

**A REVIEW AND COMPARISON OF BREAST CANCER AND BREAST CANCER
SCREENING IN COSTA RICA AND GUATEMALA IN THE CONTEXT OF THE
HISTORICAL DEVELOPMENT AND HEALTHCARE INFRASTRUCTURE
OF EACH COUNTRY**

by

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ABSTRACT

A Review and Comparison of Breast Cancer and Breast Cancer Screening in Costa Rica and Guatemala in the Context of the Historical Development and Healthcare Infrastructure of Each Country

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BACKGROUND: Breast cancer is the most frequently diagnosed cancer in women worldwide. Costa Rica has rates of breast cancer and breast cancer survival comparable to those of highly developed nations and has had tremendous success in the prevention and treatment of the disease. Guatemala has made limited progress in its approach to breast cancer due to its fractured health system and the effects of a recent civil war. Both Central American countries have universal healthcare but have vastly different health outcomes. This dissertation will examine breast cancer and breast cancer screening as it pertains to each country's historical sociopolitical development and healthcare infrastructure.

METHODS: A historical review was performed on the development of the government, social security, health system, and population demographics of Costa Rica and Guatemala. An academic review of literature pertaining to breast cancer and breast cancer screening in each country was performed utilizing PubMed searches and health databases.

RESULTS: Over the past century, Costa Rica has enjoyed stability and economic growth while Guatemala was devastated by a brutal civil war and genocide. Costa Rica developed an organized and comprehensive public healthcare system which allowed the country to launch successful breast cancer prevention and treatment programs and keep breast cancer-related mortality low despite an increasing incidence rate. Unfortunately, Guatemala has not developed a cancer registry, so all cancer statistics are estimates, but it appears breast cancer mortality has been continuously rising over the past decade. Guatemala's inadequate health system cannot meet the basic healthcare or cancer needs of its population and significant health disparities exist between its rural, indigenous and urban, non-indigenous populations.

CONCLUSION: Key differences in the countries' abilities to manage their health systems and thus prevent and treat cancer may explain the observed differences in the respective breast cancer mortality trends. Guatemala remains decades behind Costa Rica in its ability to track and prevent breast cancer throughout the country. As Guatemala continues to develop, many lessons can be learned from its Central American neighbor, Costa Rica, in regard to health system management and breast cancer control programs.

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DEFINITIONS

ASR	Age-standardized rate
CCSS	Caja Costarricense de Seguro Social (Costa Rica Social Security Administration)
EBAIS	Equipos Básicos de Atención Integral en Salud (Basic Teams for Comprehensive Healthcare)
GNI	Gross National Income
HDI	Human Development Index
IGSS	Instituto Guatemalteco de Seguridad Social (Guatemalan Institute of Social Security)
LACCS	Latin American Cancer Control Scorecard
MIS	Modelo Incluyentes de Salud (Inclusive Health Model)
MSPAS	Ministerio de Salud Público y Asistencia Social (Ministry of Public Health and Social Services)
PEC	Programa de Extensión de Cobertura (Extension of Coverage Program)
PHC	Primary Health Care
UHC	Universal Health Coverage
U.N.	United Nations
U.S.	United States
WHO	World Health Organization

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Chapter One: Introduction

Breast cancer is the most frequently diagnosed cancer and cause of cancer-related deaths in women worldwide.¹ Aging is the strongest risk factor for breast cancer with the median age of diagnosis at 61 years.² Genetic mutations are responsible for less than 10% of breast cancers and women with a first-degree female relative with a history of breast cancer have 1.75-fold greater risk of being diagnosed with the disease than those without a family history.³ The majority of breast cancer risk is conferred through reproductive/hormonal and modifiable lifestyle factors as factors that increase exposure of breast tissue to hormonal estrogen also increase breast cancer risk. According to the 2016 *Clinical Obstetrics and Gynecology* article “Breast Cancer Epidemiology and Risk Factors,” these risk factors include prolonged exposure to combined hormonal therapies, specifically hormone replacement therapy in postmenopausal women, obesity/physical inactivity, heavy alcohol use, and later menopause. Smoking, chest radiation, and mammographically-dense breast tissue are also associated with an increased risk of breast cancer.² Reproductive/hormonal factors that decrease risk by modulating estrogen exposure are breastfeeding and high parity. Other potential risk factors such as age at menarche and age at first birth require further investigation due to contradictory existing evidence on their relationship to breast cancer risk.²

Breast cancer screening guidelines vary by country and oftentimes vary within a country. For example, in the United States (U.S.), the American Cancer Society, the U.S. Preventive Services Task Force, and the American College of Obstetricians and Gynecology all offer slightly different breast cancer screening guidelines for women.⁴ A recent review summarizing the breast cancer screening guidelines of twenty-one high-income countries found the recommendations to be very similar. Most countries recommended screening via mammography

every two years for women aged 50-69 years old.⁵ The World Health Organization (WHO) acknowledges that mammography is costly and requires substantial healthcare infrastructure to be effective at a population-level. This results in a significant disparity between countries since those with limited resources are unable to screen women in the early stages of the disease. This results in a high proportion of patients being diagnosed in later stages, which inherently have greater morbidity and mortality.⁶

In a review of the literature, a factor that is not historically considered as a breast cancer risk factor is a woman's country of origin. The epidemiology of cancer and cancer-related deaths changes as countries are stratified by level of development. The Human Development Index (HDI) was developed by the United Nations (U.N.) to provide a more nuanced picture of a country's overall development by assessing three dimensions of human development. The dimensions considered are health, assessed by life expectancy at birth, education, assessed by mean years of schooling for adults and expected years of schooling for children, and standard of living, assessed by gross national income (GNI) per capita.⁷ The 2020 Human Development Report ranks 198 countries by the indices described above and divides the ranked countries into four categories – very high, high, medium, or low human development.

In countries with very high HDI, including the United States, France, and Australia, the incidence of breast cancer in women rapidly increased from the 1980s to the early-2000s as detection increased due to advances in screening technology. In those and similarly very high HDI countries, overall breast cancer incidence has stabilized or fallen throughout the twenty-first century.⁸ Overall, breast cancer mortality has decreased in countries with very high/high HDI.^{8,9} Increased screening, and thus earlier detection, in combination with improvements in treatment modalities are likely responsible for the decreasing mortality in these countries. In contrast, in

countries of medium and low HDI ratings, including many countries of Central and South America, Africa, and Asia, the incidence of breast cancer has been rising continually from the 1990s to 2018, but remains lower than in countries with a higher HDI. The increase in incidence is likely attributable in part to increasing public awareness, increasing life expectancy, and an increase in the number of breast cancer risk factors, including obesity, earlier menarche, and delayed childbearing.⁸ Unfortunately, in those countries with limited resources, breast cancer mortality remains disproportionately high, likely in part because large-scale screening programs involving mammography and advanced treatment options are less likely to be feasible.^{8,10}

Costa Rica, ranked 62nd by HDI, is considered to have very high human development. Life expectancy at birth for Costa Ricans is 80.3 years, expected years of schooling for children is 15.7 years, mean years of schooling for adults is 8.7 years, and the GNI per capita (converted to international dollars based on purchasing power parities) is \$18,486.¹¹ Guatemala, ranked 127th by HDI, is considered to have medium human development. Life expectancy at birth for Guatemalans is 74.3 years, expected years of schooling for children is 10.8 years, mean years of schooling for adults is 6.6 years, and GNI per capita is \$8,494.¹² Despite these significant differences in human development, the World Bank classifies both countries as upper-middle-income countries, meaning they both have a GNI per capita of \$4,045 to \$12,535 in U.S. dollars.¹³ As demonstrated by the HDI rankings, Guatemala and Costa Rica have great systematic differences that have resulted in significant disparities between the life expectancy, education, and income of each country's citizens. Therefore, it can be projected that significant differences exist between rates of breast cancer and breast cancer screening in each country.

