Bureau, 2014).

The Japanese tourist industry and the U. S. military are the backbone of Guahan's economy (Guam Economic Development Authority, n.d.). The U.S Air Force, Navy, National Guard, and Army military bases are settled on one-third of Guahan's land mass. The U.S. military controls much of the northern region of the island, which is the most densely populated area of Guahan. The central region holds many of the businesses, government structures, and

tourist areas, while the southern region is remote and holds the largest concentration of agricultural lands (ICF International, 2009).

Guahan's current political status is that of an unincorporated U.S. territory. Its history of colonization is first recorded in 1521 when Ferdinand Magellan, a Portuguese explorer sailing under the jurisdiction of King Charles I of Spain, set foot on the island (Sanchez, 1987). Over three hundred years of Spanish colonization ensued until Spain ceded Guahan to the United States under the Treaty of Paris in 1898 after the Spanish-American War. With the exception of Japanese subjugation during World War II, the U.S. has held Guahan under its administration until the present day. It was the 1950 Guam Organic Act that established Guahan as an unincorporated territory of the United States. Signed into law by President Truman, the act granted the termination of U.S. Naval rule over Guahan, the appointment of a civil governor, and conferred U.S. citizenship upon residents. To date, any person born on Guahan is granted rights to U.S. citizenship by virtue of the 1950 Guam Organic Act. Currently, the U.S. Department of Interior maintains federal administrative power over Guahan. In spite of U.S. citizenship, however, island residents are not able to vote for the U.S. president, nor does the Guahan representative in U.S. congress have any voting power. As an unincorporated territory, Guahan is subject to only select parts of the U.S. constitution as determined by U.S. Congress. As such, various U.S. federal and administrative policies either do not apply or are modified in their application. For example, Guahan residents do not qualify for Supplemental Security Income, and federal Medicaid funding is subject to an annual cap.

In the international arena, Guahan is one of seventeen remaining countries on the United Nations (UN) list of non-self-governing territories (UN, 2009; UN, 2013). This is predicated on the UN Declaration on the Granting of Independence to Colonial Countries and Peoples that

recognizes the right of colonized peoples to self-determine their political status in order to freely pursue economic, social, and cultural development (UN, 1960). In recognition of this right, Guam Public Law 23-147 (1997) mandates the appointment of a Commission on Decolonization to implement and exercise Chamorro self-determination. At present, the commission has created three task forces on Statehood, Free Association, and Independence to advocate for and provide educational outreach to the public about self-determination, and to ultimately hold a plebiscite on Guahan's political status.

Impact of Colonization on Chamoru Health and Wellness

The impact of U.S. colonization on Chamoru health and wellness is documented by Chamoru historian Anne Hattori in her monograph entitled *Colonial Dis-Ease: U.S. Navy Health Policies and the Chamorro on Guam, 1898-1941*. After the Spanish-American war and subsequently, laying claim to Guahan, the U.S. Department of the Navy assumed both administrative and governing authority over the island in both civil and military matters. Hattori (2004) explores the institution of U.S. Naval health policies and the introduction of Western medicine for their impact on Chamoru. She gives voice to Chamoru oral histories via interviews with Chamoru elders that provide nuanced and varied responses to four areas of colonial health policy: the management of persons with Hansen's disease; the regulation of pattered (Chamoru midwives); the first hospital on Guahan for women and children; and the treatment of hookworm. In her examination of "medicine as a colonial force," Hattori argues that Western health practices were often in contradiction to Chamorro values, beliefs, and practices, and that the U.S. colonial health system by its punitive and isolationist nature intrinsically discouraged the participation of many Chamoru (p. 56). For example, she describes that Chamorro children were subject to being force fed toxic medicines to combat hookworm in

school and often sequestered for treatments that lasted over a week without parental knowledge or consent. Healing customs as practiced by suruhãna (female healers) were largely ignored, and the function of the pattera (midwife) was heavily regulated through licensing laws, testing, and education requirements as attempts to institute the medical authority of the American physician at the expense of native practitioners (p. 95). Hattori further explains that Navy health policies were heavily influenced by strategies used on the U.S. continent to control overcrowding, infectious disease, and sewage marked by the increase in immigration and the rapid growth of American cities in the early 1900s. Similarly, U.S. Navy officials on Guahan subscribed to the theory of tropical disease as an environmental paradigm. Scientific approaches and health policies thus reflected the neo-colonial attempt to control the island environment and the Chamoru through sanitation, hospitalization, and efforts to dismantle Chamorro healing practices considered antiquated and uncivilized.

Hattori (2004) ultimately emphasizes, however, that “Chamorro people acted neither unanimously nor predictably” and cautions against the use of binaries in portraying Chamoru participation in colonial health practices. Instead she returns to Chamoru oral histories to exemplify nuance, texture, and the varying degrees of Chamoru response to colonial health policies.

Historical trauma related to colonization has negatively affected Chamoru behavioral health and wellness (Pier, 1998, Rapadas, 2007). Historical trauma is the mass trauma experienced by a population marked by four underpinning assumptions: there is deliberate and systematic subjugation and domination of a people, the trauma is experienced over an extended length of time and beyond that of a single event, the entire population is impacted in a manner that effects a universal experience, and the magnitude of the trauma creates a legacy of health,

social, and economic disparities that persist across generations (Sotero, 2006). A key element of historical trauma is the intergenerational transmission of physical, social, and psychological distress produced by the traumatic event(s) to secondary and subsequent generations, resulting in a cycle of trauma response (Sotero, 2006).

For the Chamoru, historical trauma is exemplified by the multitude of consequences of Guahan's 400 years of colonization. Among them is war, genocide, depopulation, loss of ancestral land, lack of political self-determination, and the erosion of Chamoru language and cultural practices (Pier, 1998). Examples of consequent behavioral health challenges among Chamoru are depression, anxiety, substance abuse, suicide and violence (Pier, 1998, Rapadas 2007). Pier, like Hattori (2004), draws attention to diversity within Chamoru culture and communities. Chamoru do not experience historical trauma uniformly and may respond in varied manners, ranging for example from apathy, to hopelessness, to rage (1998). Colonization, with all its ill effects, has also provided opportunity to recognize and highlight Chamoru resilience and strength that manifests in Chamoru attributes such as courage, generosity, reciprocity, spirituality, and close familial connections.

Overview of Cancer Services on Guahan

Epidemiological data and a review of cancer research studies in the Pacific Islands echo the need for increased attention to Indigenous populations and cancer disparities (Hughes, Tsark, Kenui, & Alexander, 2000; Ka'opua, White, Rochester, & Holden, 2011; Moore et al., 2010). Previous assessments on cancer screening and diagnosis capacity underline the critical issue of addressing cancer disparities in Guahan and other U.S. territories due to challenges in the surveillance, detection, diagnosis, and treatment of cancer on these islands (GCCCC, 2013; Tsark & Braun, 2007; Tseng, Omphroy, Cruz, Naval, & Haddock, 2004).

Early detection. Recommendations from a cancer needs assessment on Guahan highlight the necessity for an increase in cancer prevention capacity and improved early cancer detection for priority cancers such as lung, prostate, breast, cervical, and colorectal cancers (Tseng et al., 2004). Indeed, although cancer is a primary concern, medical services and accessibility of care is limited. At present there are three hospitals on island, but up until 2015 there were only two. The Guam Memorial Hospital Authority (GMHA) is a public hospital for local residents with a restricted capacity of 158 acute care beds on-site and 40 long-term care beds at its skilled nursing facility in a separate location. Guahan legal mandate dictates that GMHA serve all persons who seek medical services regardless of financial ability. The hospital has historically struggled with U.S. accreditation. The Joint Commission recently accredited GMHA in 2010 after almost thirty years of failed attempts. Severe financial debt, staffing, bed capacity, and overcrowding at GMHA remain critical issues (Office of the Governor of Guam, 2012).

The U.S. Navy manages the second hospital located on its military base. Service is restricted to military personnel, retirees, veterans, and eligible dependents. A third hospital, Guam Regional Medical City (GRMC), opened to the public in July 2015. The privately funded hospital is a 132-bed acute care facility. All three hospitals have the capacity to perform colonoscopies and sigmoidoscopies. Guam Regional Medical City is the only facility with the capacity to perform a computed tomographic colonography also known as a virtual colonoscopy, although the U.S. Preventive Services Task Force (USPSTF) reports limited evidence for evaluating its effectiveness at this time (USPSTF, 2016). In addition to the three hospitals, there are four private cancer-related clinics, all of which are situated in the central or northern areas of Guahan.

Technology for cancer screening on island is available albeit limited. Shortages in trained technicians, physicians, and other medical staff, as well as inadequate screening equipment and supplies are pervasive (GCCCC, 2007; Office of the Governor of Guam, 2012; Tseng et al., 2004). It is difficult to determine what the overall screening capacity for the island's cancer-related centers are, and each center differs in their insurance acceptance policies. For instance, of the four centers that perform mammograms, only one accepts Medicaid or the locally funded Medically Indigent Program (MIP). Furthermore, diagnostic laboratories perform at minimum capacity. It is not uncommon for specimens to be sent off-island for analysis (Office of the Governor, 2012; Tseng et al., 2004), risking loss of specimens and delayed diagnosis.

Treatment. Options for treating cancer on Guahan have improved but are limited. Radiation therapy was recently restored in 2009 after a seven-year absence of radiation treatment due to a super typhoon that destroyed the island's only radiation equipment in 2002 (GCCCC, 2007). Chemotherapy is available at three cancer clinics although issues with importing of and contracting for necessary medical supplies persist. Consequently, it is typical for residents to seek cancer care off-island and travel to the Philippines, Hawai'i, and other U.S. states for medical attention, often exacerbating the high cost of cancer treatment and requiring increased family support (GCCCC, 2007; Tsark & Braun, 2007; Tseng et al., 2004).

Surveillance. Data on cancer and screening on Guahan is collected by the Guam Cancer Registry (GCR). The GCR is funded and maintained by the University of Guam, University of Hawai'i Cancer Center, GDPHSS, and the National Institute of Health (NIH). It is the only comprehensive cancer data system on island (Haddock, 2010). By virtue of Guam Public Law 24-198, both medical and non-medical providers of services to persons diagnosed with cancer must submit reporting on new cancer cases to the GCR. Although established in 1998 through

local legislation, it was not until 2007 that the CDC National Program of Cancer Registries (NPCR) provided training to the GCR staff in order to standardize reporting methods (GCR, 2010). The GCR contains standardized data on patient demographics; patient insurance status; tumor site; histology type; patient status; receipt and type of cancer screening; receipt and type of treatment; method of diagnosis; and date of first cancer diagnosis. In addition, GCR contains information on patient address and village of residence. Although receipt and type of screening is recorded by the GCR, preventive screening is not differentiated from diagnostic screening.

An additional source of data on screening is the Behavioral Risk Factor Surveillance System (BRFSS). The BRFSS is a U.S. data collection survey to monitor information on health risk behaviors, preventive health practices, and healthcare access. The Centers for Disease Control and Prevention (CDC), together with the U.S. states and territories, support and administer the BRFSS via a statewide/islandwide telephone surveillance system on an annual basis (CDC, 2008). Guahan began implementation of BRFSS in 2001, but the optional module for Cancer Survivorship that includes questions about cancer diagnosis and screening was only collected in the year 2010 and 2014 (CDC, 2015; Uncango et al., 2012). While information is limited, BRFSS data on cancer screening and related health practices provides a potential portal for analyzing health behaviors associated with colorectal and other cancer screening.

Colorectal Screening Guidelines and Participation on Guahan

Standards for colorectal cancer screening on Guahan adhere to U.S. national guidelines. Routine screening is recommended at the age of 50 continuing until the age of 75, with the exception of persons with personal or family history of colorectal adenomas, colorectal cancer,

or inflammatory bowel disease (USPSTF, 2016). Among numerous risk factors to consider are obesity, smoking, diets high in red or processed meats, Type 2 diabetes, and heavy alcohol use (ACS, 2013).

Colorectal screening is commonly performed through use of a fecal occult blood test (FOBT), standard colonoscopy, or sigmoidoscopy. The former is utilized to detect blood in the stool and the two latter methods examine the lining of the colon and rectum for abnormalities. The use of FOBTs is often considered an initial albeit inconclusive step in colorectal screening, as blood in the stool may be indicative of other ailments such as hemorrhoids, ulcers, or colitis (ACS, 2013). Colonoscopies and sigmoidoscopies are more invasive, costly, and require surgical expertise and corresponding surgical facilities. Recommended frequency of screening for the age-appropriate population is FOBTs once a year, sigmoidoscopies every five years in conjunction with an FOBT every 3 years, and a colonoscopy every 10 years (CDC, 2014).

According to a recent Guahan BRFSS report, the proportion of adults age 50 and over that have ever had a colonoscopy or sigmoidoscopy was 38.3% in 2008 and 37.8% in 2010 (Uncangco et al., 2012). These are lower than reported rates showing colonoscopy utilization in the U.S. at 55% in 2010 and overall colorectal screening in Hawai'i at 64.8% in 2012 among the same age cohort (ACS, 2014).

There are currently six facilities on Guahan that can provide endoscopic screening services, i.e., sigmoidoscopies and colonoscopies. These are comprised of the three aforementioned hospitals, two private non-emergency ambulatory surgical facilities, and a physician's office that has its own surgical suite. According to the 2012 Guam Survey of Endoscopic Capacity (SECAP) the typical wait time for a screening colonoscopy is 1 to 2 weeks. Surgeons perform all colonoscopies, as there are no gastroenterologists on island. This differs

considerably from national trends wherein gastroenterologists conduct 82.0% of colonoscopies and surgeons conduct only 11.5% of them (Manninen, Dong, & Wings, 2013). Screening facilities on Guahan also reported that the primary limitations to the provision of colonoscopies are a physician's availability to perform procedures, prep/and or recovery rooms, endoscopes or monitors, and reimbursements (Manninen, Dong, & Wings, 2013).

In spite of the low screening rates, SECAP found that Guahan's capacity was more than adequate to meet the increased need for colorectal cancer screening on island. The survey indicates that approximately 2250 colonoscopies are performed annually (for screening, surveillance, and diagnosis) but there is capacity for an additional 10,313 colonoscopies per year to screen the estimated unscreened population (Manninen, Dong, & Wings, 2013). In order to meet increased demands, however, the most common needs reported were for an increased number of physicians, increased staff or physicians to monitor sedation, and more rooms for procedures and recovery (Manninen, Dong, & Wings, 2013).

To summarize, cancer is the second most common cause of death on Guahan. The Chamorro are overrepresented in both cancer incidence and mortality compared to other ethnic populations on the island. With regard to colorectal cancer, the Chamoru have the highest mortality rates on the island, suggesting the need for earlier detection given the likelihood of surviving colorectal cancer if found in the early stages. Cancer services on Guahan for treatment, surveillance, and prevention have improved over the years but continue to face challenges and limitations connected to issues such as geographic location, insufficient funding, inadequate staffing, and limited resources. Colorectal cancer screening rates are low among residents age 50 and over compared to rates among the same age group in the continental United States, but a recent study on Guahan's capacity to perform endoscopic procedures such as colonoscopies and

sigmoidoscopies indicate the potential to meet an increased demand for these colorectal cancer screening procedures. Significant to the comprehension of Chamoru health and wellness is the recognition of Guahan's political and colonial status as an unincorporated U.S. territory and a non-self governing territory as defined by the United Nations. Chamoru have yet to exercise their right to political self-determination and have been profoundly affected by colonization as evidenced by historical trauma and health disparities.

CHAPTER 2

Literature Review

Cancer Screening Among the Chamoru

Literature specific to cancer screening among the Chamoru is limited and has focused predominantly on breast cancer and Chamoru women living in California. In general, these studies vary in focus from descriptive analysis of screening rates, predictors of screening utilization, and culturally tailored education interventions. Outside of these, a few studies have been conducted on Guahan and will also be discussed below.

California studies. Research in California has spanned several studies on breast and cervical screening (Cruz et al., 2008; Tanjasiri & Sablan-Santos, 2001; Tanjasiri, Sablan-Santos, Merrill, Quitugua, & Kuratani, 2008) and colorectal cancer screening rates (Nguyen et al., 2003) among Chamoru women. One study has been published on prostate and colorectal cancer screening rates among Chamoru men (Wu et al., 2004). Prevalent methodological characteristics among these studies were use of secondary data analysis, surveys (on knowledge, attitudes, and beliefs [KAB]), focus groups, mixed method designs, use of translator or bilingual services, adaptation/creation of culturally tailored educational materials, Community-Based Participatory Research (CBPR), and nonprobability sampling.

Primary significant correlates of breast or cervical cancer screening utilization for Chamoru women in California were having health insurance (Cruz et al., 2008; Sadler et al., 2010; Tanjasiri & Sablan-Santos, 2001) having a regular source of care (Cruz et al., 2008; Sadler et al., 2010), having had a recent annual physical exam (Sadler et al., 2010), and knowledge about the specified type of cancer (Sadler et al., 2010). These predictors are congruent with those found in previous mammography utilization research among women (Mounga & Maughan,

2012; Oh, Zhou, Kreps, & Ryu, 2012; Schueler, Chu, & Smith-Bindman, 2008). Findings varied, however, regarding sociodemographic covariates such as income and education. Tanjasiri and Sablan-Santos (2001) report that higher education and higher income are significant correlates of breast cancer screening. Cruz et al. (2008) found these descriptors to be insignificant, presumably due to relatively high socioeconomic status among respondents, half of whom were affiliated with the U.S. military and received military health benefits.