In order to appropriately contextualize the state of breast cancer and breast cancer screening modalities in Costa Rica and Guatemala, a review of each country's contemporary

history and the development of each healthcare system will be discussed in this dissertation. Current breast cancer epidemiological and screening trends in Costa Rica, which has a very high HDI rating, and Guatemala, which has a medium HDI rating, will then be examined and analyzed as it pertains to each country's sociopolitical development and healthcare infrastructure. Both countries are located in Central America, both are classified as upper-middle-income countries by the World Bank, and both offer universal healthcare but with vastly different government investment. To obtain the information for this dissertation, a historical review was performed on the development of the government, social security, health system, and population demographics of Costa Rica and Guatemala. Sources include reports from the United Nations, World Health Organization, history textbooks, anthropological journals, and newspapers. An academic review of the literature pertaining to breast cancer and breast cancer screening in Costa Rica and Guatemala was performed utilizing PubMed searches containing the words "breast cancer," "screening," "Costa Rica," "Guatemala," and "Central America." Health databases produced by each country were also examined to determine breast cancer trends as they relate to population demographics within each nation.

Chapter 2: History, Healthcare, and Demographics of Costa Rica

History of Costa Rica

Unlike many of its surrounding nations, Costa Rica had a relatively small indigenous population in the pre-Columbian era. Those indigenous peoples that did populate the country were largely absorbed into colonial society through marriage with the Spanish.¹⁴ When Christopher Columbus arrived in the region in 1502, he named it Costa Rica or "Rich Coast." Due to local resistance, Costa Rica did not become a Spanish colony until the mid-1500s.¹⁵

In 1821, Costa Rica joined the Federal Republic of Central America, which eventually became the United Provinces of Central America, created to assert independence from Spanish rule.¹⁵ By 1838, Costa Rica, discouraged by the unrest of the other nations, chose to formally withdraw from the United Provinces and become a sovereign nation.^{14,16} During the latter half of the nineteenth century and early twentieth century, the Costa Rican coffee and banana trade with Europe flourished, augmented by foreign investment in railway infrastructure. Unfortunately, this push to develop the “coffee frontier” resulted in the displacement of many remaining indigenous groups from their ancestral lands, forcing their migration into the jungle and thus into greater poverty.¹⁷

Throughout the 1870s to 1917, Costa Rica enjoyed a period of peace with democratic elections, avoiding much of the conflict plaguing its Central American neighbors. Two periods of unrest occurred in the country’s recent history. In 1917, Federico Tinoco led a coup to overthrow the republic and ruled the country as a dictator. His repressive regime could not gain U.S. recognition and eventually became unpopular with the Costa Rican people, resulting in his resignation in 1919. Following Tinoco’s dictatorship, democratic elections were restored in the nation until the six-week civil war of 1948.¹⁴ The grounds for this civil war were set when Dr. Rafael Angel Calderón Guardia was elected president in 1944. During his presidency, Calderón enacted major progressive reforms including the development of a social security system and new laws bolstering worker’s rights, making him incredibly popular with the working class. However, the reality of his poorly managed social welfare programs in combination with financial strains related to World War II resulted in unease amongst the wealthier classes.

The subsequent president, largely viewed as a Calderón figurehead, met significant resistance and, allied with communist supporters, frequently utilized the military to violently

quash this opposition.¹⁸ The tumultuousness of the time resulted in the election of 1948 being placed under the control of an independent tribunal, which pitted opposition candidate, Otilio Ulate, against the ruling party candidate, Calderón. Ulate was declared the winner but Calderón, largely believed to be seeking a corrupt dictatorship, contested the results claiming fraud and demanding the election be annulled. The annulment was granted triggering a civil war with resistance led by the National Liberation Army. The war between pro-government forces and the oppositional National Liberation Army lasted for 44 days and resulted in the deaths of approximately 4,000 people.¹⁹ The resistance won and a compromise was reached where Ulate would eventually take power and significant sociopolitical reforms would be issued.

Following the end of the war, a provisional constitution was drafted which strengthened and enacted many of the progressive reforms begun but not fully executed by Calderón in the early-1940s.²⁰ These reforms abolished the army, ended institutionalized racism, granted women the right to vote, nationalized banks, and importantly, fully developed the social security system.¹⁴ The 1940s reforms allowed for significant social and economic development by mandating public education, codifying labor laws, and creating the Caja Costarricense de Seguro Social (CCSS, Costa Rica Social Security Administration), which universalized healthcare. It was the enactment of the CCSS which set the framework for the current healthcare system in Costa Rica.²¹

Healthcare System of Costa Rica

The Political Constitution of the Republic of Costa Rica, stating human life is inviolable, was expanded under the 1973 General Law of Health to establish that “*all residents have the right to healthcare provisions*” maintained by the State.²¹ This made the Costa Rican State responsible

for the public availability of high quality healthcare facilities, the accessibility of those facilities, and the provision of ethical care.

The CCSS finances healthcare throughout the country via contributions from the worker, employer, and the government. Ninety percent of the financial contribution of the health system originates from the worker salary which is taxed at 22.9%. Of that 22.9%, 8.25% is directly taken from the worker, 14.2% is from the employer, and 0.50% is contributed by the State. The Costa Rican State participates in the system by employing public workers and provides nearly 7% of the financing for the CCSS via taxes on lottery winnings, tobacco, and alcohol.²¹ Health services are available to all residents, including the uninsured, and by the 1990s this was expanded to include undocumented immigrants as well. The system underwent significant reform by the Ministry of Health in the 1990s following an economic recession. These reforms changed the responsibilities of both the CCSS and the Ministry of Health, giving the Ministry control of national health policy and the coordination of all healthcare activities, public and private, while the CCSS is responsible for population prevention, recovery, and rehabilitation of health. The CCSS based its healthcare organization on a national primary care model and established a three-tier health system to improve geographical access to care throughout the country.^{21,22}

In 1995, the Equipos Básicos de Atención Integral en Salud (EBAIS, Basic Teams for Comprehensive Healthcare) were established as the central and first level of care in the country. EBAIS teams, along with small local clinics, provide primary and preventative care to all local community members in their designated territory. The establishment of the EBAIS was the most successful effort to provide assistance to the poor, indigenous, elderly, and other vulnerable groups with limited access to care.²³ By 2012, EBAIS teams covered nearly the entire population

of Costa Rica and accounted for 80% of the care received by the population.²² The EBAIS teams typically include a physician, nurse, social worker, pharmacist, and administrator and are responsible for providing care to several thousand patients in their assigned area. Teams will also go out into the communities to conduct home visits for those patients that are elderly or have movement restrictions.²³ The second care level involves large clinics and regional hospitals that provide emergency services, minor surgical care, and more specialized outpatient management teams. The third care level is comprised of the national hospitals that provide specialized care and major surgeries.^{21,23}

Costa Rica's public health insurance also follows an integration model meaning all levels of care are progressively united under a single financial and administrative organization, the CCSS. Services provided under the system include primary care for children, teenagers, adults, senior citizens, and women. Women are provided prenatal and postnatal care, basic assessments for infertile couples, detection of violence against women, birth control, and, importantly, screening for cervical and breast cancer.²¹ The national primary healthcare structure developed by the CCSS decades ago has remained incredibly successful today. Costa Ricans' life expectancy is currently 80.3 years, the 32nd highest in the world and the second highest in the Americas after Canada.⁷ In 2000, the WHO released a report ranking the health systems of 191 countries and Costa Rica's was ranked 36th, one rank higher than the United States.²⁴ Recently the system has faced challenges including long wait times for elective procedures, low doctor to patient population ratios, and budgeting troubles. Long wait times have resulted in a greater number of Costa Ricans seeking care in the private sector, which opened in 2006, putting the public health sector at some risk and begging the question of new reforms on the horizon.²⁵

Demographics and Access to Care

As of 2016, Costa Rica has a population of approximately 5 million people, 76.8% of which live in urban areas. Per the 2010 census, White and Mestizos (those identifying as mixed race with both Spanish and indigenous ancestry) made up 83.7% of the population. Seven percent identified as Black and 2.4% as Indigenous.^{26,27} The eight indigenous groups of Costa Rica are the Huetar, Maleku, Bribri, Cabécar, Brunka, Ngäbe, Bröran, and Chorotega people.

In 2015, 21.7% of Costa Rican individuals, a significant proportion being indigenous peoples, were living in poverty. Amongst indigenous groups, rates of poverty are often as high as 50%, a tragic parallel seen in many other indigenous populations.^{26,28} Like many indigenous peoples throughout the world, those of Costa Rica are similarly disadvantaged, living in poverty 2-5 times more frequently than their non-indigenous neighbors.²⁸

Generally, when it comes to healthcare and care access, Costa Rica is viewed as providing fairly equitable universal public healthcare. Its population benefits from the distribution of diverse health services with equal access across income levels.²⁹ Unfortunately, this comes at a cost of extremely long wait times, sometimes up to a year, for elective surgeries. This is likely due, in part, to the stagnation of the number of medical graduates in recent years and the lower number of physicians serving the population, with an average of 2.2 physicians per 1,000 people. Limitations to primary care have also resulted in the congestion of emergency rooms for non-emergency problems. These issues have led to greater out-of-pocket spending on healthcare, risking a shift towards a two-tier system of public and private care in the country.²⁵

In 2019, the efficacy of health services in 204 countries and territories with universal health coverage (UHC) was assessed through the Global Burden of Diseases Study. The UHC effective coverage index, scaled numerically from 0-100, was created to reflect 23 unique

indicators, such as health promotion and disease prevention, to understand how effectively a given country's UHC provides healthcare to its population.³⁰ On this index, Costa Rica achieved a score of 79, putting the country in the 80-90th percentile of all countries with a health system comparable to those of the U.S., New Zealand, and Portugal. Although Costa Rica does face some challenges in its provision of universal care, this score indicates the overall success that the country has had in implementing equitable UHC.

Chapter 3: History, Healthcare, and Demographics of Guatemala

History of Guatemala

Prior to the Spanish conquest of Guatemala, the Mayan Empire dominated the region. The Mayan civilization was incredibly sophisticated with developed architecture, art, writing, and mathematics. Despite centuries of success and influence, the civilization declined in the 10th century for unknown reasons. By the time of the Spanish conquest, the once expansive empire was buried beneath the rainforest with their Mayan descendants living in rural villages.³¹

In 1524, Pedro de Alvarado led the conquest of Guatemala, meeting fierce resistance from the Mayan people. Eventually, the Spanish were successful due to their superior weaponry but also largely because of the devastating epidemics they brought that plagued the indigenous people of the region.³² Once under Spanish control, those indigenous groups that survived the Old World diseases and war brought by the Spanish were subjected to servitude and exploitation by an unjust, racist caste system that favored their conquerors.³³ Ties to ancestral cultures were diminished following the compulsory movement of people from their mountain lands into organized Spanish *congregaciones* (settlements), the forced assimilation into colonial ideals, and

the conversion to Christianity, all of which devalued the ancient cultures of the indigenous groups but also allowed them to be more easily controlled by the Spanish.^{32,33}

Guatemala declared independence from Spanish rule in 1821 and joined the United Provinces of Central America until it obtained full independence in 1839.³⁴ In the nineteenth century, while Costa Rica enjoyed largely peaceful democratic governance, Guatemala saw significant unrest and dictatorship under Rafael Carrera, who had been appointed the country's first president in 1844. Carrera strengthened government and military power under his conservative regime but did succeed in growing the national economy and limiting the exploitation of rural indigenous populations, which at the time were viewed as "subhuman" by many in power. Unlike the isolationist policies of Costa Rica at the time though, Guatemala frequently intervened in the political and military involvements of its Central American neighbors, likely to demonstrate its impressively powerful military forces.^{35,36} Following the overthrow of Carrera's successor in 1871, Guatemala enjoyed a period of significant economic growth and social reform along with further militarization of the country under dictatorship regimes. The expansion of coffee exportation also allowed for the development of more modern infrastructure throughout the country.

In 1944, a civilian revolt overthrew the U.S.-backed incumbent dictator, electing Juan José Arévalo as president. Arévalo, a professor of philosophy, and his successor assisted in the reconstruction of a post-dictatorship Guatemala, drafting a new constitution which would grant extensive civil liberties to their people. Thus, Guatemala enjoyed a brief period of progressive social reforms including education programs, suffrage for women and the illiterate, social security, labor laws, and the redistribution of land to the poorer classes.^{34,37} Importantly, Arévalo founded the Instituto Guatemalteco de Seguridad Social (IGSS, Guatemalan Institute of Social

Security) to provide hospital and clinical services for the injured, medical services for work accidents, and which was eventually expanded to include maternity and child protection coverage.³⁸

Arévalo's populist ideology of "spiritual socialism," known as *Arevalismo*, was intended to end oppression within his country, but which, gravely, in a post-World War II America was misinterpreted as communism.³⁹ His democratically-elected successor, Jacobo Arbenz, also strengthened land reforms, which were widely supported by the working class but were viewed as sympathetic to the communist movement and enraged the elite landowning classes.³⁹ The U.S., threatened by what it perceived as a growing communist regime in Central America, utilized the social unrest that followed Guatemala's reforms to back a military coup ousting Arbenz, which played a role in triggering a 36-year civil war in Guatemala.³⁹

The coup was successful and Carlos Castillo Armas took power, forcing Arbenz out, reversing agrarian and suffrage reforms, and stamping out rebellion with military violence until his eventual assassination. Guatemala, further destabilized and still under repressive military rule, experienced an even greater rift in inequality and further disenfranchisement of poor and indigenous peoples. This led to the development of rebel groups that, inspired and supported by Cuba, adopted similarly Marxist ideologies of armed struggle against the government as the sole solution to their social crises.⁴⁰ By 1960, a bloody civil war began as clashes between the government and leftist rebel insurgencies, mainly composed of poor Mayan and Ladino (those of both Spanish and indigenous ancestry) groups erupted. The Guatemalan government utilized anti-insurgency and intelligence tactics, taken from U.S. training techniques utilized in Vietnam, to institute systematic policies of terror in which it killed, tortured, or "disappeared" an estimated 200,000 Mayan people from rebel groups.⁴¹ Police and military also systematically murdered

members of society that showed resistance including indigenous peoples, students, educators, politicians, journalists, and activists. The human rights violations committed during the civil war are believed to have reached the scale of genocide. Until the war ended in 1996, the country of Guatemala experienced violent unrest with frequent uprisings, state repression and terror tactics, and a constant brutal conflict throughout its society.⁴¹

By the late 1980s, elections had been renewed but were marked by corruption since civilian presidents were likely military figureheads and violence against rebel groups continued. In 1994, peace talks began between the government and insurgent groups under the guidance of the U.N. Agreements on human and indigenous rights as well as agrarian and socioeconomic policies were signed and national elections for president and Congress took place in 1995 when a ceasefire was declared. The Peace Accords were finalized in 1996, bringing an end to the bloody 36-year civil war that ravished the country.^{34,41}