Two studies independently examined colorectal cancer screening rates for Chamoru men and women in California. Both record high rates of screening that were above or comparable to national screening guidelines at the time. Overall, 61% of Chamoru women age 50 and above (N=128) self-reported receipt of colorectal screening through use of a stool blood test, sigmoidoscopy, or colonoscopy (Nguyen et al., 2003). Parallel screening for Chamoru men in the same age bracket (N=100) was 79.1 percent (Wu et al., 2004). These studies show no significant association between screening and key sociodemographic variables including education, income, employment status, and health insurance coverage. These uncommon findings may be due in part to the limitations of the studies. Both studies are limited by selection bias as a locally compiled directory of Chamoru in San Diego was used to recruit a convenience sample for the study. Authors also document small sample size and the possibility of higher socioeconomic status and mainstream acculturation among those consenting to participate (Wu et al., 2004). These characteristics may vary from the Chamoru population on Guahan and will be explored in this study.

Guahan studies. Three studies related to cancer screening have been conducted on Guahan (Balajadia, Wenzel, Huh, Sweningson, & Hubbell, 2008; Moss, 2013; Rosario, 2010). Balajadia et al. (2008) explore cancer-related knowledge, attitudes, and preventive behavior

(KAB) of the Chamoru on Guahan. Self-identified Chamoru over the age of 50 (n=266) were given English language surveys on KAB for breast, cervical, lung, colorectal, and nasopharyngeal cancers. Receipt of screening was measured by self-reports of having been screened within the past two years. Results for having ever had an FOBT (38.3%), sigmoidoscopy (15.5%), and colonoscopy (33.1%) fell below U.S. national goals of a 50 percent colorectal screening rate for persons age 50 and older (National Center for Health Statistics, 2012). Having health insurance ($p<0.05$) and having seen a doctor within the past year ($p<0.005$) were positively associated screening, while living in the southern part of the island was negatively correlated.

With regard to KAB, respondents generally did not believe that cancer was caused by taotaomo'na (ancestral spirits). Although over a third had been to a traditional healer for medical care, few believed that traditional healers could treat cancer (7.7%) and an even smaller percentage indicated they would visit a traditional healer for cancer treatment (3.8%) (Balajadia et al., 2008). Authors noted that knowledge of FOBT, colonoscopies, and sigmoidoscopies were very limited and concluded that early detection for prostate and colorectal cancers was lagging behind breast and cervical cancer screening utilization for the Chamoru.

Rosario (2010) engaged in qualitative research to more closely examine the link between culture and preventive health-seeking behavior on Guahan. Fifteen Chamoru women participated in interviews on the connection between cervical cancer screening behavior (Pap test) and the Chamoru concept of mamåhlao (shame/embarrassment). Participants were asked to describe what mamåhlao means to them, appropriate versus inappropriate reasons to get a Pap test, and the relationship between modesty and mamåhlao. Interview questions/samples of questions were not provided although general descriptions were given. Study findings indicate that shame,

religion, and morality affect Chamoru women's health-seeking behavior. Unique to this article is the exploration of a Chamoru cultural concept (*mamåhlao*) in relation to preventive screening and the inclusion of religious morality (Catholicism) as a determinant of screening behavior. Rosario (2010) also discusses the perceived stigmatization of gynecological exams (e.g., promiscuity). Although this study focuses on cervical cancer, there are possible implications for colorectal cancer given the invasiveness of a colonoscopy/sigmoidoscopy and the association these potentially have with rectal exams.

Moss (2013) explores cancer experiences of the Chamoru, but expands its purview beyond screening to include treatment and caring for someone with cancer. In-depth interviews were conducted with eleven Chamoru (7 women and 4 men). Eligibility for study participation included persons who a) were accompanying someone who sought cancer screening or treatment; b) sought screening only; or c) were currently receiving or had received treatment. Findings suggest that Chamoru face significant hurdles when seeking screening or treatment, foremost of which are financial barriers such as lack of health insurance coverage. Additional barriers were limited knowledge about cancer and the benefits of cancer screening, as well lack of adequate information about insurance coverage.

Chamoru Perceptions on Health and Well-being

Traditionally, the Chamoru believe that illness is not merely the absence of disease but determined by *taotaomo'na* (ancestral spirits or the people who have become before). Ancient Chamoru practiced veneration of deceased ancestors of a clan or family group believed to be *aniti* (spirits) that influence present day life and reside in nature, most especially the *trunkununu* or banyan tree (Arriola, 2009). Displeasing or disrespecting the spirits could lead to illness. Well-being is maintained through use of *suruhånas* (female traditional healers) or *suruhånus*

(male traditional healers) who utilize medicinal plants, roots, herbal preparations, ointments, dietary advice, and massage to heal illness and promote good health (Lizama, 2011, McMakin, 1975; Pobutsky, 1983; Hattori, 2004). These traditional healers have honed skills that are carefully passed down to them through the generations.

While Chamoru still adhere to cultural values and belief in taotaomo'na (ancestral spirits), Chamoru on Guahan are predominantly Catholic. The Catholic religion, spirituality, and faith in God are highly valued and relied upon to cope with illness and promote healing. At present, the more prevalent form of healthcare on island has been the Western medical system of hospitals, physicians, and health clinics. Chamoru still seek traditional forms of healing for certain ailments and illnesses, but may turn to Western medicine and the U.S. health system to treat cancer and other diseases (Balajadia et al., 2008; Torsch & Ma, 2000; Twaddle, Roberto, & Quintanilla, 2002).

Torsch and Ma (2000) conducted a qualitative comparison of the health perceptions and coping strategies of Chamoru elders on Guahan and elder Chinese in Houston and Philadelphia with chronic disease based on their shared characteristics of ancestor veneration, respect for elders, close kinship ties, and practice of traditional healing. Among their findings were that Chinese and Chamoru elders held common health-seeking behaviors such as self-treatment and home remedies, and use of both Western and traditional physicians and practitioners. The Chamoru elders expressed confidence in the traditional healers and conceptualized that illness had either natural or spirit causes, e.g., making sure to respect the taotaomo'na (ancestral spirits) to avoid illness. Notably, these same elders also consulted Western medical physicians and clinics when faced with serious illness. In a similar finding, Tanjasiri and Sablan-Santos (2001) report a positive correlation between practices of traditional healing and having a mammogram

among Chamoru women. They suggest that utilization of traditional practices are not at odds with use of institutional medicine and services, and may be connected through the intent for self-care.

From the perspective of Chamoru traditional healers, modernization and colonization have severely undermined the cultural practices of traditional healing. Lizama (2011) explored the status and preservation of traditional Chamoru healing practices from the perspective of *suruhânas* and *suruhânus*. She interviewed 11 Chamoru *suruhâna/u* regarding the utilization of traditional healing practices on island and the challenges to the preservation and perpetuation of these practices. According to the practitioners in her study, persons on Guahan are still seeking care and services from *suruhâna/u*. Some of them felt, however, that this has become secondary to accessing Western medicine or as a last resort (Lizama, 2011). Lizama asserts that challenges to the growth and sustainability of traditional healing practices are multi-layered due to colonization, militarization, and the current economy. Examples of these challenges are finding and accessing medicinal herbs due to military land-takings, loss of land to local development and environmental degradation, and the absence of local regulations specific to the preservation of traditional healing practices. Despite these, Lizama concludes that traditional healers on Guahan continue in their commitment to heal, to provide care, and preserve and perpetuate traditional healing practices (2011).

In a study of Chamoru perspectives on mental health, Twaddle et al. (2002) found that the Chamoru seek help first from their family members, and then the broader community where they solicited advice from the village Catholic priest or held strong belief in the healing powers of the *suruhânas* or *suruhânus*. Similar to Balajadia et al. (2008) and Torsch and Ma (2000), Twaddle, et al. (2002) found that the Chamoru also availed of Western mental health services

and that some used this as a primary source of care. The authors construe these potentially conflicting perspectives as “a cooperative existence of Chamorro traditions and Western ways” but which also demonstrate “Chamorro resistance to Western hegemony” (pp. 54-55).

Cooperation, resistance, or other varied responses to Western healthcare and mental health systems should be contextualized within the cultural, historical, and political environment of the Chamoru, particularly with regard to colonization (Arriola, 2009; Hattori, 2004; Pier, 1998; Rapadas, 2007). Pier (1998) examines the connections between historical trauma among Chamoru and the intergenerational transmission of unresolved trauma, stating that “culturally responsive counseling and psychotherapy is best facilitated by the knowledge of the culture, people, values, customs, traditions, history as well as aspects of the Chamorro culture that create barriers to clients in need of mental health services” (p. 257). Arriola (2009) goes further to explore the Western construct of mental health against the light of Chamoru epistemology, highlighting Chamoru cultural values he deems pertinent to Chamoru well-being. Among these key values are *ina’famaolek* (interdependence), *Sainan Yu’us* (God), *tano’* (land), *mangaffa* (family), *mamåhlao* (respect of shame), *man’ayuda* (assistance or cooperative help), *chenchule’* (gifted reciprocity), *man’amko* (respect for elders), and *taotaomo’na* (ancestral spirits) (Arriola, 2009).³ According to Arriola, “re-valuing indigenous knowledge” will lead to new understandings of Chamoru, that in turn will promote interventions that are relevant to and congruent with Chamoru well-being (p. 107).

Lastly, Chamoru health and well-being is inextricably linked to familial ties and structures (Arriola, 2009; Dames, Hasugulayag, Schwab, & Natividad, 2013; Natividad, 2010; Pier, 1998). For example, in an examination of cancer survivorship, Natividad (2010) employed

³ Translations in parentheses are Arriola’s but are simplifications of the meanings of these Chamoru words. In his thesis, Arriola delves much further into the nuance and deeper connotations of these Chamoru values.

a phenomenological research method to discover how Chamoru women with breast cancer experienced familial support. After conducting 10 interviews in Chamoru to explore the essence of living with breast cancer, Natividad concluded that siblings played an essential role in the social support of these breast cancer survivors and that “the absolute inclusion of family members in the treatment process is essential” (2010, p. 12). Dames et al. (2013) offer a broad but pertinent insight on the centrality of families to health and social welfare across Micronesian cultures such as Chamoru:

The strongest and most stable and competent providers of social welfare in Micronesia remain the familial and kinship networks. Despite the many societal changes and many problems, the connectedness of people with the land, their ways of sustainable island living, and the maintenance of networks of reciprocal relationships are still the cardinal principles that generate the means and meaning for everyday living for most people in the Micronesian islands. (p. 194)

Barriers to Cancer Screening Utilization for Pacific Islander Women

Additional barriers to cancer screening utilization for Pacific Islanders have been documented and are worth noting here. Among these are fear, privacy concerns, lack of awareness of services, and cultural beliefs that impact health seeking behavior (Aitaoto, Tsark, Tomiyasu, Yamashita, & Braun, 2009; Prior, 2009; Wong & Kawamoto, 2010). Examples of beliefs that affect health behavior are fatalistic attitudes toward cancer, notions that cancer is a Western disease with minimal cultural and language translation, and attribution of cancer to corrupt spirits (Aitaoto et al., 2009; Mouna & Maughan, 2012; Prior, 2009).

Theoretical Framework

Access to care is characterized by the properties of both the individual and the systems navigated to attain health services. While issues of access are often associated with cost impediments and insurance status, conceptual models examining factors contributing to healthcare utilization are inclusive of but not limited to financial barriers (Aday & Andersen, 1974; Andersen, 1995; Mechanic, 1966; Penchansky & Thomas, 1981). One of the most frequently utilized theoretical frameworks for examining access to care is Andersen's Behavioral Model of Health Services Use (BMHSU). The model was developed in the 1960s to analyze health service use, measure equitable access to healthcare among families, and affect healthcare policy (Andersen, 1995). Later edits by Andersen, Newman, and Aday established the individual as the primary unit due to the complications of measuring family behavior, and the model was expanded to include environmental variables related to the healthcare system and other external impacts on individual health behavior (Aday & Andersen, 1974; Andersen, 1995; Andersen & Newman, 1973). The BMHSU has been used to investigate healthcare use across varied population categories, by disease, and by type of health service, including among Indigenous communities (Choi, 2009; Cunningham & Cornelius, 1995; Lee, Lundquist, Ju, Luo, & Townsend, 2011) and on cancer screening utilization (Lee et al., 2011; Potvin, Camirand, & Béland, 1995; Xu, 2002). The majority of studies apply the 1995 version of the model, which is the fourth revision of the model since its inception (Andersen, 2008; Babitsch, Gohl, & von Lengerke, 2012). Although a more recent version was created in 2001, this one was most commonly utilized to examine variables such as ethnicity, culture, and health beliefs (Babitsch, Gohl, & von Lengerke, 2012). Thus, the 1995 version will also be used in this study.

The BMHSU proposes that a person's participation in health services is a function of the environment, population characteristics, and health behavior (see Figure 1). Environmental variables are categorized under the healthcare system (e.g., staffing, facilities, organization, policies, etc.) and the external environment (e.g., politics, economic climate, community components, etc.). Population characteristics reflect individual- and provider-related determinants in connection to the predisposition to use services, factors which enable or hinder use, and the need for care (Andersen, 1995). These are labeled in the model as *predisposing characteristics*, *enabling resources*, and *need*.

Predisposing characteristics are those that exist prior to symptoms or illness, such as demographics (age, sex urban/rural residencies, etc.), social structure (education, occupation, ethnicity, community interactions, etc.), and health beliefs (knowledge, perceptions, values) (Aday & Andersen, 1974). Enabling resources potentiate access to care and encompass personal and provider-related resources. Examples of these are income, health insurance, regular source of care, transportation to medical appointments, and patient wait time to avail of services (Andersen, 1995). The concept of need in the model represents a patient's perceived or evaluated need for care, e.g., perceived illness, having symptoms of a disease, or diagnoses.

In the context of the model, Andersen defines "potential access" as the presence of enabling resources, while "realized access" is determined by an individual's health behavior through actual use of services (Andersen, 1995, p. 4). In order to further effect health policy, the model includes consideration of health outcomes as designated by a patient's perceived health status, evaluated health status, or patient satisfaction. Lastly, all components of the BMHSU act to inform one another as feedback loops such that health behavior affects health outcomes, which in turn inform predisposing characteristics, enabling resources, and need (Andersen, 1995).

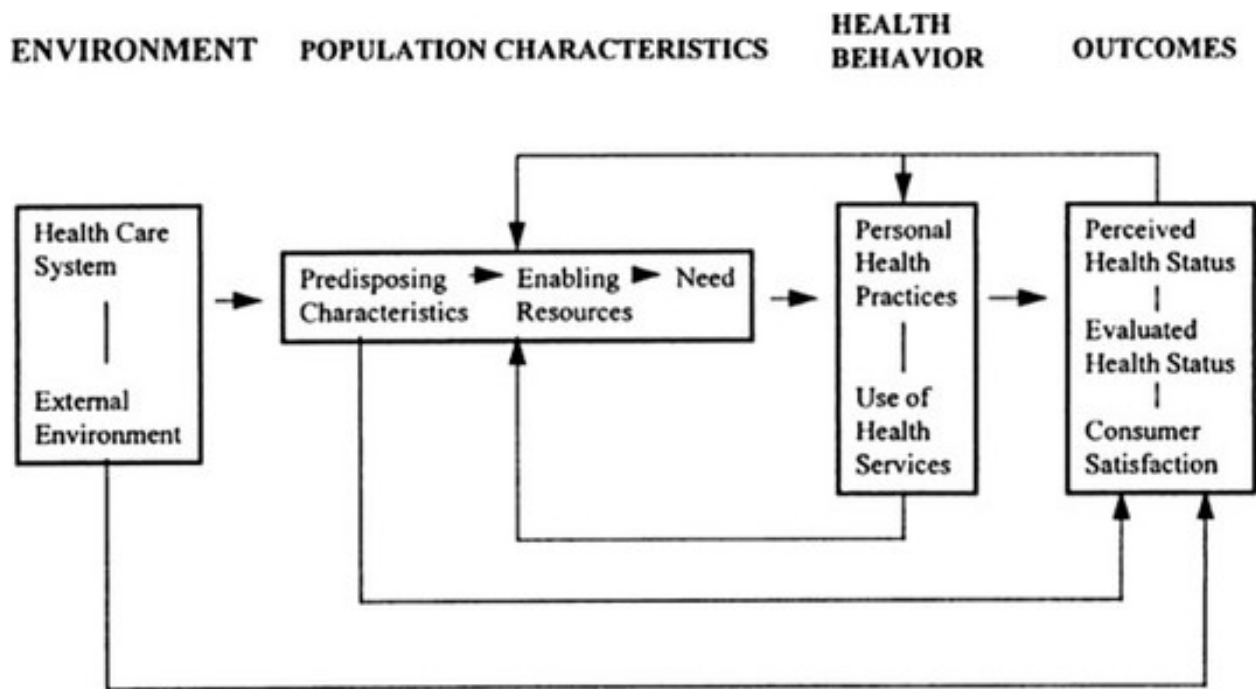


Figure 1. Andersen's Behavioral Model of Health Services Use, 1995 (Andersen, 1995, p. 8)

In general, critics of access to care frameworks find that the concept lacks precise definition and is difficult to operationalize (Gold, 1998; Kullgren & McLaughlin, 2010; McLaughlin & Wyszewianski, 2002; Penchansky & Thomas, 1981). The BMHSU has not escaped this criticism, but continues to be a dominant conceptual framework in analysis of healthcare utilization. Systematic reviews on BMHSU find, however, that studies are primarily descriptive and without complex statistical analysis in part due to the limited variables studied (e.g., environment variables are less often researched than population characteristics) and the lack of specific or uniform measures across studies (Babitsch et al., 2012; Phillips, Morrison, Andersen, & Aday, 1998). Ricketts and Goldsmith (2005) further recommend that a healthcare access model should include a measure of non-use as well as actual utilization in order to genuinely evaluate healthcare delivery interactions.