Only two decades removed from a civil war, Guatemala is still experiencing significant sociopolitical challenges. Political corruption has plagued the democratic nation and gang violence remains a constant threat.³⁴ However, the country continues to have democratic elections with high public involvement and voter turnout rates have often been in the 60%-range over the last decade. Unfortunately, despite Guatemala's economic stability in the 21st century, its people still experience high rates of poverty and inequality, especially amongst its indigenous populations.⁴² Since the civil war, the State has also struggled to adequately supply care to the Guatemalan people despite the constitutional guarantee that all citizens have a right to healthcare.⁴³

Healthcare System of Guatemala

Although the civil war brought healthcare and other improvements to a standstill, the 1996 Peace Accords placed control of the healthcare sector into the hands of the newly elected democratic government. The Ministerio de Salud Público y Asistencia Social (MSPAS, Ministry of Public Health and Social Services) is responsible for overseeing the health system of Guatemala at three levels of care: primary and preventative care at the first level, permanent comprehensive health centers at the second level, and regional and national hospitals at the third level. Relative to the rest of Central America, Guatemala has some of the lowest health expenditures in the region, with only 2.6% of the country's GDP spent on public health expenditures. This pales in comparison to Costa Rica, which dedicates 7.1% of the country's GDP to public health expenditures.⁴³ The significant underfunding of the health system at least partially explains the limited access to quality healthcare in Guatemala.

Recognizing the need for accessible primary care, the MSPAS established the Programa de Extensión de Cobertura (PEC, Expansion of Coverage Program) shortly after the end of the civil war. The PEC was organized as part of the first level of care and expanded coverage to rural areas of Guatemala. The PEC operated by contracting out healthcare administration to nonprofit NGOs to increase access to primary and preventative care for poor, rural, and indigenous people.⁴³ At the height of the program, the PEC provided approximately 70% of the care in rural areas and strengthened primary care in Guatemala, especially for women and children, until its abrupt cancellation in 2014. Unfortunately, the overall impact of the PEC was diminished by significant underfunding from the government.

The majority of the PEC contracts were service provision contracts for accredited NGOs, many of which were local organizations. Regions of care were divided into jurisdictions of

10,000 people, which were assigned one physician, one nurse, and one community administrator to organize health visits throughout the area.⁴³ NGOs were also required to hire additional staff depending on specific needs of the community. For example, if an area had high rates of maternal mortality, an additional qualified maternal and neonatal nurse was hired. NGOs had been subject to regular auditing by the government of Guatemala, but the technical teams that performed those audits were eliminated in 2008 due to underfunding. As such, the supervision and verification of health reports released by NGOs became much more limited in scope. The NGOs also rarely met their health targets. In 2011, only 39% of the 28 indicator targets were met for the entire PEC. Stated reasons for not meeting targets included delayed payment by the government, limited funding, and inadequate physician numbers.⁴³

As part of the basic health package promised by the PEC, women were granted family planning services, care during pregnancy, birth, and the postpartum period, and cervical and breast cancer detection. Children were granted basic primary care services including nutritional evaluation. Illness and emergency care were also provided for infections ranging from sexually transmitted infections to tuberculosis and dengue. And, finally, public health services such as waste disposal and water treatment were also provided by the PEC. Centers for Integral Attention of Maternal and Child Health were included within the second care level to provide basic primary care and uncomplicated birth care but lack access to more advanced services such as a blood bank, which only exist within hospitals, the third level of care.⁴⁴

This model of utilizing NGO support to provide care to vulnerable populations was intended to be a temporary measure due to its largely unsustainable model. Additionally, few improvements have been made to the healthcare infrastructure in the country since the turn of the century and most hospitals and clinics, which are concentrated in urban areas, remain in

dilapidation today. In 2014, the MSPAS cancelled the PEC after experiencing frequent management turnover, a growing financial crisis, and indigenous communities disenfranchised with receiving a perceived lower quality of care. A proposal to reform the country's healthcare framework was drafted in the same year, but the abrupt cancellation of the PEC essentially eliminated healthcare services to the majority of Guatemala's rural areas, home to the indigenous communities.⁴⁵ The reforms formally institutionalized primary care and prioritizes rural communities to receive care from new primary health care (PHC) teams assigned to regions of 5,000 people.^{44,45} The implementation of this new system has proved slow and inefficient within a larger health system that remains deeply fragmented and has continued to fall short to meet the basic health needs of the population. The most recent USAID Healthcare Systems Assessment of Guatemala revealed significant problems with access to healthcare facilities, availability of staff in those facilities, and the quality of facilities and staff.⁴⁶

Today, about 75% of Guatemalans receive care via the MSPAS, 20% access the system through the IGSS, which is financed by worker-employer contributions, and less than 5% have access to private insurance.^{44,47} Although access to care has increased in Guatemala over the past 20 years and the recent health system reforms may carry hope for improvements, there are still significant strides that need to be made to increase access in the country. To date, USAID estimates that 35% of Guatemala's population, nearly six million people, lack access to basic healthcare services.⁴⁸

Demographics and Access to Care

As of 2016, Guatemala had a population of 16.7 million people with approximately 50% of people living in urban areas.⁴⁷ Estimates report that roughly 45% of Guatemalans self-identify as

Indigenous. There are twenty-four indigenous groups in the country, including, the Achi', the Akateco, the Awakateco, the Chalchiteco, the Ch'orti', the Chuj, the Itza', the Ixil, the Jacalteco, the Kaqchikel, the K'iche', the Mam, the Mopan, the Poqomam, the Poqomchi', the Q'anjob'al, the Q'eqchi', the Sakapulteco, the Sipakapense, the Tektiteko, the Tz'utujil, the Uspanteko, the Xinka, and the Garífuna.⁴⁹ Seventy percent of Guatemalans speak Spanish, the official language of Guatemala, but the country recognizes the 21 Mayan languages and two indigenous languages also spoken in the country.^{50,51}

Like many indigenous peoples throughout the world, those of Guatemala are similarly subject to systemic inequalities. When it comes to poverty, 50% of non-indigenous Guatemalans live in poverty as opposed to an estimated 79% of indigenous Guatemalans.⁴⁷ A significant disparity in health and health access also exists between Guatemala's non-indigenous, urban populations and indigenous, rural populations. Guatemala's long history of temporary contracting has resulted in a limited healthcare workforce in the country. There is also an unequal distribution of healthcare workers in urban and rural areas, with an estimated 25.6 workers per 10,000 people in urban areas, compared to only 3 workers per 10,000 people in rural areas. As an additional quantitative representation of these inequalities, in 2015 maternal mortality in indigenous women was estimated to be 1.75 times higher than in non-indigenous women in Guatemala.⁴⁶

Geographically, accessing a healthcare center in Guatemala is challenging due the remote locations of many indigenous communities. This challenge is made more difficult by poor civil infrastructure and unaffordable costs associated with travel. As such, an estimated 23% of Guatemalans live more than an hour drive from a healthcare facility.⁴⁴ Another significant barrier to accessing the healthcare system is the availability of providers who speak indigenous

languages.⁴⁷ In 2017, the MSPAS implemented a progressive new model called the Modelo Incluyetes de Salud (MIS, Inclusive Health Model) in an attempt to transform healthcare access in rural areas.⁵² The model incorporates traditional healers alongside physicians to connect with rural indigenous populations in order to increase culturally-conscious healthcare provision.⁵³

However, on the 2019 UHC assessment of 204 countries and territories, Guatemala received an effective coverage index score of 52 out of 100. This placed the country in the 40-50th percentile, on par with the healthcare systems of Bolivia and Nicaragua.³⁰ This score further indicates significant shortcomings in the provision of equitable UHC throughout Guatemala.

Chapter 4: Breast Cancer and Breast Cancer Screening

Breast Cancer and Screening in Costa Rica

Historically, cancer statistics in Central America have been fairly limited due to few cancer registries continuously collecting data.⁵⁴ Costa Rica, however, with its successful universal public health system, has a robust National Tumor Registry. The Registry has been collecting cancer data throughout the entire country since the 1970s, achieving complete national coverage by 1980. As part of the Registry system, the reporting of new cancer diagnoses across all public and private health centers is mandatory.⁵⁵ It is one of the only national cancer registries in the entirety of Central and South America and is used by Costa Rica to assess and delegate resources for cancer control throughout the country.⁵⁶ Despite the country's impressive universal health system touted for its equitable care and disease tracking, in 2016 The World Bank identified Costa Rica as one of the most economically unequal countries in the world.⁵⁷ Therefore, a deeper analysis of the equity and functionality of the health system may identify possible disparities in breast cancer identification and treatment within the country's most disadvantaged groups.

Costa Rica's breast cancer incidence and mortality has followed a similar trend to that of many other very high/high HDI countries. Beginning in the 1970s, data from the National Tumor Registry shows Costa Rica's breast cancer incidence at an age-standardized rate (ASR) of 25.5 per 100,000 people and an ASR mortality of 11 deaths per 100,000 people.⁵⁸ By 1984, the ASR incidence rate dramatically increased to 36.8 cases per 100,000 people with a mortality rate of 16 deaths per 100,000 people (Figure 1). This follows similar international trends at the time as breast cancer awareness increased and screening technology became more available.⁸ Analysis of breast cancer rates by region at this time showed significant disparities in incidence between urban and rural areas. At the same time, in developed cities throughout Costa Rica, the incidence of breast cancer was as high as 43.3 per 100,000 people. In the less developed and poorer areas, the incidence was as low as 11.9 per 100,000 people in the same year. Proposed hypotheses for this disparity include differences in fertility rates between urban and rural women as higher parity is correlated with lower incidence of breast cancer, higher alcohol and obesity rates in urban areas thus increasing the risk of breast cancer, and potentially less frequent detection of breast cancer due to more limited screening options for women in rural areas.⁵⁹⁻⁶¹

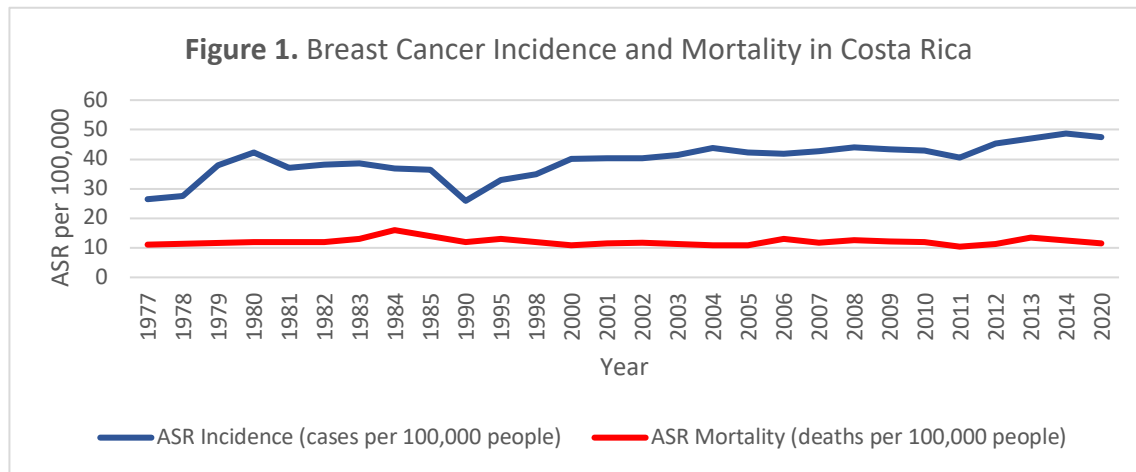
By 1995, breast cancer ASR incidence had declined to 33 cases per 100,000 people with a mortality of 13 deaths per 100,000 people.⁶² This further increased in the early-2000s with an ASR incidence reaching 42.4 cases per 100,000 people by 2005 but with mortality decreasing to 10.8 deaths per 100,000 people.⁶³ The incidence has continued to increase throughout the 2000s, reaching 45.4 cases per 100,000 people by 2012, although mortality remained fairly stagnant, around 12 deaths per 100,000 people (Figure 1).^{64,65} The geographic trends described in the 1990s continued to hold true in the 2010s. A University of Costa Rica School of Public Health analysis of breast cancer statistics from 2011-2015 again found a higher incidence of breast

cancer diagnoses in urban areas compared to poorer rural areas.⁵⁵ Explanations for these differences focus on higher alcohol consumption and smoking in urban areas, but no analysis regarding public knowledge or cancer screening availabilities in poorer regions is offered.⁵⁵ Despite these geographical differences in incidence, when the same University of Costa Rica study analyzed mortality, no significant differences could be found between breast cancer survival time and rural versus urban or wealthy versus poor populations. This may indicate that physical availability of healthcare centers may not be the primary barrier for accessing care in poorer rural areas.^{66,67}

Breast cancer remains the most common cancer diagnosed in women in Costa Rica today. In 2018, Costa Rica was noted to have one of the world's best breast cancer survival rates by the American Cancer Society's Global Cancer Facts and Figures. The analysis found that between 2010-2014, 87% of Costa Ricans diagnosed with breast cancer had a five-year net survival rate. This survival rate rivals that of the United States and Canada, which have survival rates of 90% and 88%, respectively. It is also the best record in all of Central and South America.⁸ Demonstrating this, in the 2020 country statistics reported by the Global Cancer Observatory the incidence rate of breast cancer in Costa Rica continued on an upward trend with an age-standardized incidence rate of 47.5 cases per 100,000 people, yet mortality remained low at 11.5 deaths per 100,000 people (Figure 1).⁶⁸ So, how has Costa Rica been so successful in managing breast cancer especially compared to its Central American neighbors?

The CCSS of Costa Rica, which covers 90% of the population, has an integrated model of cancer detection and care. Those people suspected of having cancer are referred from the primary level of care to the more specialized second and third levels of care where five of the 29 public hospitals have an oncology department.⁵⁶ Although the cancer burden in Costa Rica

remains high, Costa Rica launched a successful 2011-2017 cancer prevention and control plan which incorporated aspects of social determinants of health.⁶⁴ By offering cancer coverage through the CCSS universal healthcare schema, even the poorest communities are able to access cancer care free of cost. For this reason, Costa Rica's cancer plan is one of the most successful throughout Latin America. The country does face challenges, though, in its detection and management of cancers.



A nationwide 1984-1985 survey assessed the utilization of breast cancer screening in Costa Rica. As of 1982, only 48.1% of women aged 25-58 years old had undergone a clinical breast examination. Those that were most likely to have ever had a breast examination by a physician or nurse were women aged 30-49 years, those residing in wealthier urban areas, and those with higher education. Only 41.7% reported performing a breast self-examination. By comparison, at that time in the United States, 73% of women had performed a self-examination and 92% reported having had a clinical breast examination done by a physician.⁶⁹

A 2014 report published in *Breast Cancer: Basic and Clinical Research* analyzed breast cancer in a small cohort of urban Costa Rican women and found that the median age of diagnosis was age 53 years, almost 10 years younger than the mean age of diagnosis in the U.S.⁷⁰ This is

also consistent with previous studies indicating that Hispanic women are diagnosed with breast cancer at a younger age than non-Hispanic white women. Furthermore, 37% of patients in Costa Rica were initially diagnosed with stage III or IV breast cancer, much higher than other studies on Hispanic women in Latin America, which indicate only 14% of women are diagnosed with stage III or IV breast cancer.⁷⁰ Overall, Hispanic women are initially diagnosed with a later stage of breast cancer 1.7-2.5x more frequently than their non-Hispanic white counterparts. This data brings into question the current breast cancer screening and population awareness in Costa Rica, which has limitations when it comes to mammography capacity and outreach to rural communities.⁷¹ There is also room for improvement in the medications available for cancer treatment in Costa Rica as only older drugs are available to cancer patients and more novel treatments are not widely obtainable in the country.⁷²