In addition to these limitations, the BMHSU model does little to highlight cultural influence on health utilization. In light of this criticism, Andersen has suggested culture fits

adequately into the social structure category of predisposing characteristics and does not merit an additional component to the model (Andersen, 1995). Critics of behavioral models such as Andersen's argue, however, that cultural influence on health behavior should be more adequately represented (Burke, Joseph, Pasick, & Barker, 2009; Cunningham & Cornelius, 1995; Pasick & Burke, 2008; Zapka & Cranos, 2009). Burke et al. (2009) also argue that health behavior theories are based heavily on individual behavior and often predicated on white, middle-class, and male norms with minimal attention to cultural and social context even when they profess to account for it.

For the purposes of this study, the BMHSU will serve as a theoretical framework to contextualize variables and themes related to colorectal cancer screening utilization among Chamoru. The components of predisposing characteristics, enabling resources, and need will be used to specifically analyze and predict health behavior through analysis of a national data set on health risk factors and behavior surveillance, and to the extent possible, qualitative interviews. This will inform the two research questions of the study. First, how does access to care impact colorectal cancer screening among Chamoru on Guahan? Second, what are barriers to colorectal cancer screening among Chamoru on Guahan? The second question potentially addresses limitations in the BMHSU by providing Chamoru on Guahan an opportunity to share additional key contextual influences such as cultural beliefs and social forces that may impact receipt of cancer screening.

CHAPTER 3

MIXED METHODOLOGIES

This study utilized a mixed methods approach. First, secondary data analysis of existing screening data on Guahan from a national health survey was performed to examine access to care variables. Second, interviews were conducted with Chamoru men and women about positive and negative influences on the decision of whether or not to get screened for colorectal cancer.

Secondary Data Analysis

Data source. Data for this study was obtained from the Guam 2010 BRFSS through the GDPHSS. As previously noted, BRFSS is an ongoing data collection program created by the CDC to monitor information on health risk behaviors, chronic disease, preventive health practices, and healthcare access. The GDPHSS, in adherence to CDC regulations, supports and administers the BRFSS via an annual islandwide telephone survey. All responses to the survey are anonymous and de-identified. For the purposes of this study, data was restricted to the year 2010 because although Guahan has conducted BRFSS for 13 years since the nationwide surveillance system began in 1984, it is the only year that includes both a Cancer Survivorship Module that surveys CRC screening and a “state-added” ethnicity category that has a designated classification for Chamoru (CDC, 2016b).

Study participants. The 2010 BRFSS utilizes a random-digit dialing technique in each participating state or territory to sample civilian, non-institutionalized persons age 18 years and older who have landline telephones. There are 784 respondents to the survey in the 2010 Guam BRFSS. As the focus of the study is on how access to care and other factors influence the likelihood of Chamoru to be screened for colorectal cancer, respondents who did not identify as Chamoru were not included. The sample is thus restricted to persons age 50 and above who self-

identify as Chamoru. Participants ≥ 50 years of age account for 331 of respondents. Of these, 128 self-identify as Chamoru. Hence, sample size for this arm of the study is $N = 128$.

Variables. The outcome variable of colorectal cancer screening utilization is generated as a dichotomous categorical variable (yes/no) and measured as a “yes” response to either of the two screening questions on colorectal cancer in the 2010 Guam BRFSS (see Table 1).

Respondents who report “don’t know/not sure” or “refused” are excluded.

Table 1. Colorectal Cancer Screening Questions in BRFSS

Screening Questions*
A blood stool test is a test that may use a special kit at home to determine whether the stool contains blood. Have you ever had this test using a home kit?
Sigmoidoscopy and colonoscopy are exams in which a tube is inserted in the rectum to view the colon for signs of cancer or other health problems. Have you ever had either of these exams?

*Questions are reprinted from 2010 BRFSS (CDC, 2010)

Predictor variables of interest represented in BRFSS and categorized by population characteristics from Andersen’s BMHSU are listed in Table 2. These predictors are of interest because they reflect demographics (e.g., sex, education level), risk factors for colorectal cancer (e.g., smoking, diabetes, excessive drinking), or are supported in the literature as strong predictors of colorectal cancer screening (e.g., health insurance status, having a regular source of care, receiving annual check-ups).

Predictor variables with polytomous outcomes will instead be distinguished as two categorical outcomes. For example, education status will be separated into persons who have attained a high school degree or higher, and perceived health status will be segregated into fair/poor versus good/very good/excellent. This is done to create an interpretation of odds ratios that reflect community norms and values.

Table 2. BRFSS Predictor Variables for Colorectal Cancer Screening

Population Characteristics	Predictor Variables	Dichotomous Categories
Predisposing Characteristics	Sex	male or female
	Education level completion	< high school or \geq high school
Enabling Resources	Income	<\$25K or \geq \$25K
	Health insurance status	yes or no
	Employment status	unemployed or employed
	Has a usual source of care	yes or no
	Unable to see a doctor due to cost	yes or no
	Length of time since last medical check-up	< 1 year or \geq 1 year
Need	Perceived health status	fair/poor or good/very good/excellent
	Diabetes diagnosis	yes or no
	Current smoker	yes or no
	Current smokeless tobacco use	yes or no
	Current betel nut use	yes or no
	Excess alcohol consumption	yes or no
	Exercise in the past month	yes or no
	Cancer diagnosis	yes or no

Data analysis. Descriptive statistics, chi-square tests of independence, and binary logistic regressions were performed using Stata 12.1 (StataCorp, 2011). Chi-square tests of independence were used to examine the relationship between predictor variables and colorectal screening utilization. Predictors were then entered into unadjusted binary logistic regressions to determine

odds ratios outcomes. An adjusted model with variables was constructed to assess association of predictor variables to colorectal cancer screening. Odds ratios were formulated to calculate likelihood to be screened. . Cases with missing data were automatically dropped from logistic regression models. Statistical limitations will be discussed in in Chapter 5.

Short Demographic Survey

Prior to conducting interviews with research participants of this study, a short demographic survey was administered (Appendix B). Descriptive data from the short survey administered to interview participants were entered into an excel spreadsheet. The PI and research assistants created a codebook to convert dichotomous and polytomous string variables into numeric values for the purpose of performing computations in STATA 12.1 (StataCorp, 2011). These values were used to write code and compute descriptive statistics for the participants who were interviewed.

Qualitative Data: In-depth Interviews

A qualitative and inductive methodology was selected as part of this study in order to explore the barriers to accessing colorectal cancer screening for the Chamoru on Guahan. The decision to seek cancer screening is complex and often rooted in context that requires detailed examination (Aitaoto, Braun, Estrella, Epeluk, & Tsark, 2012; Ka'opua, 2008; Lantz et al., 2003). In-depth interviews allow entrance into a participant's perspective and facilitate storytelling (Patton, 2002). In congruence with Chamoru culture, storytelling creates an honored and safe space for Chamoru to express their feelings, values, beliefs, and customs; all of which contribute to the understanding of health beliefs and practices. In order to minimize risk, ensure protection, and guarantee voluntary participation of participants in the study, this research

proposal was submitted to and approved by the Institutional Review Board of the University of Hawai`i Committee on Human Studies (CHS#23203).

Study participants and sampling. Study participants were persons who (a) self-identified as Chamoru, (b) were ≥ 50 years and ≤ 75 years at the time of the study, (c) expressed interest in participating in an interview, (d) were current residents of Guahan, and (e) provided written consent to participate. The age restriction adheres to the recommended ages for colorectal cancer screening according to national guidelines set by the U.S. Preventive Services Task Force (USPSTF, 2016).

A non-probability, purposive sampling was utilized to recruit participants for interviews. Promotional flyers (Appendix C) were distributed via public health and social service networks including the GDPHSS, Guam National Social Work Association, GDPHSS Non-Communicable Disease Consortium, Guam Alternative Lifestyle Association, Guam Cancer Registry, University of Guam Division of Social Work, and the Southern Region Community Health Center. An announcement was also posted in the local newspaper community bulletin to request volunteers for the study (Appendix D). In addition, snowball sampling was utilized. Once a participant completed the interview, they were asked if they knew someone appropriate and willing to participate in the study. Prospective names and contact information were not collected. Instead, the participant was requested to let potential interested participants know about the study and to contact the PI if they wanted to volunteer. Snowball sampling was suitable due to the potentially sensitive and stigmatizing subject of colon/rectum screening processes (Goldman, Diaz, & Kim, 2009; Mikocka-Walus, Moulds, Rollbusch, & Andrews 2012; Wong, Bloomfield, Crookes, & Jandorf, 2013), which may have deterred persons from replying to the flyer or newspaper announcement. Saturation was anticipated at 20 to 25 interviews (Corbin & Strauss, 2015).

Twenty-seven participants volunteered and consented to being a part of the study. Due to a technological issue with the audio recording, one of the interviews had to be repeated and the participant, although willing, was not able to reschedule. Consequently, 26 participants were in the study.

Interview procedures. Interviews with interested participants were scheduled at a time and location convenient to the participant, e.g., the participant's home, local diner, community center, or office. After the informed consent was reviewed and if the participant agreed to its terms, the participant was provided with a copy of the consent. A short demographic survey was administered (Appendix B), after which the interview was conducted.

The PI, who was trained in interviewing skills and approaches in a graduate qualitative research course, facilitated each interview using a semi-structured transcript (Appendix E). Each interview lasted approximately 60 minutes and was audio-recorded with a digital audio recorder. Participants were asked questions related to their family history of cancer, cancer beliefs, what they knew about colorectal cancer and recommended screenings, whether they had been screened, and how they decided whether or not to get screened. Participants received a \$20 gift card in appreciation of their participation.

Qualitative Data Analysis

Qualitative data analysis was performed by a team of five members comprised of the principal investigator (PI) and four graduate students in the MSW program at the Myron B. Thompson School of Social Work (MBTSSW). All members of the team completed Human Studies Research (HSR) and Information Privacy Security (IPS) training for exempt researchers and key personnel as required by the Human Studies Program at the University of Hawai'i at Mānoa. Graduate students were trained in transcription and coding by the PI, and received three

credits per semester for their work. Two of the four students were on the team for one semester, and the remaining two assisted with qualitative data analysis for two semesters.

Aspects of Grounded Theory were utilized to analyze the interview data. Transcripts and coding were reviewed in three stages. In the first stage, interviews were transcribed and reviewed for accuracy. In the second, initial coding was performed utilizing a line-by-line coding technique to generate significant codes and potential themes. Lastly, emergent codes from the initial coding process generated focused coding themes to further analyze the data and uncover deeper contextual meaning.

Transcription. Digital audio-recordings of the interviews were transcribed by research team members and assigned a unique identifier to maintain the anonymity of research participants. Once the transcriptions were completed, the PI reviewed all recordings and corresponding transcripts for accuracy and necessary edits. The digital audio files were kept in an encrypted digital file with a password to ensure maintenance of confidentiality. In terms of Chamoru translation, participants translated their Chamoru phrases in English during the interviews. In addition, the PI consulted with a Chamoru culture expert to better understand the deeper meanings connected to the translations.

Initial coding. After the transcriptions were reviewed and edited, the PI divided transcripts randomly among research assistants for initial coding. Aspects of Grounded Theory methodology were utilized for interpretive analysis to illuminate deeper beliefs and meanings connected to colorectal cancer screening behavior among Chamoru. Given the limited research on this subject, Grounded Theory methodology is appropriate to facilitate the examination of emerging phenomena with intent to demonstrate how beliefs and meanings prompt action, and how logic and emotional factors combine to influence behavior (Corbin and Strauss, 2015).

Notes were recorded to track the coding process and to keep a log of significant codes. In examining codes for each transcript, larger themes began to emerge from the codes and were recorded. After 14 of the 26 transcripts were reviewed and coded, it was determined by the research team that saturation had been reached. In the field of Grounded Theory methodology, the definition of saturation can be complex and often contested given the varied approaches to the methodology and concerns about foreclosing analytic possibilities prematurely (Charmaz, 2006). For the purposes of this first phase of interpretive analysis, saturation was determined by the absence of new significant codes and relevant themes (Corbin & Strauss, 2015) with the intent to continue analysis of these initial findings in the focused coding process (Charmaz, 2006).

Focused coding. The research team utilized a focused coding technique to advance coding of the 26 interview transcripts. The goal in this approach is to refine earlier themes from the initial coding phase and to determine the parameters and accuracy of those themes (Charmaz, 2006). At least two research team members coded every transcript separately and manually utilizing the five aforementioned themes in a focused coding technique. Sessions were then convened to go over each transcript to determine the fit of the coding themes to the data, to discuss the criterion for each theme, and to further interpretation of the data. Notes were taken during each session. Once consensus on the focused codes were reached for each transcript, the transcript text and corresponding codes were entered into qualitative data software, QSR International's NVivo 11 Pro, to electronically manage the data, facilitate ongoing comparison of codes and data, and to allow for enhanced visual analysis of findings through NVivo tools such as charts, word trees, and graphs.

CHAPTER 4

Findings

BRFSS Secondary Data Analysis Findings

Secondary data analysis of BRFSS for Chamoru respondents for colorectal cancer screening was conducted using STATA 12.1 (StataCorp, 2011). Descriptive data are shown in Table 3. There were 784 total respondents surveyed in the 2010 BRFSS. For the purpose of this study, non-Chamorro respondents and those ≤ 49 years old (under screening age) were dropped from the sample. Self-reported identification of being Chamoru was determined by the DPHSS state-added variable “ethnicity” in which the question “What is your ethnicity?” was posed and the respondent indicated either “Chamorro” or “mixed ethnicity including Chamorro.” As a result, 128 Chamoru \geq age 50 were retained in the analysis (N=128). The mean age for respondents in the study is 61.07 ($SD = 8.24$).

Table 3. Demographics of BRFSS Respondents

Variable	Total Respondents	
	n	%
Female	86	67.0
Education < H.S. completion	28	21.9
Annual income < \$25K	33	31.0
No health insurance	16	12.5
Unemployed	12	9.5
Self-reported health as fair/poor	45	35.2
Screened for colorectal cancer	64	50.0

A chi-square test of independence was used to examine the relationship between predictor variables and colorectal cancer screening utilization. Predictor variables for excess alcohol consumption and current smoker status were dropped because more than half of the respondents did not answer these questions on the survey. Five predictor variables showed cell frequency counts with less than five observations and were also dropped from analysis, as they did not meet the assumptions for chi-square cross-tabulation. These variables were employment status, smokeless tobacco use, regular source of care, unable to see doctor due to cost, and prior cancer diagnosis. Chi-square test results and collinearity statistics of remaining predictor variables are indicated in Table 4. Multicollinearity was not an issue as indicated by VIF and Tolerance statistics.

Table 4. Chi-Square Results of Colorectal Cancer Screening (DV) and Predictor Variables (IV)

Variable	n (%)	χ^2	VIF	Tol
Female	43 (67.2)	$p=1.00$	1.24	0.81
Education < H.S. completion	7 (10.94)	$p=.003$	1.19	0.84
Annual income < \$25K	13 (24.1)	$p=.110$	1.31	0.77
No health insurance	5 (7.81)	$p=.109$	1.12	0.89
Check-up within year	55 (85.9)	$p=.001$	1.20	0.84
Poor health status	22 (34.4)	$p=.853$	1.27	0.79
Diabetes diagnosis	20 (31.3)	$p=.848$	1.20	0.83
Current betel nut use	11 (17.2)	$p=.279$	1.24	0.80
Exercise in the past month	43 (67.2)	$p=.461$	1.35	0.74

Note. Statistically significant associations ($p < 0.05$) are in bold.

Predictor variables for education (less than high school completion) and having a check-up within a year are statistically significant and indicate a relationship with colorectal cancer screening. These two variables were entered in separate unadjusted binary logistic regressions and then adjusted for the remaining predictor variables (see Table 5). Cases with missing data were automatically dropped from the regression model. Results indicate that compared to Chamoru who have not been screened, Chamoru screened for colorectal cancer have 5.94 more odds of having had a regular check-up within the year and have 0.20 less odds of not having completed high school when adjusting for sex, income, health insurance, self-reported health status, diabetes diagnosis, current betel nut use, and exercise in the past month.

Table 5. Unadjusted and Adjusted Odds Ratios for Colorectal Cancer Screening

	Variable	OR	p	95% CI
Unadjusted				
Model 1	Check-up within year	4.02	0.002*	[1.69, 9.57]
Model 2	Education < H.S. completion	0.25	0.004*	[0.10, 0.65]
Adjusted				
	Check-up within year	5.94	0.001*	[2.00, 17.78]
	Education < H.S. completion	0.20	0.01*	[0.05, 0.72]
	Female	1.28	0.63	[0.47, 3.50]
	Annual income < \$25K	0.80	0.67	[0.29, 2.21]
	No health insurance	0.45	0.28	[0.10, 1.91]
	Self-reported fair/poor health status	1.04	0.94	[0.38, 2.85]
	Diabetes diagnosis	1.06	0.90	[0.40, 2.83]
	Current betel nut use	0.65	0.50	[0.19, 2.25]
	Exercise in the past month	0.91	0.87	[0.32, 2.58]

Note. OR = odds ratio; *p* = probability value; CI = confidence interval

**p* is significant at *p* < 0.05

In summary, chi-square tests of independence and binary logistic regression were conducted to determine which independent variables were predictors of colorectal cancer screening (screened or not screened). Data screening led to the elimination of 7 predictors (two were dropped due to non-response and five did not meet assumptions for chi-square). Binary logistic regression determined two significant predictors: having a check-up within a year and education status. Regression results indicated that having a check-up within a year and having less than a high school education significantly predicted colorectal cancer screening even when adjusting for key predictors in the literature such as health insurance and lower household income.