As a quantitative demonstration of social improvements made in the country, the 2020 World Bank report found that Costa Rica was experiencing more equalizing wealth across its population.⁷³ To quantify the policies and programs in place to address cancer care and inequalities in cancer care access, *The Economist* developed a Latin American Cancer Control Scorecard (LACCS) in 2017. It assesses six domains based on a country's existing healthcare system and policies, which include, "cancer plan; monitoring performance; medicines availability; radiotherapy availability; prevention and early detection; and finance."⁷² Raw scores were assigned to each category and normalized to a 1-5 rating, with a maximum of 30 potential points. Compared to its Latin American neighbors, Costa Rica has the second highest LACCS score of 22, one point behind Uruguay. It received the following scores in each domain: 5/5 for strategic cancer plan, 5/5 for monitoring performance, 2/5 for medication availability, 4/5 for radiotherapy availability, 2/5 for early detection and prevention, and 4/5 for finance due to the

affordability of its universal healthcare system.⁷² Overall, the report acknowledged that Costa Rica is doing fairly well controlling cancer but faces challenges addressing economic inequality, limited care accessibility in rural areas, and future healthcare financing.⁷² The study analyzed cancer care in 12 Latin American countries and, unfortunately, Guatemala was not one of them.

Despite clinical breast exams becoming standard in public primary care practices, mammograms remained widely unavailable due to significantly long wait times and the fact that the machines are only present in hospitals and not ambulatory care centers. Costa Rica also lags behind many other very high/high HDI countries in the number of mammogram machines it has for its population. In 2015, it only had 6 machines per one million people, compared to Canada which had 17 machines per one million people. Efforts to increase the availability of screening resulted in the CCSS purchasing more mammography machines, bringing the total to 10 machines per one million Costa Ricans by 2019 (Table 1).^{74,75} Regarding radiotherapy, 72% of Costa Ricans were reported to have access to radiotherapy machines in 2014.⁷⁶

Table 1. Number of Mammography Machines per One Million People in Costa Rica by Year											
Year	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008
# Machines	0.2	2.9	2.8	3	3.5	3.4	3.4	3.3	3.5	3.5	3.8
Year	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
# Machines	4.25	4.6	4.8	6	5.5	6	6.2	6.5	6.3	6.6	10

Although no such surveys on public awareness or frequency of clinical breast exams have been repeated since the 1990s, numerous social campaigns and increased government funding in the country in the 2000s may indicate that public awareness has increased. October has been Breast Cancer Awareness Month in Costa Rica for many years. As such, several “pink walks” take place during that time, including the Anna Ross Foundation annual “bra walk” and Avon Breast Cancer Awareness Walk through the streets of San José to raise money for and awareness

about breast cancer (Image 1). Such events have been embraced by the people of Costa Rica and are now seen as annual traditions.^{77,78} Furthermore, in 2017, the CCSS announced the launch of a \$15 million breast cancer prevention program. The program targets women aged 45-69 years old with the goal to have everyone in that demographic enrolled by 2020 to receive a mammogram every two years. The rollout of such a targeted program is the attempt of the CCSS to enhance early detection of breast cancer in the country and its subsequent effects will be an important predictor of Costa Rica's success in the management of breast cancer.⁷⁹



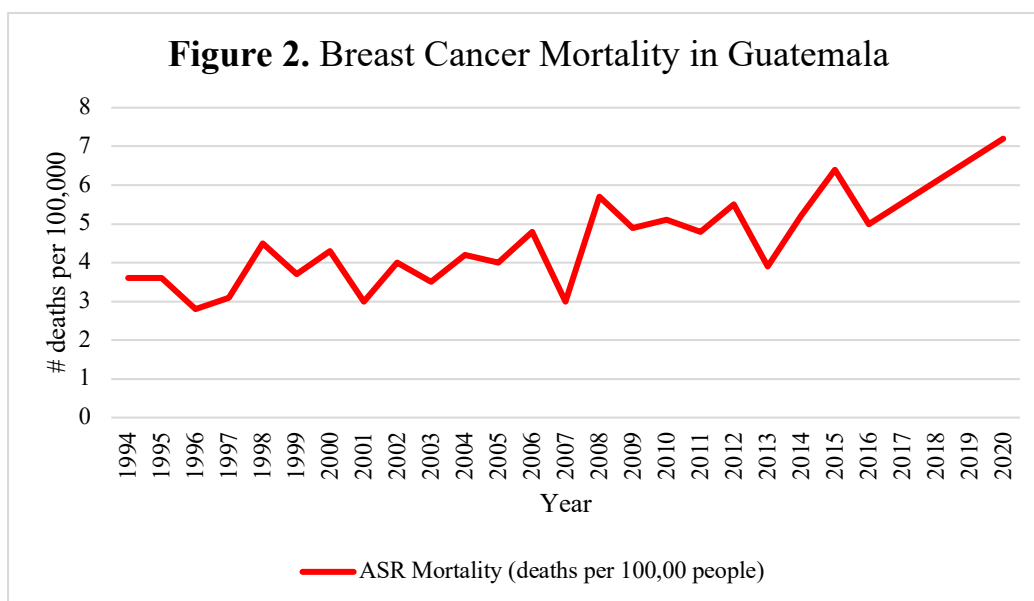
Image 1. Annual Avon Breast Cancer Awareness Walk in Costa Rica
(Source: The Tico Times, 2014)

Breast Cancer and Breast Cancer Screening in Guatemala

In the early-2000s, Guatemala created the National Reproductive Health Program which has provisions to address cancer, including the importance of breast self-exams and mammography in women over the age of 40 years.⁸⁰ However, unlike Costa Rica, the health system of Guatemala, aggressively reformed as recently as 2014, remains disjointed. Cancer epidemiology itself is an emerging field in the country and only recently have efforts been underway to develop

a country-wide population-based cancer registry. Unfortunately, the area remains grossly understudied when it comes to cancer incidence, treatments, and mortality. As such, statistics on cancer epidemiology in Guatemala remain estimates and do not necessarily reflect true quantitative measurements of the entire population.⁸¹

Guatemala is estimated to have a high burden of cancers related to infectious etiologies, including cervical, liver, and stomach cancers and the proportion of cancer deaths parallels that burden.⁸² In Guatemalan women, up until the last five years, breast cancer was reported to be the fifth most common cancer and the fourth most common cause of cancer mortality in the country.⁸²⁻⁸⁴ However, it is continually acknowledged amongst reports on cancer in Guatemala that estimates are subject to a high level of uncertainty given that there is no population-based cancer registry. Although accurate incidence rates of breast cancer in Guatemala largely do not exist, mortality estimates for breast cancer have been increasing over time.⁸⁵ Throughout the 1990s, Guatemala reported an ASR of breast cancer mortality ranging from 2.8 to 4.5 deaths per 100,000 people. Throughout the early-2000s, this increased to 3.0 to 5.1 deaths per 100,000 people (Figure 2).⁸⁵ Most recently, the 2020 WHO/Global Cancer Observatory report labeled breast cancer as the most common cancer in Guatemalan women, with an estimated ASR incidence of 29.8 new cases per 100,000 people, but with the fifth highest mortality rate estimated to be 7.2 deaths per 100,000 people (Figure 2).⁸⁶ Although extremely limited data exists on breast cancer incidence in Guatemala, it is likely that the country, with increasing rates of obesity and metabolic comorbidities especially in urban areas, is also experiencing an increase in breast cancer risk factors and thus breast cancer cases.⁸⁷



In 2010, the MSPAS published a plan by the Consejo Nacional de Lucha Contra el Cáncer (National Council on the Fight to Control Cancer) to control and prevent cancer throughout Guatemala. The plan stated that cancer would be reduced by controlling tobacco and alcohol use, combating obesity, and promoting exercise and a healthy diet. It also outlined recommendations for the implementation of a national cancer control program, which included organizational leadership, coordination of diverse parts of the program, cancer education, monitoring, and evaluation recommendations. Importantly, in the structure of the organization they also included a coordinator from the Indigenous Peoples and Interculturality Unit. The report outlined a need for a national database to track cancer incidence and mortality with mandatory reporting of cancer-related deaths to the National Institute of Statistics. The plan mentions the importance of breast cancer screening for women over 50 years and described several public and clinical health measures to increase awareness about breast cancer, clinical breast exams, and self-exams. Notably, the 2010 plan set a 5-year goal to have mammography available at all health centers to provide every woman over 50 years with screening.⁸⁸

Unfortunately, with the dismantling of the PEC in 2014 and the fractured nature of the Guatemalan health system, it is unclear if these recommendations were implemented or if they were successful. Today, only two major public hospital and one private, not-for-profit hospital have cancer referral centers in the country and all three are in Guatemala City.⁸⁹ This inherently poses a significant barrier to accessing cancer care in the country which, as previously discussed, has major challenges with public transportation, infrastructure, and affordable travel options for a population living in great poverty. For those who are able to access the limited cancer care that exists, problems arise as medications are frequently unavailable, radiation therapy infrastructure remains outdated, and overcrowding and long wait times plague the public hospitals.^{81,90} In 2014, only 54% of Guatemalans were estimated to have access to radiotherapy treatment.⁷⁶ Furthermore, there are significant barriers with referral from the primary level of care to the secondary or tertiary levels of care due to nearly absent coordination between the levels. This results in patients arriving for treatment at late stages of disease and often not completing their recommended treatment regimens.⁸¹

Significant disparities of health continue to exist throughout Guatemala today which parallel the economic and social inequities following the marginalization of indigenous Mayan communities in the Guatemalan civil war. Those living in rural, indigenous communities are much less likely to have access to care than their urban, non-indigenous counterparts in part due to limited health infrastructure in rural areas. Over two-thirds of physicians practice in Guatemala City, the nation's capital, where only 20% of the population resides. Travel to Guatemala City from mountainous areas is often arduous due to poor road infrastructure and can be incredibly costly. Language also poses a significant barrier, especially for indigenous women who are often monolingual speakers of one of the 23 indigenous languages spoken in Guatemala.

To add on to the already insurmountable barriers to access care, many indigenous peoples understandably harbor a pervasive mistrust of State-affiliated institutions and continue to face systemic discrimination within the healthcare sector.⁹¹ As such, it is not difficult to imagine that rural, indigenous communities have lower health literacy and worse health outcomes than their urban counterparts.^{92,93} A recent needs assessment surveyed 233 indigenous Mayan women with a median age 40 years and found that 84% did not have a primary care provider, 90% had never been screened for breast cancer, and 77% had never been screened for cervical cancer.⁹⁴ Unfortunately, the quantitative data does not exist to compare or comment on the disparities that exist in cancer incidence and mortality between rural and urban populations in Guatemala.

Another barrier to both cancer screening and cancer treatment to consider is the cultural belief system, specifically *fatalismo* (fatalism), regarding health among Hispanic populations. Fatalism is the belief that one's fate is predetermined and cannot be changed.⁹⁵ The construct is rooted in the deep religiosity/spirituality frequently observed in Latin American populations, a concept that is expressed in vernacular phrases such as “*si Dios quiere*” or “God willing.”⁹⁵ This is a particularly poignant belief as it pertains to cancer and may deter individuals from seeking cancer screening or treatment. Though literature studying fatalism throughout Latin America yielded mixed results, a consistent theme was that Hispanic populations were more likely to endorse the statements that health is a “matter of luck” and that “little can be done to prevent cancer” compared to white populations.⁹⁶ Furthermore, those underserved groups who have endured significant economic or social hardship, like the rural and indigenous populations of Guatemala, may feel as if they have limited control of their situation, which may make them more likely to believe in an “external locus of control.”^{95,97} A 2016 survey of religious demography in Guatemala identified 45% of the population as Catholic, 42% as Protestant, and

less than 3% as adhering to the Mayan religions.⁹⁸ Although studies stratifying the specific belief of fatalism throughout different religious groups and different geographical locations in Guatemala have not been done, it should remain a consideration as a barrier to care for Guatemalans, especially for those rural and indigenous populations.

Every few years, the MSPAS issues a National Survey of Maternal and Infant Health throughout its population. The survey is done by meeting with several households in a given region and extrapolating their provided answers to account for the opinions of that territory. In the 2008-2009 iteration of the survey, the most recent survey to include attitudes about breast cancer, maternal knowledge and habits regarding breast cancer and exams were assessed.⁹⁹ Over 16,000 women aged 15-49 years old were surveyed, approximately 7,400 urban women and 9,400 rural women. Of those, 85.8% of women in urban areas had heard of breast cancer, compared to 54.8% in rural areas. Twenty-one percent of urban women had undergone a clinical breast exam, compared to 7.4% of rural women. Thirty-eight percent of urban women had heard of a breast self-exam, compared to 9.8% of rural women, but only 33.1% of urban woman had performed a self-exam and only 8.4% of rural women had performed a self-exam (Table 2).⁹⁹ These responses comparing urban to rural women almost directly correlate with responses given by non-indigenous compared to indigenous women, indicating the majority of indigenous women are those in rural areas. This survey poignantly highlights the considerable disparity in breast cancer and screening knowledge between rural, indigenous populations and urban, non-indigenous populations. Additional efforts regarding breast cancer screening awareness need to be addressed to target rural areas.

Table 2. Breast Cancer/Screening Knowledge Survey of Guatemalan Women (Source: MSPAS, 2009)						
Region/Ethnic Group	Had heard of breast cancer	Had a clinical breast exam	Had been taught self-exams	Had performed a self-exam	No. responses	Total
Urban	85.5	21.4	38.5	33.1	7,414	16,819
Rural	54.8	7.4	9.8	8.4	9,405	
Non-indigenous	84.4	19	32.6	28	10,635	16,819
Indigenous	44.2	5.6	7.4	6.3	6,184	

Mammography is not a service available throughout most of Guatemala. To demonstrate the perceived availability of resources, a survey of Guatemalan physicians was performed that showed that public hospital physicians were less likely to recommend mammography for breast cancer screening compared to their private hospital counterparts. Perceived barriers reported by physicians to recommending preventative care were lack of time (46%), limited patient resources (31%), and perceived lack of patient interest (23%).¹⁰⁰ To encourage mammography, some private hospitals in Guatemala offer discounted mammograms to the general public during the Fall months as part of October's Breast Cancer Awareness. Discounted prices listed averaged Q250 (USD \$32).¹⁰¹ These charitable offers, in reach for upper- and middle-class urban Guatemalans, are an insurmountable cost for poorer Guatemalans when coupled with the cost of travel. Unfortunately, it is not known how many mammography machines the country possesses and what proportion of the population can access them.