Demographic Survey Results

Prior to conducting an interview, a short demographic survey was administered to each study participant (see Appendix B). The mean age of participants was 60.6 years (SD=4.83). Fifteen of the participants were female (57.7%) and 11 were male (42.3%). Twenty-five of the participants in the study report having a regular medical provider (96.1%) and health insurance coverage (96.1%). Only one person had not completed high school (3.9%) and three reported annual incomes of less than \$25,000 (11.5%). Of the 26, twenty (76.9%) had been screened for colorectal cancer. Key demographic information is represented in Table 6.

Table 6. Study Participant Demographics

Demographic	Interview Respondents	
	N= 26	
	n	%
Female	15	57.7
Heterosexual	23	88.5
Education < H.S. completion	1	3.9
College degree and higher	13	50.0
Annual income < \$25K	3	11.5
No health insurance	1	3.9
Has regular provider	25	96.2
Cancer survivor	6	23.1
Screened for colorectal cancer	20	76.9
Family history of colorectal cancer	8	30.8
Northern village resident	8	30.8
Central village resident	13	50.0
Southern village resident	5	19.2

Health insurance. Types of primary health insurance held by participants span military (Tricare), federal (Medicare, Medicaid), local government funded (MIP) and commercial coverage (Take Care, Stay Well, and Calvo insurances). Fourteen had commercial coverage, five were covered by Tricare military insurance, and four had Medicare. Only two of the 26 indicated reliance on insurance for low-income families through Medicaid or MIP, and one reported no insurance coverage. See Figure 2 for percentage distributions.

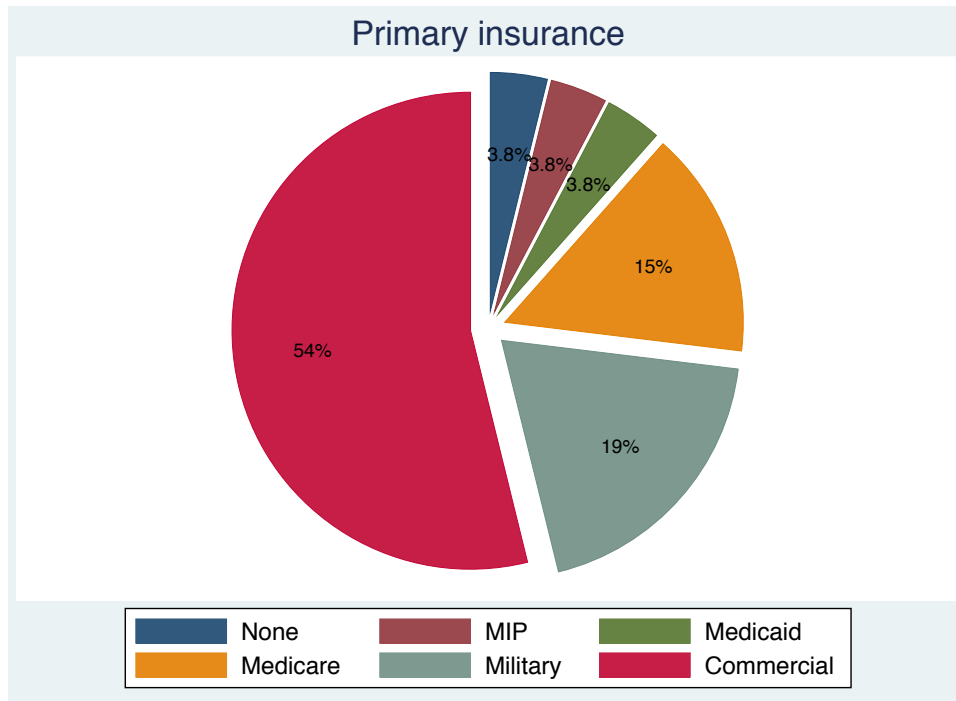


Figure 2. Health Insurance Coverage Among Study Participants

Resident village. Thirteen participants lived in central villages (50.0%), eight in northern villages (30.8%), and five in southern villages (19.2%). The average years lived on Guahan were 50.7 years (SD=12.79), with a range of 3 to 66 years.

Place of birth and ethnicity. Twenty of the participants (76.9%) were born on Guahan. Additional places of birth were Tinian (an island in the CNMI), Hawai‘i, California, Florida, and New Mexico. Although all participants identified as Chamoru, 7 reported more than one ethnicity (27%); the additional reported ethnicities were Filipino, Japanese, Black, Spanish, and White.

Sexual orientation. In terms of sexual orientation 23 participants (92.0%) indicated heterosexual orientation, one identified as homosexual (4.0%), and one wrote “happily married” (4.0%) on the survey. One participant declined to answer (4.0%).

Cancer and family history of colorectal cancer. Six of the participants (23.1%) were cancer survivors. Of the six, two had thyroid cancer, two had basal cell carcinoma, one had breast cancer, and one had colorectal cancer. Eight participants reported having a family history of colorectal cancer (30.8%), fourteen said they had no family history of colorectal cancer (53.8%), and four participants indicated that they did not know (15.4%).

Colorectal cancer screening status. Among the 26 participants in the study, 20 had been screened for colorectal cancer (76.9%) and 6 had not (23.1%). Of those screened, three had a stool test only (15.0%), eleven had a colonoscopy only (55.0%), five had both colonoscopies and stool tests (25.0%), and one had a colonoscopy and a sigmoidoscopy (5.0%). Percentage distributions for overall colorectal cancer screening are shown in Figure 3 below.

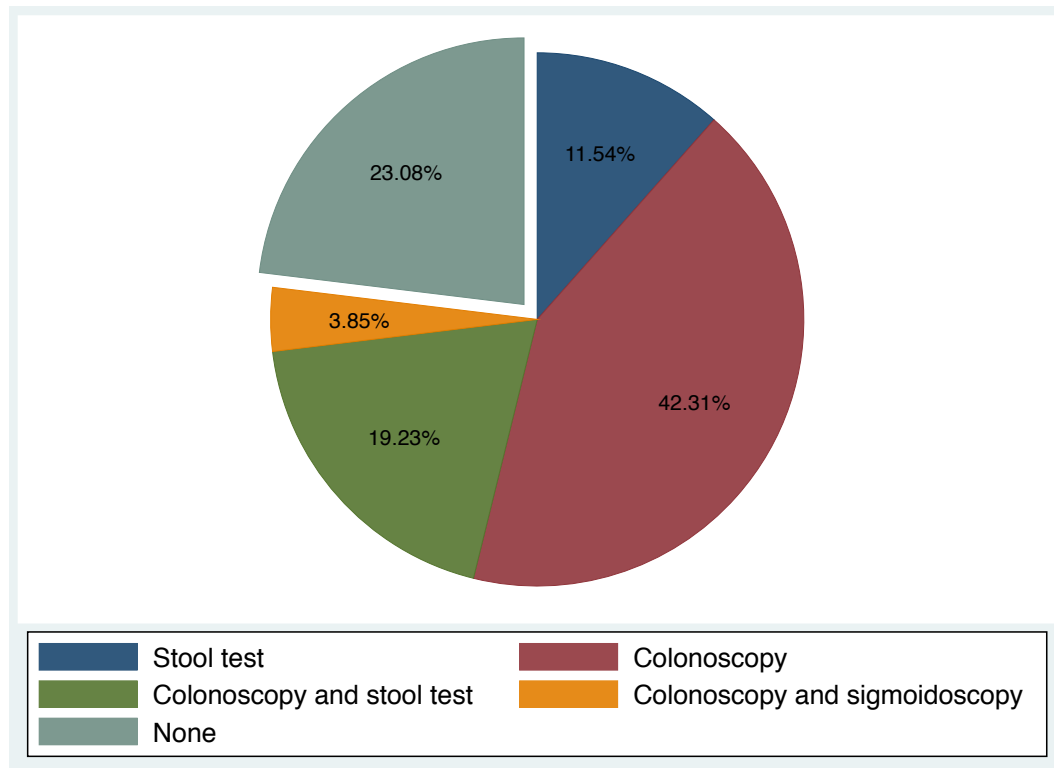


Figure 3. Colorectal Cancer Screening Status Among Study Participants

Qualitative Findings

Findings reflected here are important and intimate segments of personal stories shared by the study participants that lend familial, cultural, and social nuance to health behavior in general and to colorectal cancer screening specifically. Utilization of semi-structured interviews as a qualitative method in conjunction with aspects of Grounded Theory is intended to draw on thick description of participant experience.

Qualitative data analysis from the interviews produced five themes connected to positive and negative influences on colorectal cancer screening among participants. These were (1) being proactive in one's healthcare; (2) intergenerational consciousness; (3) social stigma associated with the colonoscopy procedure; (4) "If I'm gonna die, I'm gonna die"; and (5) negative perceptions of Guahan's medical system.

Being proactive in healthcare. All 26 participants, regardless of whether they were screened or not, talked about being proactive in their own healthcare. Self-reported proactive behavior was primarily connected to regular visits to a medical practitioner, physical exams, and cancer screening; but it also consisted of actively and independently obtaining information related to health, exercising at consistent intervals, and choosing to eat foods deemed or perceived as healthy. Participants spoke about their proactive behavior in connection to their overall health, non-communicable diseases (e.g., diabetes, high blood pressure, obesity), and cancer prevention. Specific examples of proactive health behavior among participants are in Table 7.

Table 7. Examples of Proactive Health Behavior Among Study Participants

Having an annual physical exam
Taking preventative medication for diabetes or high blood pressure
Writing down a list of questions for doctors prior to visits
Opting to get a second medical opinion
Having a mammogram, pap smear, colonoscopy, or prostate exam
Joining a government-sponsored weight loss activity
Independent self-monitoring of weight as a preventive health measure
Taking advantage of insurance incentives to earn cash back via active gym attendance
Reading news articles or searching the internet to learn about cancer risk factors
Eating fibrous foods as preventive practice against colorectal cancer
Eliminating white rice from diet
Making efforts to buy pesticide-free produce
Attempting to quit smoking
Successfully quitting smoking
Going to water aerobics or zumba at least once a week
Running regularly
Walking daily

Having a regular medical provider. Every participant except one indicated that they had a regular medical provider. Access and regular visits to a medical provider has encouraged participants in the study to monitor and field health concerns, in addition to increasing knowledge about disease, prevention, and medical procedures. For example, a 54-year old female participant reported seeing her doctor every three months as part of her routine wellness, in addition to exercising four days out of the week. She decided to take independent action in conjunction with her physician’s advice after almost having a stroke:

When I found out that I was high blood pressure [sic] and I could have had a stroke, and I could have died. I started working out. I was working out *six* days a week. Some days I would do 2-hour workouts. It was so my health can get better, so my blood pressure can get under control. Two years later I'm happy to say that my doctor says I'm doing good! He put me off my medication because I've been normal after I started exercising.

Similarly, a married couple in the study relayed how their regular doctor visits helped them to quit smoking and what incentivized them to maintain their decision:

Female: We used to [be] smokers. We quit...how many years?

Male: Seven years?

Female: Seven. It feels good. Really good.

Male: Plus it was a whole lot of savings too. Where we could up our life insurance.

Female: We got our grandbaby. So we said, "It's definitely a 'no.'" Then [our grandniece] coming for babysitting. And my sister got her grandson. Anyways it's for the better of our health.

Male: My doctor says, "Well, you just saved your life. You and your wife. You just saved your wife's life span for another ten years." I said, "Yeah, that sounds good!"

The male participant in this couple was overheard encouraging someone to quit smoking at their health clinic and was asked by the clinic staff to give a talk on behalf of the clinic's wellness program.

The relationships participants had with their regular medical providers were instrumental in their consideration of prevention and treatment. Although many voiced criticisms of the medical system and personnel, some participants also referenced areas of trust, rapport, and long-time relationships with their doctors. A 61-year old female participant explained that her family

practitioner had also been her mother's doctor. She stated plainly, "I trust my doctors. I put my life and health in their hands." Another female participant travelled to Hawai'i specifically to see a physician she feels she can rely on:

I have a good physician back there that is my physician. I know that he'll take care of me. I trust that aside from the fact that he's a doctor, he can use his expertise to find out if I do have that [colorectal cancer].

A 62-year old male participant described how part of his decision to get screened for colorectal cancer came from a long-standing relationship with his doctor and the cultural value of respect or *respetu*. He explained that he went to his doctor for many years and after his doctor retired, he went to the doctor's son who had taken over the medical practice.

I wanted to keep my doctor happy. He was a good man. We had a very good rapport. There was a part of me that felt *umbe nai*, Chamoru *respetu*. That if I didn't do it, I wasn't *respecting* my doctor. Because I knew I was always going to routinely come back. I wasn't gonna switch doctors just because I didn't get a colonoscopy and a sigmoid [sic]. So out of respect for the doctor, being a good Chamoru, that's part of what nudged me to get it.

Contrary to this, a 58-year old female participant touched on the challenge of developing a relationship with a regular physician at Naval Hospital given the military system of rotating personnel on Guahan:

Unfortunately with Naval Hospital your doctors change every two to three years. They have military, they rotate in and out. You don't have that doctor for your entire life. Not like here on Guam. If you're GovGuam⁴ you basically have your doctor for almost your whole life, right? So that's where we differ. It just depends on who you get. How active

⁴ Refers to being a Government of Guam employee.

or proactive they are. How supportive they are in as far as what you're seeking from them.

From her perspective, even though she had a regular provider at Naval Hospital, the ability to establish a long-term rapport and mutual understanding of healthcare needs was absent.

Annual physical exams. Participants referenced physical exams as an occasion to access various screenings that were either a routine part of the exam or ones that they requested specifically due to health concerns. A 68-year old male described how he insisted several years ago on an MRI scan at Naval Hospital. He said, "I ask the doctor, I said why don't you do a complete – I want a complete physical. I never had an MRI done on me." When questioned about what motivated him to request an MRI, the participant responded, "I go online sometimes then I read a lot too. I just felt like...there's something in me that might be wrong. I said, 'I need to go through that MRI because it shows everything.'" Results from the MRI indicated a lump on his thyroid and subsequent biopsies demonstrated malignancies on both sides of the thyroid. He received treatment and is a cancer survivor.

Participants in the study also called attention to getting their physical exams off-island. For instance, local insurance companies provide coverage for a full physical work-up in the Philippines called the Executive Check Up at St. Luke's Hospital located in Metro Manila. In addition to a routine physical exam with urinalysis and blood work, a battery of special examinations such as high-resolution chest CT scans, bone densitometries, and colonoscopies are conducted over a 3-day period. One 65-year old female participant described how travelling

with a group of friends to the Philippines for the purpose of having an Executive Check Up prompted her colonoscopy:

Well, when we all went to the Philippines everyone got it. 'Cuz we got the executive check up. We all went to that wellness center. They said, "Okay, these are all the tests." All of us said, "Okay." That was it. If we didn't go to the Philippines, I wouldn't have gotten it [the colonoscopy].

It was not uncommon that the annual physical exam provided opportunities to get screened for colorectal cancer, whether intentional or unexpected. For example, it was often the case that fecal occult blood testing, commonly referred to as stool tests, occurred during these exams. Three participants who initially indicated on their demographic survey that they had never been screened for colorectal cancer, revealed in their interviews that they had completed an FOBT during a physical exam. They did not know that the FOBT was a screening method for colorectal cancer.

Cancer screening. Cancer screening practice in general was prevalent among participants. As noted previously, 77 percent of them were screened for colorectal cancer. Although only two male participants spoke directly about having prostate exams, 11 of the 15 female participants told stories about their mammograms and half of them mentioned having pap smears. Notably, the two female participants who were not screened for colorectal cancer were both committed to getting routine mammograms.

Some participants testified to their intentional practice of colorectal cancer screening. One participant went to see the surgicenter facility on island where the colonoscopy would be performed to get a sense of what it would be like. She eventually decided to have the procedure done off-island. Other participants wrote down questions about the procedure beforehand,

requested photos of polyps that were found, or asked to see their full medical chart post-procedure. One male noted that he wanted to be sure the screening was thorough:

I check my colon, I get a physical every year. I'm due for a check up end of this year, early next year for another colonoscopy. I plan to get that done either here or in the Philippines. The last two I got were in the Philippines. And it was all good. I asked the question, 'Does this go in the whole colon?' I wanted to make sure it was the whole colon.

Two of the participants below discuss being conscious about getting a colonoscopy once they reached the recommended screening age for colorectal cancer. A 65-year old male participant described how he only had to hear the message once:

I forgot whom but someone who had it before, many years ago, said the best thing you can do when you get over 50 and if possible before that, is to have a colonoscopy. In my lifetime, I think I've had four. Based on that advice, I got the message early. I've been diligent. I just had one a year ago. I'm clear supposedly for the next ten years. They did find some polyps. They cleaned it. Which is preventative care, basically. I teach my kids the same thing. My two boys.

A female participant recounted her process when she reached the age of fifty:

When I turned 50, I went in and just thought, "Okay, I'm 50 now. Gotta go see the doctor and see what types of things need to be done." 'Cause at Public Health, you have those preventive task force suggested screenings for particular ages. I went in with that thing and I would ask her, "Do I need this? Do I need that? Do I need this? Do I need that?" She goes, "Yes, yes, no, maybe, maybe later." She and I had a discussion that I knew in advance that these were the things at age 50 that you needed to go and have done. Or at

least discuss with your doctor....I've always been pretty good about it 'cause I didn't want to be telling people to go do it and I myself don't follow it. If I say, "Go in and get screened for colon cancer," I wanted to make sure that I was speaking from a place of knowing, rather than saying, "You go, but I won't."

Intergenerational consciousness. Intergenerational consciousness as a focused theme is connected to a) expressed family genealogies of cancer; b) accounts of how parents or siblings opted for or against medical treatment and/or cancer screening in general; and c) stories about the passing down of knowledge or values regarding wellness or disease to the next generation. Woven throughout participants' narrative of illness, death, cancer, and survival were stories about mothers, fathers, grandparents, siblings, in-laws, nieces, cousins, children, and grandchildren. Although the semi-structured interview included prompts for family associations to cancer screening, participants spoke about generations of their family consistently throughout the interviews and at varied moments.

Cancer genealogies. Interviews brought forth oral histories and current expressions of who had or has cancer in the family inclusive of intimate details and circumstances under which family members survived or passed away. Each telling lent to the formation of a family cancer genealogy from the perspective of the participant. One female participant detailed the incidence of cancer across three generations of her family:

My oldest brother is military and retired. He had been diagnosed having thyroid cancer. Both were removed so he's on medication for life for that. My older sister, she has breast cancer. Both were removed. She's been in remission.... My third oldest sibling, he's had colon cancer. He passed away three years ago. My mom's sister passed away of colon cancer. My father's mother died of colon cancer.

Another participant also described cancer across family generations and the loss of her father and brother to lung and esophageal cancer, respectively. She began by talking about her brother:

Right at the tip of the stomach? And his esophagus where it meets. So it's cancer. His only son was going through cancer also. [short laugh] My brother and my dad died two weeks apart from each (other)...on a Friday and a Friday.

Iterations of cancer in the family spanned past and present. A 61-year old female participant immediately responded when asked what comes to mind when she hears the word cancer:

Cancer is very hard. Very painful. In fact right now as we speak, we have our niece [who is] a 4-year-old. She's got brain cancer. She's going on six chemo. Then my grandma died of lung cancer. She never smoked. I don't know if it's the mama' she chews.⁵ My sister is a ten-year cancer survivor.

More often than not, recollections of cancer in the family were accompanied by concerns not for the participant themselves but for their children and generations to come. One male participant responded, "Cancer? When I hear cancer I feel...maybe not a lot with me...I think my wife, my children, my grandchildren. Siblings, brother, sisters." Similarly, another male participant verbalized his apprehension:

But our family...one part of them...they've suffered through four generations for leukemia. I always think about that. You know, how fortunate I am. Because of that, I fear that a lot of things could happen to us, to our bodies. I'm not so concerned about myself because I'm up there in age, but my kids, my grandkids, who knows? Fear mainly because there's not a solid cure for all types of cancer.

⁵ Mama' is betel nut mixed with lime, pepper leaf, and tobacco.

Another male participant expressed that he would not get screened for colorectal cancer but that he would recommend it to his child. He said, “I kinda believe in that early detection cuz I advise my daughter and my grandkids. But not for myself. I’m at 64, man, if I get it then [laughing] I’m in the food chain too.” In contrast, a 66-year-old male said that he promotes colorectal cancer screening by reminding other Chamoru to stay healthy for their children:

I try and tell them, “Hey, you got children. And you wanna see your children grow.” Or, “You have a grand [sic].” So getting check up is something good – that’s good for you. I’m pretty sure your children will want you around for a while.

Almost all participants referenced their children and/or their grandchildren in their stories connected to health, cancer, and well-being. It is customary in Chamoru culture to emphasize the value of family and promote consciousness of intergenerational well-being. Intergenerational narratives also included a broad sense of extended family that included for example, cousins, nieces, and in-laws.

Reference to family decisions regarding cancer screening and/or treatment.

Discussions about prevention and treatment of cancer elicited stories of whether family members opted for or against cancer treatment or screening in the past or present. These anecdotes centered on parents and siblings, and were rich with the particulars of personal beliefs and the circumstances of family lives.

Parents. Parents were a key point of reference as participants discussed cancer, health beliefs, and values. The decisions a parent made to seek treatment or get screened were catalogued in participants’ memories. A female participant spoke about her father’s decision not to get treated for an early stage of pancreatic cancer at the age of 36-years old and contrary to his poor prognosis, had lived until the age of 58. Most notably, she states that her dad “pretended

like he forgot about it.” She said:

He was diagnosed in '69? He did not die until '91. When they diagnosed it, Dad just kind of pretended like he forgot about it and just went on with his life...He didn't want [treatment] because he told us that if he goes to treatment, he's going to die already. We were mad at him because we wanted him to live longer but I guess he did the right thing. He stayed a little bit longer. Cuz in '69, they said he only had six months to live but he lived up until '91!

This participant later revealed that she does not ever want to know if she has cancer or not. When she had her colonoscopy she gave written instruction that results should be explained to her daughter and boyfriend, but not to her. She emphasized:

I don't need to know, just let my daughters know and my boyfriend? So that they can do something about it. Don't tell me because I'll be scared. It might kill me! It might kill me even before it got malignant. That's why I said I'm scared. But you know when I had the thing [colonoscopy]? They told my daughter. And then my daughter told me it was negative.

Another female participant spoke about how her mom would adhere to a doctor's advice to purchase medication but would not take the medicine. She explained:

My mom...she really hates doctors. So we never really went to the doctor either when we were little. My mom never even *did* a mammogram! And she lived to be 75! My mom don't even take her prenatal pills! I remember when we were little, she would throw those pills away! [laughing] She didn't believe in taking those kind of pills. My mom would never take her medication. She would just throw it. She'll get it because they give

it to her but when she comes home...shoop! She would just scatter that in the yard and the chickens will eat it.

In a parallel story, the participant later depicted the similarity in her own health behavior when she was informed she had gout.

He put me on medication and I pick up the medication. But I've *never* taken the medication. [laughing] 'Cause I'm thinking, I don't know what the hell gout is supposed to feel, what are the symptoms? All I know is my levels were high and the doctor says I have gout. But the only medication I took was for blood pressure because when he said that could lead to a stroke, I know I don't want to have a stroke. My mom had a stroke before, and that was not...that wasn't nice, and it wasn't easy.

Siblings. Participants came from large families, ranging from 4 to 17 siblings with an average of 8 in a family. Due to the substantial number of siblings in a family, brothers and sisters were close in age to one another or they were a generation apart in some cases. Most participants were in contact with their siblings and discussions among them about health issues, including cancer screening and treatment, were common. They relayed personal stories of whether or not some or all of them had mammograms, prostate screenings, or colonoscopies.

Siblings encouraged one another to get screened for breast, prostate, or colorectal cancer, especially if any of those cancers had been diagnosed among them. A 60-year old female described her family's inclination to share about medical concerns when asked if she knew if her siblings had been screened for colorectal cancer:

We all have had it. We're all over 50. And we all kinda see the same doctors. So I know my older sister seen it [sic], I know my other sister has done it. My brother is seeing a doctor now for his colon. My brother-in-law has colon cancer. He's in Hawai'i....I know

my oldest brother just saw the doctor the day before yesterday for his colon. We're very open with our medical issues. Our family is very open with medical issues. Everybody's kinda putting a: "You're reaching fifty, you gotta—!" "Ah! That's not fun!"

One male participant conveyed that his brother was diagnosed with cancer of the mouth and his siblings decided to start a messaging group chat to stay informed of his treatment and recovery.

We have our own group with just my brothers and sisters. So there's one in the states and the rest here. They all have their own things going with their stuff. Sometimes we don't get to meet and talk. But when my brother was in the Philippines. When they started his treatment - can't really talk. So my sister said why don't we create our siblings on Whatsapp. We've been communicating, we've been very close.

While participants talked about staying in touch with their siblings about health and medical care, the level of influence they had on one another with regard to getting screened varied. Within a family of siblings, some had been screened and some had not, regardless of whether there was incidence of cancer among siblings or parents. One female participant who was a cancer survivor from a family of ten described sibling interactions and varied beliefs about screening:

I think with [my brother], I think he did it because he was scared. Because he had other things wrong with him already and then he had seen my mom die of cancer. We had two cousins that died of cancer - colon cancer. My brother told my [other] brother to do it. Then my brother told my sister to do it. I think siblings telling one another to do it. Then I did it because I got scared.

She went on, however, to talk about a sister who refused to get screened for breast or colorectal cancer:

She hasn't had a colonoscopy. She hasn't had a mammogram. I said, "Why do you do that? Why don't you want to do it?" She says, "Well, I'm gonna die, I'm gonna die. I don't wanna *know* how I'm gonna die. I just wanna die naturally." I said, "Don't you wanna get checked out, so you can—?" She goes, "I don't trust doctors."

Similarly, one 64-year old female participant who made sure to have her annual mammogram expressed mixed emotions about her siblings' screening practices. She accredited her sister for encouraging her to get checked for lumps in her breast and possibly saving her from breast cancer. But she also indicated frustration with her other sisters and brothers for not getting screened given the history of breast and colorectal cancer among their siblings. The participant was a strong advocate for cancer screening among her siblings, but she had not gotten screened for colorectal cancer herself. (In her excerpt below, "P" is the participant and "I" is the interviewer.)

P: My sister had breast cancer and had surgery. She said I need to go have my breast check. She said, "Do you feel lumps or anything?" I said, "Yeah, I have this lump on my right and I never thought of it." She said I should have it checked. Through that, that's how I found that [lump]...It's just the fear that's there, it's still there. I said to myself, "Hey, people survive." [laughter] Early prevention. I have to be there with them.

I: You're very consistent with your mammograms and ultrasounds?

P: Since '95. Yes...every year. It's always together—ultrasound after every mammogram.

I: Do your other sisters talk about it somehow?

P: Yes we do. Unfortunately, the three younger siblings? They're not that dedicated.

I: Even though you talk about it?

P: Yeah. Isn't that something? It's all about attitude and concern. It's really up to them, we can't push them. We can say so much every time. "Think about it." Is it money? Now that you have insurance, go get checked. Go to public health because they offer free programs for free mammo. My sister went. That was two years ago. *Finally*. Cuz she never had insurance.

I: How about your brothers? Do they talk about screening as well?

P: They're very private. Men. They're very private. I don't hear them going to the doctor for their physical. I don't hear them. They don't share...They're just too busy in their lives that they just don't think of their personal health. That's one thing about it. But oh my gosh. I don't know...Education is needed, man, for these guys. [laughter] We can say so much, right? Let them *decide* if they want to go get their check-up. Like my second oldest brother—when my third oldest sibling died of colon cancer. I wasn't shocked because knowing that my aunty and my grandmother had it, so it's in the blood. I'm more prepared for that cuz it could happen to me. See that thought?

Passing down knowledge or values regarding wellness or disease. In addition to recounting incidence of screening and treatment among parents and siblings, participants relayed messages received about wellness, disease, and cancer passed down from their parents or grandparents. For some participants, these messages were congruent with their present beliefs and practices, while others considered the notions inaccurate. Regardless of whether participants

concluded with these beliefs, the acknowledgment of these beliefs held significance for all participants. The following excerpts exemplify stories of lessons and values recounted by participants connected to cancer.

In the first excerpt, a 62-year old female participant that worked in the field of public health delineated the difference between her father's and mother's perspective on the medical system and its influence on her brothers. She acknowledged her mom's belief although she herself trusts in the potential for colonoscopies to save lives through early detection.

My dad was not your typical male. If the doctor says, "You take this pill 'X' number of times per day," he was very religious about being compliant with the doctor's regimen. So he was very good about that. My brothers, on the other hand, are not compliant as my father was about his health. They're scared to go in to get a colon test or even see a doctor. 'Cause they don't want to hear the results of it. My mother was like that. "If you go into the hospital, you're gonna die." In her mind.

In this second excerpt, a female participant recounted her mom's opinion on why cancer exists and why Chamoru aren't living as long:

My mom died at 88 years old. She's always says that the reason why we have cancer – during her time – was that the food is just too...people don't raise their own cattle, their chicken, their farm. That's why she's also sick she said. [I said,] "Mom, you don't have cancer."... Cuz she used to have a cage back here. Chickens. Then she'll go to the ranch and go farming. Then she said ever since the American introduced them to fast food, "Ai, everybody's dying at 80. Used to be 90, 100." That's what she say [sic]. I asked her, "Why's that, mom?" "Too much fast. Nobody wants to grow their own."

Lastly, one female participant shared a cultural belief about spirits that she grew up with.

I heard my parents and grandparents say this: When you hurt someone, your neighbor, it could be a curse. To me, actually what they were trying to say that it's karma. That when you hurt someone, it comes back to you. That also the spirits around you can affect how your health and your food, your intake [sic]. Also when something is caught and it was caught in an area where you shouldn't have been? Like it's not your property. And you went and caught the fish there. That fish is tainted. So that fish could make you sick. That's how you get cancer or diseases. We always have to remember that where we got our food? That food that you feed your children? Make sure that you got your food honestly. It wasn't stolen. It wasn't caught in a bad place. Because the spirits are there that can make you sick.

Social stigma associated with the colonoscopy procedure. Transcript entries were coded under this theme if a participant associated stigma with a stool test or a colonoscopy regardless of whether they were screened or not. Stigmatization was coded if the participant indicated a) embarrassment or humiliation about the procedure, b) a deep sense of privacy or secrecy connected to the procedure, c) being teased about the procedure; and d) fear of compromising masculinity. In addition, this code was applied whether the participant referred to hearing stories that were stigmatizing from others, e.g., family, friends, or co-workers, or whether the participant themselves experienced or expressed the stigmatization.

Embarrassment, humiliation, privacy, and teasing. Colonoscopies require the examination of the entire length of the colon and rectum to determine the presence of polyps. In order to complete this procedure, a thin flexible scope with a small camera called a colonoscope is inserted in the anus and moved through the rectum into the colon. Interview participants were

vocal about the embarrassment or personal humiliation associated with the procedure, particularly as it involved the examination of the buttocks, or *dåggan* in Chamoru.

A 62-year old participant described the sensitivity of the topic from a female viewpoint and the likelihood of being teased in Chamoru culture:

Your theme is colorectal cancer? That is really a touchy subject, because that's in the most private part of your body. Even the other part of your female body, which produces children and they come out through that hole [laughing], that's nature. That's mother nature at work. But Mother Nature at work isn't some scope that they put in your butt and they're lookin' at you. You're sitting there and there's probably a whole bunch of nurses and doctors there. It's an embarrassing thing, but I think that also science once said every 10 years you should get it... That part is a hard part to do, especially on the island because everybody teases you on your , you know! [laughing] They always say, "Y *dåggan* mu!" (Oh, your butt!) You know? So that's part of the embarrassment of that part of your body.

The participant went on to add that having a colonoscopy alleviated her worry about having colorectal cancer but emphatically stated "I sacrificed my ego!" in order to get it done.

The practice of Chamoru teasing about the *dåggan* was implicated throughout participant interviews. Twenty-two of the 26 participants referenced butt or *dåggan* in a derogatory way in connection to having colonoscopies. The phrase "stick something up my butt" in English or Chamoru was often mentioned by participants with a sense of humor but was simultaneously indicative of an uncomfortable and indecent action. A female participant reiterated as she

laughed: “You don’t tell anybody you’re gonna get a colonoscopy!” When asked why not, she exclaimed:

Because oh my gosh, everybody makes remarks, right? In Chamoru? They’ll say something like, something obscene, right? Not really obscene but they think it’s funny, like “Oh, ma dǎggan hao!” Or “Ma na’hǎlom este ya ma dekká’ hao!” They stick something up your ass, pretty much.⁶ You know? And they *laugh*.

The same participant who referenced sacrificing her ego further explained:

Whenever you want to humiliate a Chamoru, you talk about their dǎggan. How big it is! That’s just the opening where waste comes out of, you know? Like I was telling you before we started, that patient in Hawai’i who told me he was there for a “procedure.” His wife whispered to me. I don’t even think she said “colonoscopy.” She said, “It’s for his...(she points behind her)... dǎggan.” Because it’s humiliating, you know, to even say it or to show people that part of you. Especially while you’re asleep. So I think that’s really why it’s so hard.

As expressed above, embarrassment also stemmed from knowing that there would be more than one person in the operating room to witness the colonoscopy. This was further complicated by a participant’s feelings about being anesthetized. Whether a participant was sedated or not via anesthesia elicited varied responses. Some were relieved and adamant about being anesthetized, some wanted to be awake, while some were uncomfortable with either prospect of being conscious or asleep for the procedure. For example, one of the unscreened female participants had not been to the hospital since the birth of her son many years prior. When discussing the option of anesthesia during a colonoscopy, she began to consider the procedure:

⁶ Exploration of and consultation on “Ma dǎggan hao” indicates that in this phrasing, the noun dǎggan is turned into a verb, which connotes a more invasive action. “Ma na’hǎlom este” infers that they put something inside you and “dekká” translates to “poke,” as in they poke you.

And you're not going to die under that anesthesia right? I never heard of anyone dying under that so I'll wake up... But I think that's one of the things I don't want to do because you know, I don't know what they're doing to me in there.

In addition, some participants were embarrassed about potentially knowing someone in the clinic or hospital before, during, or after the colonoscopy. For example, one female participant deliberately chose not to get her procedure done on Guahan to maintain her sense of privacy. When she was due to get a check up for her thyroid off-island, she also arranged to have her colonoscopy done.

I hopped on a plane, did my thyroid check up, and they did it. I went to the hospital and I was very very happy with it. First of all, I didn't know anybody. I didn't know anybody! [laughing] Any of the nurses. There's an area in the hospital that's dedicated just for that [colonoscopies]. There was six of us in the waiting area and we were all there for the procedure. I was very pleased.

A 67-year old female participant expressed an even deeper sense of privacy that she said precluded her from ever having a colonoscopy despite her doctor's recommendation. She explained that it was a personal, cultural, and generational perspective connected to exposing her body:

We Chamoru too, we're very...we're private. Especially older Chamoru! My age – my generation and my mom's generation - our body is sacred. Is very private. You don't flaunt what you have. You cover up. Your private parts are just...very private!

Generationally speaking, the older you are, the more protective you are of your self, your body. Your physical body. From generation to generation I'm sure there are differences in how we perceive our bodies. I know the younger ones, they'll go out there in their

bikinis. Or they'll go and have a photo taken of their bodies. Imagine myself and my parents, or your parents – well, your grandparents – that is just *so* unheard of. It's taboo!

An unscreened female participant in the study who consistently declined her doctor's annual recommendation illustrates the tension between preservation of privacy and the intent to screen for colorectal cancer:

When I turned 50, my doctor says “OK hon, you need to do your colonoscopy ‘cause you’re 50.” And I’m like, “*No*, doc. I don’t think so.” He says, “Why not?” Of course I have older friends that went through the procedure. Before I turned 50 they would say, “Oh, they’re gonna make you drink this yucky stuff! A gallon full of this yucky stuff and you have to drink it all. They’re gonna knock you out, and they’re gonna stick something up your ass.” Excuse my French... So no, I don’t think I’m gonna get a colonoscopy when it’s my time. Then sure enough I turn 50, and my doctor says you gotta get a colonoscopy. I said, “No doc, not if I have to drink that chalky yucky stuff, not if I’m gonna have to—.” He says, “Ok but then there’s an alternative. You can collect your stool.” I’m like, “No, I’m not gonna do that either. I remember when I was a little kid and my mother had to do that to us. I’m not gonna do that for myself.” So no I’m not gonna get a colonoscopy. Then I turned 51 and then my doctor told me again. ‘Cuz that was the only thing I’ve never done. I get my mammogram annually, my pap smear annually, I do physical annually. Everything. Do my lab work every three months! “No doc, I’m not gonna do it.” Then I turned 52, still didn’t do it. Try 53, still didn’t do it! Now I’m 54 and I STILL don’t want to do it. So you know, he keeps reminding me. But I always think I *should* do it.

Fear of compromising masculinity. The stigmatization surrounding colonoscopies for males encompasses aforementioned themes on humiliation and privacy but is further explicated in the context of masculinity. Perspectives on why Chamoru men are resistant to colonoscopies point to unspoken notions of masculinity. Male participants who had been screened said that other men who haven't had a colonoscopy just refuse to do it but don't talk about it. One male participant ventured that some were "resentful...when they consider it a personal matter" and that they "choose not to discuss it."

Female participants corroborated this sentiment using words like "very private" or it's "personal" to describe how men in their lives feel about colonoscopies. One female participant remarked that her husband did not even want her to see the photos from his colonoscopy procedure. Another female participant recounted her husband's refusal to have a colonoscopy when he said, "No, I don't want anybody touching me there." She states that her sons also will not consider the screening procedure for the same reason.

Male participants, regardless of whether they had undergone colonoscopies or not, alluded to the procedure as an affront to masculinity. A 64-year old male described male resistance to the colonoscopy as "male ego."

Well, for the male part, I think its male ego. The process of having something going through your rectum is, for a lot of males...they don't desire to have it. That's my belief. But because I went through what I went through, I understand the need for it and the *importance* of getting it screened. From day one when I had the surgery I was told that I would be a high-risk for colorectal cancer. In my mind, I said: I'll do anything to get early detection, prevention if I can. When we discuss those kind of things among men,

some of them just say, “No way.” Even though they know it’s going to benefit them, some of them still say no.

Another 64-year old male participant identified himself as being from “the macho side of Guam” where men challenge each other on how “tough” they are. He had never been screened. He described his reaction when his doctor suggested he get a colonoscopy: “They wanted to do that to me and I looked at the guy [and said] ‘Yeah, I’ll see you later.’ Then I’m never going back.”

Analogous to portrayals of male ego and toughness, a male participant characterized male resistance to preventative health practices as a “Superman mentality.” This participant was the only colorectal cancer survivor in the study. It had been a little over a year since he had been diagnosed with stage 2 colorectal cancer. He had recently returned to Guahan after having surgery, chemotherapy, and radiation off-island to treat his cancer. After additional rounds of chemotherapy on Guahan, he was still returning to “normalcy” several months later. The participant explained that after he turned 50, he had been scheduled for several screening colonoscopies. In his words, he had “ignored” them. He said:

I kept ignoring it... Stupid, ya? I’m not sure what is the culture with the guys I grew up with my age. Like going to clinic or doctor. I wasn’t good at that. If I have to go to a doctor it really has to be *serious*. I think a lot of my peers? I think we have that mentality that, you know, nothing’s gonna happen. There’s still that mentality: I don’t want to, I don’t need to. Basically, it’s like a Superman mentality. “Nothing’s gonna happen to me.”

Now when he sees men who are younger than him, he encourages them to “get checked.” He reflected, “For me cancer just...came out of nowhere. [long pause] But I felt if I went to my first follow-up? I wouldn’t be in that situation. It’s a lesson learned.”

“If I’m gonna die, I’m gonna die.” This in vivo code describes participant attitudes and beliefs about screening for colorectal cancer in relation to cancer diagnosis and the prospect of surviving it. In Grounded Theory, in vivo codes preserve participants’ perspectives and provide condensed meaning while prompting broader analysis for social context (Charmaz, 2006). Transcripts were coded with this theme when participants expressed (a) narratives related to God’s will in the determination of one’s life or death; (b) feeling prepared to die; and (c) “cancer as a death sentence” or perceiving that a cancer diagnosis means death is inevitable.

The predominant religion on Guahan is Catholicism with approximately 80 percent of the population claiming membership in the Catholic Church. Assumptions that Catholic beliefs are mutually shared underlie commonplace conversation and stories connected to faith in God are often expressed. Through the phrase “If I’m gonna die, I’m gonna die,” participants gave voice to perceived connections between cancer, death, and their belief in God. The phrase itself is multi-layered. While it may connote a deep faith in God’s guidance and will, it can also be used as a more mundane response to loved ones’ concerns, judgments, or disapproval of potentially unfavorable health behavior. For example, when asked why Chamoru might opt not to get screened for cancer, a female participant responded: “Why they don’t do it? Maybe it might have a lot to do with their faith. I think they think that God’s gonna take us. We’re in our 50s. ‘If I’m gonna die, I’m gonna die.’” She went on to describe her brother’s outlook on his long-time smoking habit and subsequent cancer diagnosis.

We would say: Hey, stop smoking, ‘cuz you’re gonna get lung cancer. [He’d say] “Hey doll, if I’m gonna die, I’m gonna die. I might as well die happy! I leave it in God’s hands.” And now he’s dying of lung cancer. I ask him often, “Are you scared?” His answer is, “It is what it is. If God’s gonna take me, God’s gonna take me.”

Another female participant alluded to her father's refusal of cancer treatment despite the family's objection:

Most of my families are dying of cancer... You know these manámko' nai (elders), they don't take care of themselves. "If I'm gonna die, I'm gonna die." Our parents are—very naughty! Even if you try... [they] say no.

The essence of the in vivo code was also represented in participants' personal beliefs, albeit phrased differently. Regardless of whether they had been screened or not, the sense of God's will and control over cancer outcomes was prevalent. One male participant who had been screened regularly for colorectal cancer expressed:

What is it really that causes cancer?... I don't fully understand so... I just have this general fear that despite what I'm doing, I can still get it. Now we're going into the spiritual realm where you're destined to have it, whatever you do.

He clarified shortly after: "I believe that He controls everything. If you have it, you were meant to have it. Despite how proactive you were, despite how early you got screened for it. That's what I believe."

Another male participant who had not been screened, described himself as a regular drinker and smoker and echoed a similar sentiment:

I don't really believe in doctors and formal medicine. We always have that saying in Chamoru: "Si Yu'os la'mon." That means God takes care of your life. So I'm thinking, no matter what you do?... Here I am, you know. Everybody that died probably wasn't a smoker and a drinker like me.

An additional layer to the meaning of the phrase, however, incorporated the necessity of personal action in tandem with belief in God's ability to dictate life or death. A female

participant spoke about lessons in faith passed down to her children.

That God is always the center of our lives. That as easily as He gives - just a snap of the finger can take it all away. So that's my thing. Everything is guided by God. There's an old Chamoru saying: "Nå'i hao chetnot-mu, espiha i amot-mu." It means, "I've given you some illness - or something to deal with - now find your medicine to fix it." So I live by that. I give you this challenge, and now to look for your answers.

A male participant who worked as a health educator also proffered his viewpoint:

I say this respectfully as a Catholic – there's an interesting dichotomy that we allow ourselves as Catholics or Christians with regards to our own faith. We will simultaneously use the terms "free will," which we believe in, and "It's God's will."

He later added:

We want to have it both ways for our convenience. When it's convenient I want to say, "I have free will. It's my decision." But when we're gonna be called to the task, "That was God's will." I respectfully offer the struggle – from a spiritual standpoint – that when someone says, "When it's my time, it's my time" or "It's God's will when I go" that we're abrogating the concept of free will that we say we *believe* in! Because if we have free will, then there are things I can do to control my destiny. I offer that God's will, in fact is He wants us to us to treat ourselves *well*! I'm gonna make the argument that it's God's will that we take better care of ourselves.

One female participant put it succinctly: "You know what? I believe that if we're gonna go, we're gonna go. But if there's a way of preventing the 'go,' we gotta get there."

Cancer as a death sentence. The belief that a cancer diagnosis leads inevitably to death was prevalent among participants despite having taken steps to get screened. Part of this belief is rooted in the memory and deep sense of loss of family and friends to cancer. A female participant who had been screened stated emphatically in her interview:

I'm tired of people dying of cancer already. We need to know what's causing it. Where is it coming from? A lot of people don't know where it's coming from. It happens to us and there's people that don't have a history of cancer and their children...their children are the ones suffering. Where is it coming from? It's not a hereditary thing. I don't think it is. It's something that just...comes to anybody's body! And it *kills* them.

When asked what comes to mind when hearing the word cancer, one female participant who hadn't been screened responded:

Death. You'll be dying. You may die anytime. How long are you gonna be with it? Did it just come suddenly or give you a chance, just a little longer? That's what I think of cancer. Death. Dying. Oh my gosh, you're dying.

A 57-year old male who had two colonoscopies thus far was under the impression that being diagnosed with colorectal cancer meant death was inevitable. He expressed surprised upon learning that early detection meant greater chances of survival. He said, "I heard if you got colon cancer...now see, there's a miscommunication. When I hear of somebody that has colon cancer...It's not if, it's *when* [emphasis added]."

One male participant expounded on why he thought cancer might still be considered a death sentence despite advances in medicine.

I mean, cancer's a real growing issue. The good thing about cancer is that it doesn't have the same stigma it did...back in our grandparents' day. It isn't the same death wish that it

was back then too. But clearly, here in a community that's not diagnosing it early – or misdiagnosing it and treating for the wrong thing – then it might as well be a death sentence.

Negative perceptions of Guahan's medical system. Eighteen of the 26 participants were coded for having negative perceptions of Guahan's medical system. A transcript entry was coded for this theme when: a) the participant shared stories in which they questioned the professionalism, competence, or expertise of medical professionals they've received service from; (b) indicated a lack of trust in the system; (c) did not feel fully informed about results from a test, screening, or medical appointment; (d) perceived a lack of specialists on Guahan; (e) reported experiences of medical incompetence that were permanently harmful to them or others; and (f) stated a preference for off-island medical service.

Participants were explicit in their disappointment, misgivings, and distrust of the medical system on island. Comments ranged from nagging doubts to statements of unequivocal distrust. For example one participant mentioned: "Sometimes in the back of my mind...I hope they're very competent [laughter] and what they discover and what they say is truly accurate." In contrast, another participant emphasized, "That's when I didn't trust Guam. Man, what are they doing here? Frying us." This statement was in reaction to finding out from off-island doctors that the dosage of radioactive iodine prescribed to her on Guahan was 10 times more than she needed.

A primary sentiment expressed by participants was a lack of investment in and attention to patient care. One male participant articulated his opinion on the matter:

Just putting pamphlets, that's not gonna help. When you see your doctor. To think about it, I just had a physical [on Guahan] and he said everything was right but he really didn't

sit down with me like the way they do in the Philippines. I tell you, one of the things I learned in the Philippines – they take a vested interest. They had a lot of people sitting down with you. They had specialists sitting down with you. It was a breath of fresh air that you knew you were okay. ... The guy seemed to be legitimate here [on Guahan] but it's just "Next! Thirteen...fourteen." You're just a number. And maybe that's the best way to put it. In Guam I was a number. In the Philippines, I was a person.

Another key occurrence was the perception that specialized medicine and specialists on Guahan were lacking. One female participant explained how she thought this applied directly to colorectal cancer:

First of all, we don't have many gastroenterologists. If we have, it's probably one. And if he's on vacation, we have none. I don't even know if we have one. On top of that, are we getting someone who's qualified and certified to look – not just to do it because it's their time to do it.

She expounded on the connection to misdiagnosis, technical expertise, and mortality:

I think that one of the main reasons why people get cancer is that they probably don't have a good gastroenterologist that really takes the time to look around. Or misdiagnoses here on Guam. Don't call it ... an ulcer! Or bacterial ulcer. They should be sending testing. I think that we should have better diagnostics out here. I don't think machines help. Because then you gotta have good people that can know [sic] how to read those machines. So Guam...it's getting there? But...per population, they don't have enough gastroenterologists.

While several stories highlighted significant issues similar to those above, participants also shared heavier narratives about severe and potentially fatal health outcomes. One

participant's eardrum was unintentionally damaged in a procedure causing permanent hearing loss. Another participant's vocal cords were permanently injured due to the incorrect insertion of a breathing tube during surgical treatment for cancer. The participant is no longer able to sing and singing was an important part of her identity. Another participant's brother was diagnosed with an ulcer for stomach pain, repeatedly prescribed medication for it, and told to "watch what you eat." A year later it was discovered he had stage 4 pancreatic cancer and he died shortly after. Two different participants told similar stories of their aunts going off-island for vacation and discovering abroad that they had cancer, even after receiving negative screening results and seeking medical advice for pain on Guahan.

Late diagnosis or misdiagnosis of cancer. Accounts of late or misdiagnoses of cancer were pervasive during interviews with participants. They were told with emotional intensity but also conveyed in a manner as if they were a commonplace occurrence. One 65-year old female participant said she automatically associates death and misdiagnosis with cancer on Guahan.

I just think of death. People dying. Because I have so many friends and relatives that have died of cancer. As soon as I hear the word cancer, I said, "Who's your doctor?" First thing if someone tells me they have cancer, I'll say to them, "Who is your doctor?" And "how did they diagnose you?" Then I would say, "That was your doctor? That was so-and-so's doctor. How come it took so—?" I tell my kids: "Don't go to that doctor because it took him a long time—."

One example of misdiagnosis was from a 54-year old female participant who shared a personal story about her breast cancer. Although she diligently had her mammograms on Guahan, one year when she went to the Philippines to repair an unsuccessful knee surgery she decided to have her mammogram done as well. She was shocked when she was told that she

needed to remove a growing tumor in her breast. Upon request and review of her records from Guahan, her doctor in the Philippines discovered that her radiology files indicated a growing tumor. The participant had a double mastectomy as a result and forewent the knee surgery.

So when I came back, I went back to my doctor and I said, “What happened here?” The radiologist in Guam who was reading the results – his yearly reports were showing that these masses were increasing in size but I kept getting these letters that said oh it’s negative, you’re fine, see you next year. Her only response was, “Well, you know, anything could have happened.” At that point, I already knew I wasn’t gonna come back to that doctor, that clinic. I couldn’t even deal with that.

One male participant who hadn’t been screened gave voice to the fear that accompanies the prevalence of stories such as these:

I think what scares me the most about cancer on Guam is you hear repeatedly stories about how somebody was treated for high blood pressure or was diagnosed as stomach ulcers or gastrointestinal. For whatever reason, they’re off island, they go to the emergency room, they have an incident...And the doctor is trying to figure out why are you treating things with high blood pressure medication or gastrointestinal? When you clearly have a cancer diagnosis here and it’s not just beginning stage but usually it’s stage 3 or stage 4. You hear about that a lot. And the doctors all say the same thing! “This is a progressive type of cancer. They would have been symptomatic way early on. How is it that you guys are not diagnosing these cases a lot earlier?” I hear it again and again and again and again and again.

Mixed Findings

Comparisons of interview participant demographics to the larger 2010 Guam BRFSS respondent pool are in Table 8. Results indicate that while there were fewer women represented in this study, more interview participants overall completed higher levels of education, had incomes greater than the federal poverty level, and had health insurance coverage than the 2010 Guam BRFSS respondents. Further noted is that interview participants in this study had higher percentages of colorectal cancer screening (76.9%) than BRFSS respondents (50.0%).

Table 8. Demographic Comparison of Study Participants to 2010 Guam BRFSS Respondents

Variable	Interview Respondents		BRFSS Respondents	
	N	%	n	%
Female	15	57.7	86	67.0
Education < H.S. completion	1	3.9	28	21.9
Annual income < \$25K	3	11.5	33	31.0
No health insurance	1	3.9	16	12.5
Screened for colorectal cancer	20	76.9	64	50.0
Has regular provider	25	96.2	109	85.16
Heterosexual	23	88.5		
Cancer survivor	6	23.1		
Northern villages	8	30.8		
Central villages	13	50.0		
Southern villages	5	19.2		
College degree and higher	13	50.0		
Family history of colorectal cancer	8	30.8		

Shared findings from analysis of BRFSS and qualitative interviews indicate having an annual medical check-up is a positive influence on colorectal cancer screening. Mean age is close between the two groups (approximately 61 years) [60.6 for interviewees, 61.07 for BRFSS respondents].

CHAPTER 5

Discussion and Implications

This mixed method study utilized secondary data analysis of the 2010 Guam BRFSS and qualitative interviews to explore colorectal cancer screening among Chamoru on Guahan. Two research questions are addressed. First, how does access to care impact colorectal cancer screening among Chamoru on Guahan? Second, what are barriers to colorectal cancer screening among Chamoru on Guahan?

The strengths of the study are that both questions are addressed by the use of multiple methods that complement each other so that the study results are not an artifact of method. Findings from the qualitative arm provide further insight into population characteristics and screening utilization, while data from the quantitative arm highlight Chamoru perspectives and narratives connected to health and cultural beliefs in relation to colorectal cancer screening. Given that the PI is of Chamoru descent and the daughter of a parent who died from colorectal cancer, another strength of the study is the use of an iterative coding process with research team members and ongoing consultation with the dissertation chairperson to check researcher bias and ensure reflexivity in the analysis of qualitative interviews.

Limitations of the study arise from sampling for both methods. Findings from the BRFSS analysis cannot be generalized to the population of Chamoru on Guahan as the number of overall respondents for the Guam 2010 BRFSS was not even ten percent of the population (N=784). Use of purposive and snowball sampling, albeit advantageous given the stigma associated with colorectal cancer screening, also biased the qualitative sample. Participants were self-selecting and possibly more proactive, articulate, and educated about healthcare and colorectal cancer screening. In addition, dichotomizing continuous variables in the statistical analysis of BRFSS

data lends itself to reflect community characteristics and values that are less complex to interpret and easier to present to communities. The limitation, however, is that the statistical power to detect the relationship between the variables is weakened and the risk of misunderstanding variation or non-linearity in the relationships is high (Altman & Royston, 2006). Lastly, dropping cases with missing data from the regression reduces the sample size and representativeness, and may bias the statistical results as the values for variables from missing cases are unknown.

Limitations notwithstanding quantitative analysis rendered two significant predictors of colorectal cancer screening among Chamoru: education status and having an annual medical check-up. Findings indicate that having an annual medical check-up was a strong predictor of screening. Persons who had a regular medical check-up within the year had greater odds of being screened for colorectal cancer. In addition, a person who did not complete high school had greater odds of not getting screened. These findings are consistent with previous studies on determinants of cancer screening among Chamoru (Balajadia et al., 2008; Sadler et al., 2010; Tanjasiri & Sablan-Santos, 2001). It was, however, uncommon that income level and health insurance status were not significant predictors based on the BRFSS data analysis as these have been strong determinants of cancer screening in prior research studies (Cruz et al., 2008; Sadler et al., 2010; Tanjasiri & Sablan-Santos, 2001). This may be due to limited overall 2010 BRFSS sampling and the consequent small study sample size.

Five themes emerged from the qualitative data analysis on access and barriers to colorectal cancer screening among Chamoru. The first theme is that participants in the study practiced proactive healthcare behavior such as maintaining regular visits to a medical practitioner, having annual exams, exercising frequently, and getting screened for cancer. While the rationale for proactive behavior varied, e.g., to improve general health or to prevent the onset

of diabetes, participants' stories demonstrate their propensity for active participation in their health and wellness. With regard to colorectal cancer prevention, 20 of the 26 participants (76.9%) had been screened via blood stools test, sigmoidoscopy, and/or colonoscopy.

The second theme is that there is an intergenerational consciousness exhibited in the narratives of participants connected to cancer, cancer screening, and shared knowledge and values regarding wellness and disease. This theme is congruent with previous studies that emphasize the vital role of family to Chamoru health (Arriola, 2009; Natividad, 2010; Pier, 1998, Twaddle, et al., 2002). Cancer death and survival genealogies were intrinsic to conversations about participants' cancer beliefs and screening practices. While family cancer histories and patterns of screening behavior were influential in the decision of whether to get screened or not, it cannot be assumed that the relationship between the two is causal or predictable. For example, if a participant's mother refused any type of cancer screening it was not necessarily the case that the participant would also opt not to get screened for cancer. Although the manner and extent to which the intergenerational consciousness impacts a participant's screening behavior is complex, it remains central to the participant's decision-making process.

The third theme that emerged from the qualitative data is the social stigma associated with having a colonoscopy. Participants conveyed embarrassment or humiliation and a deep sense of bodily privacy connected to the examination of the buttocks, or *dåggan*, and the insertion of a colonoscope to check for polyps throughout the colon. Cultural implications of being teased about the *dåggan* are nuanced and contextual in meaning. These encompass but are not limited to light playful humor, varied degrees of the intent to embarrass, and implied obscenities. In participant narratives about colonoscopies, teasing was framed as a real or perceived source of humiliation and public ridicule. Female participants also spoke about the

resistance to exposing a part of their body that they regard as an intensely private and personal, even in a medical setting with professional medical staff. For some male participants the procedure presents an affront to notions of hegemonic masculinity, which is defined by Connell as “the idealized form of masculinity at a given place and time” (as cited in Courtenay, 2000, pp. 1388). This is congruent with previous studies that report dominant norms of masculinity and “machismo” as barriers to colorectal cancer screening among men (Getrich et al., 2012; Ritvo et al., 2013; Winterich et al., 2009). Nevertheless, masculinity as a social construct is complex and may be challenging to examine. Similar to findings here, studies on gender difference and colorectal cancer screening described some male participants as “vague”, “ambiguous”, and “lacking in detail” when explaining their reluctance to get a colonoscopy (Ritvo et al., 2013; Winterich et al., 2009). In addition, male perspectives are diverse even within cultural and ethnic groups. Courtenay (2000) cautions that “the construction of health and gender does not occur in isolation from other forms of social action that demonstrate differences among men. Health practices may be used simultaneously to enact multiple social constructions, such as ethnicity, social class and sexuality” (p. 1390). Further examination of how cultural and hegemonic norms of masculinity influence colorectal cancer screening among Chamoru men is merited.

The fourth theme is represented by the theme “If I’m gonna die, I’m gonna die.” This phrase transmits attitudes and beliefs connected to the prospect of surviving a cancer diagnosis with implications for screening behavior. The *in vivo* code illustrates participant beliefs in God’s will to determine one’s life or death, especially if diagnosed with cancer, or the conveyed feeling of being prepared to die. Most participants had been screened for colorectal cancer and all report proactive health behavior, however, the notion of “cancer as a death sentence” remained prevalent among participants.

In consideration of these attitudes and beliefs, it is paramount not to jump to conclusions that Chamoru carry fatalistic beliefs and therefore, are not likely to engage in preventive health measures or get screened for colorectal cancer. On the contrary, layered representations of the phrase “If I’m gonna die, I’m gonna die” in participant narratives, reveal self-motivation to take personal action in tandem with the belief in God’s ability to dictate life or death. In addition, further education on colorectal cancer screening may negate some of these beliefs given that some participants expressed surprise that early detection of colorectal cancer potentiates cancer survival. Having said this, the association between lack of cancer service utilization and fatalism is documented as a concern for Indigenous and minority groups (Shahid, Finn, Bessarab, & Thompson, 2009; Sinky, Faith, Lindly, & Thorburn, 2016; Winterich et al., 2009). Further research on cancer fatalism and Chamoru cancer screening behavior may be warranted.

The fifth theme is negative perceptions of Guahan’s medical system. Participants voiced critical concerns about and distrust of medical services on Guahan with regard to medical expertise, availability and access to specialists, and delayed or misdiagnosis of cancer symptoms. Those with adequate health insurance and who were able to afford the cost opted to travel off-island for their colonoscopies. Participant stories gave testimony to recent unfavorable healthcare experiences on a personal level but these also potentially connect to negative sentiment passed on through generations.

Applications to the Behavioral Model of Health Services Use

The BMHSU as a theoretical framework defines health service utilization as a function of the environment, population characteristics, and health behavior. The model, as the fourth iteration of Andersen’s framework, further delineates population characteristics into three components: predisposing characteristics, enabling resources, and need. Incorporated feedback

loops in the model indicate that outcomes of health service use can inform and affect population characteristics and future health behavior (Andersen, 1995).

Applied to colorectal cancer screening, predisposing characteristics describe a participant's predisposition to utilize screening services based on individual-related determinants that exist prior to symptomatology or diagnosis of colorectal cancer. Enabling resources encompass individual- and provider-related resources that potentiate access to care/screening. Health behavior reflects personal health practices and utilization of colorectal cancer screening. Findings from the qualitative and quantitative arms of the study as they are categorized by the BHMSU are shown in Figure 4.

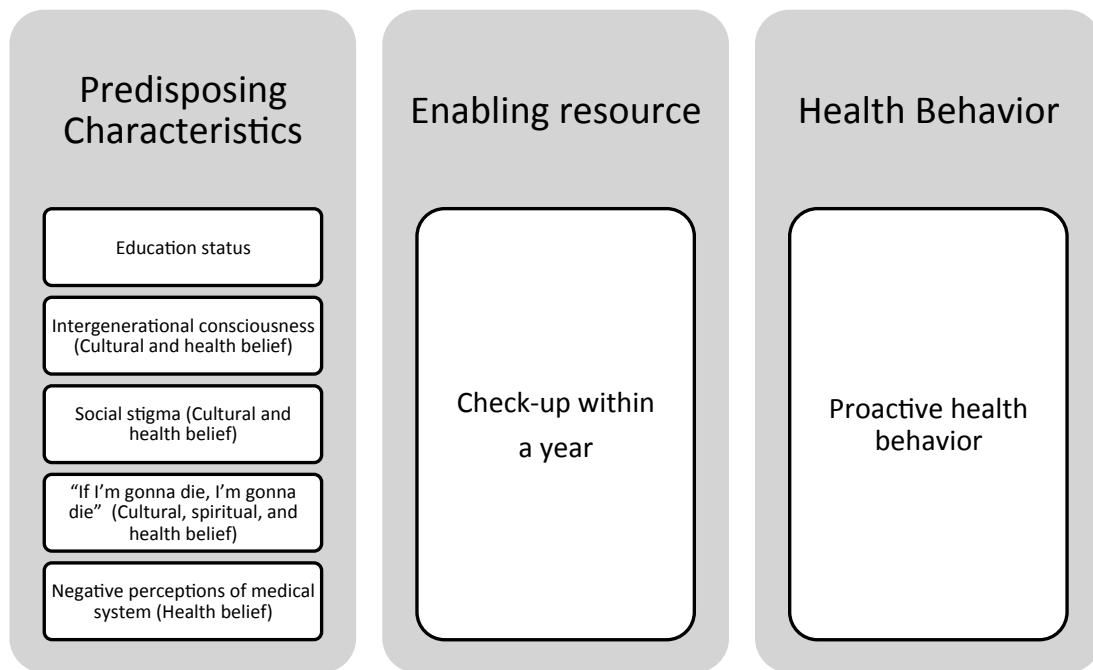


Figure 4. Applied Components of Andersen's Model to Study Findings

Variables associated with health service utilization within the BHMSU lend themselves to varying degrees of mutability, or the ability to be altered (Aday & Andersen, 1974; Andersen 1995). Variables or factors that are mutable can be further utilized to promote equitable access or

point to policy changes that may influence screening behavior (Andersen, 1995). A demographic such as educational degree attainment has low mutability as it is not possible to change this in order to influence screening utilization. The implications, however, are to provide colorectal cancer screening outreach and interventions to persons with less than a high school degree or communities with limited educational resources to address this.

Health and cultural beliefs can be potentially modified and are thus considered to have a medium degree of mutability. Enabling resources that represent access to care variables such as having a check-up within a year are considered high in mutability (Andersen, 1995). Given the statistical significance of this variable as a predictor of colorectal cancer screening, it is imperative to continue to advocate for and expand health policies that support affordability of medical care and insurance coverage for preventive screening on Guahan. This will help ensure that Chamoru can receive annual medical exams and potentially afford follow-up care as necessary. Additional findings in the context of this theoretical framework in Figure 4 have the potential to inform colorectal cancer screening education interventions and are explicated in implications for screening education and literacy below.

Implications for Colorectal Cancer Screening Education and Literacy

Rates of screening for colorectal cancer across the U.S. were approximately 60 percent in 2013 (NCHS, 2016). The National Colorectal Cancer Roundtable (NCCR), a national coalition established by the ACS and the CDC, has committed to a collective goal of increasing colorectal cancer screening rates in the U.S. among adults age 50 and over to 80 percent by 2018. The GCCCC has followed suit in efforts to increase colorectal cancer screening on island. Local rates of colorectal screening fall considerably below the current national average, however, and smaller goals have been established to reflect more feasible outcomes. The most recent Guam

Comprehensive Cancer Control Plan aims to increase colorectal cancer screening on Guahan by five percent in 2017. Based on statistics from the 2012 Guam BRFSS, goals are set to increase screening among persons age 50 and above who have ever had a sigmoidoscopy or colonoscopy from 42.6 percent to 47.6 percent, and to increase the percentage of those in the same cohort who have had a blood stool test within the past two years from 7.7 percent to 12.7 percent (GCCCC, 2013). Ongoing colorectal cancer education and prevention efforts have included public service announcements on nutrition and physical activity on cable television and local movie theaters, education workshops and cooking classes in partnership with the ACS during colon cancer awareness month, and the distribution of a colon cancer brochure in English and Tagalog (GCCCC, 2013). Colorectal cancer screening promotion materials in Chamoru language do not yet exist.

To effectuate increased rates of colorectal cancer screening among Chamoru, findings from this study point to a need for culturally tailored screening promotion and increased screening education and literacy (see Figure 5). Culturally competent promotion of screening will necessitate language access and acknowledgement of cultural, spiritual, and health beliefs held by Chamoru. While Chamoru language access was not an integral part of this study, data from the interviews suggest that utilization of common Chamoru phrases or terms will be meaningful in discussions about colorectal cancer and screening. Findings from this study provide initial strategies to promote culturally tailored messaging. As indicated, screening promotions might address stigma and recognize intergenerational consciousness, however, a deeper assessment of cultural beliefs in connection with colorectal cancer and screening is recommended.

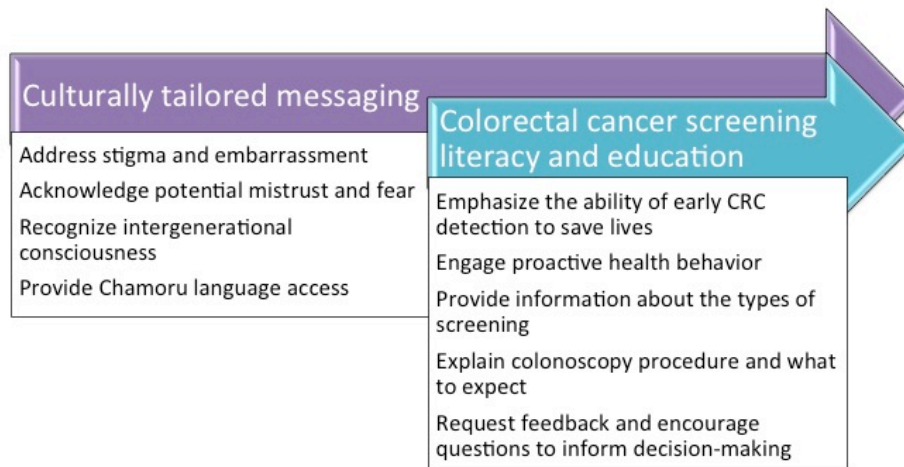


Figure 5. Increasing Colorectal Cancer Screening Awareness Among Chamoru

As an Indigenous people, the Chamoru generally, have a proclivity for collectivist norms and use of the Indigenous oral tradition as a means for sharing cultural knowledge, transmitting cultural wisdom, and emboldening preferred social and family norms (Hattori, 2004; Rapadas, 2009). The sharing of family health stories imbued with lessons for well-being is a phenomenon frequently described in the Indigenous published literature (Hattori, 2004; Ka'opua, 2008) and in the Guahan social work literature in particular (Lizama, 2011, Natividad, 2010). The phenomenon of sharing health stories across the generations also is revealed in the narratives of those participating in the current research. Cancer-related stories transmitted by trusted family members tended to be held with respect, appreciation, and credibility. Sharing family stories in the context of CRC screening promotion may be a promising means for intervention and would be in line with and an expansion of the "enabling resources" variable enunciated in the Andersen model (1995), which guided this CRC study. Future research might pilot the feasibility of family health stories as one means for increasing screening participation among Chamoru residing in Guahan.

Health literacy is a function of both the ability of the patient to comprehend and process health information in order to make an informed decision and the capacity of the health provider to communicate relevant and meaningful information to the patient (CDC, 2016b). Higher health literacy has been associated with increased knowledge of colorectal cancer screening (Arnold, Rademaker, Liu, & Davis, 2017; Davis et al., 2001; Peterson, Dwyer, Mulvaney, Dietrich, & Rothman, 2007), although measurement of screening knowledge in these studies have varied (van der Heide, Uiters, Jantine Schuit, Rademakers, & Fransen, 2015). Additional studies report the positive impact of communication skills training for physicians when relaying significant colorectal cancer screening information to patients with inadequate health literacy (Davis et al., 2001; Dolan et al., 2015). Although the association of health literacy and how it applies to colorectal cancer screening provision for Chamoru requires further exploration, findings suggests that colorectal screening literacy for Chamoru should include: a) an emphasis on early cancer detection in the saving of lives; b) a review of colorectal cancer screening terminology and types, c) provision of information about colonoscopies and other procedures; and d) physician-initiated interaction with Chamoru patients and their families about the decision to screen.

Political Status as a Determinant of Health Services

Access and barriers to colorectal cancer screening and other cancer services for Chamoru are intrinsically linked to the governance, functioning, and capacity of healthcare service delivery on Guahan. Findings from this study thus, compels examination of the broader scope of Guahan's current political status as an unincorporated U.S. territory as embedded in U.S. colonization and the Chamoru right to self-determination as Indigenous people of Guahan. As defined, an unincorporated territory is "a United States insular area in which the U.S. Congress has determined that only selected parts of the United States Constitution apply" (U.S.

Department of the Interior, n.d.). Availability and provision of public services and programs on Guahan are subject to U.S. federal policies that predetermine funding and regulate access to social services, education, and health for island residents. The capacity for local government to leverage funding and effect overarching program and policy changes is severely limited by the conditions of unincorporated territorial status.

Current U.S. territories include Puerto Rico, the U.S. Virgin Islands, American Samoa, the Northern Mariana Islands, and Guahan. Although the terms of territorial status vary among them, all territories are subject to the plenary power of the United States. Territorial rights are limited in numerous ways compared to those of U.S. states, but significant among them are the non-voting status of congressional representatives from U.S. territories and the inability of residents to vote for U.S. presidency despite being granted U.S. citizenship at birth.⁷ The U.S. Department of the Interior maintains federal administrative power over all of these islands via the Office of Insular Affairs with the exception of Puerto Rico.

Research on the impacts of territorial status on health service delivery and health outcomes is scant; however, a small number of scholarly works point to the unique conditions and significant social service and health disparities faced by the territories compared to U.S. states (Dames, 1992; Dames, Hasugulayag, Schwab, & Natividad, 2013; Ka'opua, 2017; Nunez-Smith et al., 2011; Rodriguez-Vila, Nuti, & Krumholz, 2017). Inequities in healthcare funding to the territories may contribute to the disparities in quality of care, health outcomes, and healthcare infrastructure on these islands. Compared to the states, for example, territories are subject to lower federal insurance reimbursement rates, a set federal medical assistance percentage (FMAP) of 55 percent without consideration of per capita incomes, and an annual cap on federal

⁷ The exception to this is persons born in American Samoa who are not granted U.S. citizenship upon birth.

Medicaid funds (Medicaid and CHIP Payment and Access Commission, 2017).

Federal regulations exert significant influence on Guahan's health system and infrastructure. On Guahan, approximately 24% of the population is enrolled in Medicaid (Center for Medicare & Medicaid Services, n.d.). Medicare and Medicaid payments account for approximately 51% of patient revenues at GMHA, the sole public hospital on the island (Guam Office of Public Accountability [GOPA], 2017). Up until the opening of a new private hospital two years ago, GMHA was the only hospital on island to serve local, non-military residents and is mandated to serve all who seek care regardless of their ability to pay. Due to high demand for services, accrued debt, and limited funding, GMHA has struggled to provide adequate services and maintain operations (Office of the Governor of Guam, 2012). In a recent annual audit, independent auditors opined for the third consecutive year: "GMHA has incurred recurring losses and negative cash flows from operations that raise substantial doubt about its ability to continue as a going concern" (as cited in GOPA, 2016). A local government needs assessment for GMHA indicate extensive shortfalls such as physician shortages due to financial issues and low-salaries, repairs to equipment like sterilizers, infant incubators, and ventilator systems, and an insufficient 158-acute care bed capacity at 0.9 beds per 1,000 population (Office of the Governor of Guam, 2012). This is approximately half of the average 2.1 beds per 1,000 population that Alaska, California, and Washington have. Unfortunately, the type of difficulties faced by GMHA may not be uncommon across territories. A study on disparities in hospital performance indicates that US territories have significantly higher 30-day mortality rates for acute myocardial infarction, heart failure, and pneumonia compared to U.S. states (Nunez-Smith et al., 2011).

Past and present challenges faced by Guahan's healthcare services and infrastructure are reflected in the finding that study participants bear negative perceptions of Guahan's medical system. Participant narratives speak to the deficits, inconsistencies, and limitations of Guahan's health services that have been personally experienced, resulting in mistrust of the system. While this mistrust in the context of colorectal cancer screening may be attributed to various factors, previous studies on preventive health and colorectal cancer screening have shown that minority and Indigenous communities experience mistrust in healthcare systems connected to historical and racially-based maltreatment (Hammond, Matthews, Mohottige, Agyemang, & Corbie-Smith, 2010; Ward et al., 2015). Further research is recommended to explore the association of territorial status and Chamoru mistrust of Guahan's medical system as a barrier to preventive health behaviors such as colorectal cancer screening, with attention to Chamoru rights to self-determine their political governance and systems of health and wellness on Guahan.

Implications for Future Research

Findings from this study compel further research in three areas. First is the assessment of how and to what extent cultural beliefs act as positive or negative influences on colorectal screening among Chamoru. Efforts in this direction may include deeper examination of stigma and embarrassment, social norms on Chamoru masculinity, and the role of spiritual beliefs in the decision to get screened for colorectal cancer. Second is the exploration and development of health literacy among Chamoru as it applies to colorectal cancer screening. Third is a broader examination of political status as it influences Chamoru access to vital cancer and other health resources; emerging research considers the impact of territorial status as a social determinant of health (Ka'opua, 2017) in the context of Indigenous rights to self-determine options for cancer prevention, treatment, and survival. Although these are substantial research projects and may

take time to implement, all three potentially lend to the provision of culturally relevant and informative cancer screening interventions to engage Chamoru families and communities in meaningful ways.

Relevance to Social Work Education and Social Welfare

Social work education has long been committed to understanding human behavior from an ecosystems perspective with attention to micro-, mezzo-, and macro-level influences. Contextualizing the person-in-environment is a cornerstone of social work curriculum. Study findings exemplify this lesson by providing a deeper and critical comprehension of the complexities of health behavior and health disparities for Chamoru. Attention is drawn not only to the recognition of social determinants of health but to the specific circumstances of cancer survivorship for Indigenous peoples in U.S. territories. It is imperative that social work education examine health equity for Indigenous peoples from a broader ecosystemic perspective in order to think more critically about factors that impact Indigenous health and subsequent interventions. This is congruent with all social work education competencies but particularly the advancement of human rights, attention to social, economic, and environmental, justice, and the engagement of diverse communities (Council on Social Work Education, 2015).

Social work curriculum can address health equity for Indigenous communities in U.S. territories in several ways. First, it is critical to highlight the U.S. history of colonization of Indigenous peoples across the Pacific and U.S. territories. Second, the paucity of health data compels the strengthening of research capacity with and for Indigenous populations in these territories (Ka'opua, 2017). Curriculum for social work research should require the instruction of research ethics and methodologies relevant to Indigenous populations given the need for further health research in these communities. Third, it is paramount that classroom content and

pedagogy foster understandings of health equity from Indigenous perspectives, in culturally relevant ways, and in the context of self-determination.

Health equity and access is a critical issue in the United States. Recent recommendations to President Trump's administration from the National Association of Social Workers (NASW) urge the prioritization of healthcare access and the elimination of healthcare disparities among racial and ethnic minorities as a matter of ethical and economic imperative (NASW, 2017). Health disparities and access to healthcare are pertinent to social welfare as issues of social justice and population survival. This is evidenced by Chamoru who are overrepresented in both cancer incidence and cancer mortality on their home island. Addressing these disparities as it relates to health as a human right is in the purview of social welfare, and can be further understood in the context of Indigenous rights and the effects of colonization, especially as it pertains to self-determination. As a consequence of colonization, Indigenous peoples such as the Chamoru have experienced loss of Indigenous lands that are inextricably bound to kinship, livelihood, and well being. Global recognition of the historical grievances and rights of Indigenous peoples by the UN is documented in the Declaration of the Rights of Indigenous Peoples, which was adopted in 2007 to address the comprehensive human rights of Indigenous peoples. Among these are the individual and collective rights to be recognized as distinct peoples who are entitled to full participation in all decisions that will affect their lives, inclusive of health and health-related interventions in their communities (United Nations, 2008).

It is within this wider context of human rights, history, and the self-determination of Indigenous peoples that inquiry into cancer disparities - in this case, colorectal cancer - is essential to social welfare with and for Chamoru communities, with implications for healthcare access and social determinants of these disparities. Indeed, although Chamoru health is not limited in scope to the absence of disease, examination of factors that enhance or deter the quality of life and survival of Chamoru peoples merits dedicated exploration.

APPENDIX A
Demographic Survey⁸

1. Age: _____ 2. Village of residence: _____
3. Where were you born?: _____
4. How long have you lived on Guam?: _____ years
5. Sex: Male Female
6. Gender Identity:
 Man Woman Transgender man Transgender woman
 Other (please specify): _____
7. Sexual orientation:
 Heterosexual Gay Lesbian Bisexual
 Other (please specify): _____
8. What is the highest level of education you completed?
 Never attended/kindergarten only High school/GED Associate degree
 Grade 1 thru 8 Some college College degree
 Some high school Technical school Graduate degree
9. Your household income per year (annual):
 less than \$15,000 \$25,000 - \$49,999 \$75,000 - \$100,000
 \$15,000 - \$24,999 \$50,000 - \$74,999 more than \$100,000
 not sure
10. Do you identify as Chamoru?
 Yes No

⁸ Original font was larger. It has been modified to fit into this appendix.

11. What other ethnicities/races do you identify as? (You can check more than one.)

- | | | | |
|---|---|--|---|
| <input type="checkbox"/> None | <input type="checkbox"/> Filipino | <input type="checkbox"/> Native American/
Alaska Native | <input type="checkbox"/> Taiwanese |
| <input type="checkbox"/> Black/
African American | <input type="checkbox"/> Japanese | <input type="checkbox"/> Native Hawaiian | <input type="checkbox"/> Vietnamese |
| <input type="checkbox"/> Carolinian | <input type="checkbox"/> Korean | <input type="checkbox"/> Okinawan | <input type="checkbox"/> White |
| <input type="checkbox"/> Chinese | <input type="checkbox"/> Kosraen | <input type="checkbox"/> Palauan | <input type="checkbox"/> Yapese |
| <input type="checkbox"/> Chuukese | <input type="checkbox"/> Latino or Hispanic | <input type="checkbox"/> Pohnpeian | <input type="checkbox"/> Other: _____
(please specify) |
| | <input type="checkbox"/> Marshallese | | |

12. Have you ever been diagnosed with cancer?

- Yes No I don't know

If yes, please specify type of cancer: _____

13. Has anyone in your family ever been diagnosed with colorectal cancer?

- Yes No I don't know

14. Have you ever been screened for colorectal cancer?

- Yes No I don't know

If yes, please specify:

- Stool test/Fecal Occult Blood Test (FOBT)
 Colonoscopy
 Sigmoidoscopy
 Not sure

15. Do you currently have health insurance?

- Yes No I don't know

16. If yes, what is your primary source of health insurance? (Check one)

- Commercial insurance (e.g., TakeCare, SelectCare, Staywell, Moylan's NetCare)
 Medicaid MIP (Medically Indigent Program)
 Military (e.g., TRICARE) Medicare
 Other (please specify): _____

17. Do you have a regular physician, nurse practitioner, or other health care provider that you go to?

- Yes No I don't know

APPENDIX B

Promotional Flyer⁹

Want to help improve cancer survivorship on Guam?

VOLUNTEERS needed for a research study:
Colorectal Cancer Screening Among Chamorro on Guam¹⁰
Barriers and Access to Care

This study is open to Chamorro men and women
ages 50 to 75 years old.

Colorectal cancer is the third most frequent cause of cancer death on Guam. Chamorro have the highest rates of death from colorectal cancer compared to others on island.

The **PURPOSE** of this study is to learn more about what factors influence the decision to get screened for colorectal cancer. This research is part of a dissertation study at the Myron B. Thompson School of Social Work at the University of Hawai'i.

Participation involves volunteering for an in-person interview. Chamorro who *have* or *have not* been screened for colorectal cancer are welcome to join.

A gift card will be provided to study volunteers in appreciation of their time.

For more information, please contact Tressa P. Diaz at
(671) 687-0629 or guahancrc@gmail.com.

⁹ Original font was larger. It has been modified to fit into this appendix.

¹⁰ Note that the spelling of "Chamorro" is used deliberately here (not Chamoru) in cultural sensitivity of its common use/spelling for this generation of potential participants.

APPENDIX C

Newspaper announcement

Colorectal cancer screening research: Volunteers needed for a research study on colorectal cancer screening among Chamorro on Guam.¹¹ The study is open to Chamorro men and women ages 50 to 75 years old. Participation involves volunteering for an in-person interview. The purpose of the study is to learn more about what factors influence the decision to get screened for colorectal cancer. You can join the study whether or not you've been screened. A gift card will be provided to study volunteers in appreciation of their time. This research is part of a dissertation study at the University of Hawai'i. Call Tressa Diaz at 687-0629 for more information.

¹¹ Note that the spelling of "Chamorro" is used deliberately here (not Chamoru) in cultural sensitivity of its common use/spelling for this generation of potential participants.

APPENDIX D

Semi-structured Interview Transcript

Before the interview begins, the PI will provide the participant with informed consent form and review the consent with the participant. After the participant signs the informed consent and is provided with a copy, the PI will utilize this semi-structured interview guide. Participants will be encouraged to speak freely. Probes in this guide will only be utilized as necessary.

Introductory information

Hafa adai, my name is Tressa Diaz and I am a Chamoru and Filipina who was born and raised here on Guam. I am conducting this study as part of my dissertation research on Chamoru and colorectal cancer screening. In this study, I am interested in learning about what factors influence the decision of whether or not to get screened for colorectal cancer. I hope to use what is learned in this study to help improve access to colorectal cancer screening on Guam and increase cancer survivorship for Chamoru.

Before we begin, please fill out this short demographic survey as mentioned in the informed consent. Note that it will not have your name on it. It should take about five minutes to fill out. *(Pause for survey to be completed).*

This interview is meant to be informal. I encourage you to speak freely. There are no right or wrong answers. As you have given consent, I will audio record our conversation. You can skip any questions, take a break, or stop this interview at any time.

Thanks so much for taking the time to meet and share your experiences with me. Let's start off by finding out a little bit about you.

Interviewee background

1. Please share about your background. For example, where did you grow up?

Probes:

- i. What village or where are you from?
- ii. What is your family like?

iii. What was it like to grow up in a Chamoru family?

2. In general, how is your health?

Probes:

- i. How are you feeling today?
- ii. What, if any, major health concerns do you have?
- iii. Who do you trust to talk about your health concerns with?
- iv. Where or who do you go to when you aren't feeling well?

Transition question (Knowledge, beliefs, and experiences with cancer)

3. What do you think of when you hear the word “cancer”?

Probes:

- i. Have you or anyone you know been diagnosed with cancer?
If yes, How did you/they find out they had cancer?
- ii. What, if any, health or cultural beliefs do you have about cancer in general?

Knowledge about colorectal cancer

4. Tell me what you know about colorectal cancer.

Probes:

- i. What do you associate with colorectal cancer?
- ii. How did you learn about it?
- iii. Have you or someone in your family ever been diagnosed with colorectal cancer?
If yes: If you're comfortable sharing, what was that like for you?
- iv. What, if any, health or cultural beliefs do you have about colorectal cancer in particular?

Colorectal cancer screening

5. Tell me what you know about colorectal cancer screening.

Probes:

- i. Who, if anyone, has discussed colorectal cancer screening with you?
- ii. What does your family think about cancer screening in general, and colorectal cancer

screening in particular?

6. Have you ever been screened for colorectal cancer?

a. If yes: Please tell me the story of how you decided to get screened.

Probes:

- i. Why did you decide to get screened?
- ii. What/who helped you decide to get screened?
- iii. Before you got screened, what did you think screening would be like?
- iv. What was your experience with screening like?
- v. Would you recommend screening to a friend or family member?
- vi. What do you think was good about screening?
- vii. What do you think was difficult about screening?

b. If no: Have you ever considered being screened for colorectal cancer?

- i. If no, please describe why.
- ii. If yes: Please describe why you considered being screened and what that process was like.

Probes:

- iii. Why did you decide not to get screened?
- iv. What prevents you from getting screened?
- v. What do you think screening for colorectal cancer is like?
- vi. Do you have any questions/concerns about colorectal cancer screening? If so, what are they?
- vii. What might influence you to seek screening? Thinking about your family, friends, and others in your community--who might influence you to seek screening?

7. I recently analyzed data on colorectal cancer screening and Chamoru and found that...

(Approximate results of analysis were provided here -- for example, less than half of Chamoru over the age of 50 have been screened for colorectal cancer). Why do you think this is so?

This wraps up our interview. Is there anything else you'd like to share with me about colorectal cancer or screening?

After the interview, the researcher will answer any questions the participant may have regarding the interview process or dissemination of results of the study. Participant will be thanked for their time and sharing their story. A gift card will be given regardless of whether the participant completes the interview or not.

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