Current breast cancer awareness events do exist in Guatemala today. These include light shows to honor Guatemalan women lost to breast cancer, cycling and walking events, and even donations from private companies to Fundecán, a Guatemalan breast cancer organization which raises awareness about breast cancer among poor women in Guatemala (Image 2).^{102,103} The MSPAS has also made strides to educate local communities about breast cancer and breast exams, emphasizing the importance of detection with mammograms and treatment with

medications and radiotherapy (Image 3).¹⁰⁴ A regional population-based cancer registry was also launched in 2015 and covers Guatemala City, a developed area where such a registry is more feasible to trial before its nation-wide implementation.⁸² The registry and its respective hospital network are managed by the country's National Cancer Institute, an important step in the advancement of cancer epidemiology and prevention throughout the country.¹⁰⁵



Image 2. Annual Breast Cancer Awareness Walk in Guatemala (Source: MSPAS, 2019)



Image 3. Breast Cancer Education in Guatemala (Source: MSPAS Twitter, 2019)

Chapter 5: Discussion and Comparative Analysis

The health system designs of Costa Rica and Guatemala are incredibly similar. Both offer their populations universal healthcare as a constitutional right, both utilize a three-tier system with an emphasis on primary care, and both countries are challenged to provide care to their rural, indigenous communities. For many reasons, though, the health system of Costa Rica is significantly more functional than that of Guatemala. Arguably, the two most notable reasons for this are Costa Rica's history of political stability over the last 80 years and the State's decision to adequately invest in public health. Guatemala, wracked by a gruesome civil war that only ended 25 years ago, has continued to struggle with government stability, trust in the State, and gang-related violence in the region. Furthermore, the ghosts of state-sponsored genocide of the Mayan people remain with indigenous groups, which make up roughly half the population and

experience significantly greater economic and social disenfranchisement than non-indigenous Guatemalans.⁸³ With one of the lowest GDP allocations to healthcare spending in all of Central America, Guatemala has also failed to adequately invest in its healthcare system despite its population size of nearly 17 million people.

The disparities in the two countries are laid bare when it comes to who in each nation is able to access the respective health systems. Costa Rica, with roughly 2.4% of its population self-identifying as indigenous, is generally regarded as having a fairly equitable health system. Several studies report that significant disparities in accessing healthcare between populations could not be identified.²⁶ Given this, the country also scores amongst the top tier of nations with UHC as of 2019.³⁰ Numerous studies in Guatemala, however, have reported significant challenges to accessing care within rural populations. These challenges include a geographic lack of healthcare centers in rural regions, unstable road conditions, poor public transportation infrastructure, prohibitive costs of travel, and language barriers for those that only speak indigenous dialects. The elimination of the PEC by the Guatemalan government also decimated what was largely the only primary health care system in all of rural Guatemala. The subsequent failure of the State to organize a replacement model left whole communities without access to basic healthcare, further exacerbating healthcare inequities in the country and deepening the mistrust of the government. As such, it is unsurprising that worse health outcomes are reported among rural populations compared to urban populations. In urban areas, both countries report challenges when it comes to the number of available healthcare personnel and extremely long wait times for elective procedures.

In terms of cancer prevention and management in the two countries, Costa Rica developed a nationwide population-based cancer registry in 1975 and has a mandated cancer

mortality reporting system that further allows the government to record and track cancer deaths in the country. On the other hand, Guatemala only recently initiated a project for a regional registry in 2015. The ability to accurately track and calculate cancer incidence and mortality rates has allowed Costa Rica to fully understand and address cancer trends over time, develop prevention strategies, and provide treatment modalities in the country. As such, recognizing the need for a greater number of mammography machines and radiotherapy infrastructure, the state chose to invest millions of dollars in breast cancer prevention in the nation in 2017. Guatemala launched a cancer control plan in 2015, outlining approaches to take to understand incidence and mortality followed by recommendations for preventative measures. Unfortunately, these recommendations were largely based on personal lifestyle modifications without a concrete strategy to increase healthcare personnel training or care center expansion in rural areas. This brings the future efficacy of these plans into question, especially given the recent cancellation of the PEC which had single-handedly provided care to most rural areas in the country. Strides have been made as the country launches its regional population-based registry, but it is clear that Guatemala remains decades behind Costa Rica when it comes to both healthcare access and cancer control.

Addressing breast cancer, Costa Rica has seen an increase in incidence since the 1980s, a trend that many very high and high HDI countries are also experiencing. This international trend may be in part due to an increase in obesity, later age at first pregnancy, and earlier menses. Although Costa Rica's mortality rate from breast cancer has overall increased in the last 50 years as well, it has remained fairly stable over the past decade despite the gradually increasing incidence rate.⁸ This indicates that Costa Rica's efforts to prevent and manage breast cancer are likely fairly successful. Additionally, breast cancer incidence has also been found to be higher in

urban areas in Costa Rica, potentially due to greater rates of obesity, alcohol use, and tobacco use in urbanized cities, actually making rural living a protective factor.

Since Guatemala lacks a nationwide population-based cancer registry, accurate breast cancer incidence rates remain unavailable. However, breast cancer mortality in the country has been estimated and has been shown to be steadily increasing over the past 20 years, with the most recent estimate of 7.2 deaths per 100,000 people in 2020 compared to 5.0 deaths per 100,000 people in 2015.⁸⁶ Given the known unavailability of accurate cancer statistics in the country though, these estimates should be interpreted with caution. Importantly, Guatemala did survey breast cancer and screening knowledge amongst urban and rural women as recently as 2009.⁹⁹ The results of the survey concretely demonstrated significant inequities regarding knowledge about breast cancer, knowledge about breast cancer self-exams, and healthcare provider clinical exam screening between rural, indigenous and urban, non-indigenous women in Guatemala. Although this information cannot necessarily be accurately extrapolated to disease incidence and mortality, rural women clearly had much more limited health literacy than urban women. This may result in rural women being less likely to seek care for a breast cancer related issue and therefore more likely to experience greater disease morbidity and mortality.

Chapter 6: Lessons Learned and Recommendations

While it is notable that both countries offer universal healthcare as a constitutional right, it is clear that Costa Rica has had significantly more success implementing this model than Guatemala especially when it comes to cancer care. Key takeaways from Costa Rica's model are the importance of government investing in public health and health system infrastructure, developing healthcare centers in rural areas, and instituting a robust referral system between tiers

of the health system. Regarding cancer, the success of Costa Rica's management of cancer and development of prevention strategies is due in part to its established cancer registry and its investment in preventative screening technology. An area of improvement that the country should focus on is increasing physician and nurse graduates in the country, which would also likely improve the significantly long wait times Costa Ricans experience in the public health sector. The continued investment in modern technology and cancer treatments is also key to tackling cancer-related mortality.

Guatemala has many more barriers to adequate care and cancer prevention than Costa Rica. Its public health sector is grossly underfunded in part because the Guatemalan government failed to increase healthcare spending following the dismantling of the PEC which relied on the funding of NGOs. This has resulted in limited numbers of health centers and staff, especially in rural areas. Improvements in civil projects and public transport to provide indigenous communities with a means of travel to urban health centers would also decrease barriers to care for those populations. Expanding the regional cancer registry to a nationwide registry would allow for the quantitative analysis of cancer rates in the country, providing the State with valuable information on areas that need more resources. Public education and awareness campaigns, though underway in urban areas, need to be expanded to rural areas as well, especially when it comes to knowledge about breast health and clinical breast exams. Finally, investment in modern mammography technology, medications, and radiotherapy will also be key for Guatemala to decrease its rising breast cancer mortality rates.

Interestingly, Guatemala launched a widely successful campaign to tackle high rates of cervical cancer in the country in the 1950s, a campaign which was reinvigorated with the founding of the National Reproductive Health Program in the early-2000s. It established and

invested in robust cervical cancer screening infrastructure including cytology labs, colposcopy centers, and pathologists at no cost to the patient.¹⁰⁶ Public surveys show that as of 2015, 80.1% of rural women had heard of cervical cancer, compared to 91.1% of urban women and 78.8% of rural women had heard of a pap smear and of those 46.9% reported ever having one compared to 90.4% of urban women who had heard of a pap smear of which 52.8% had ever had one. This is overall very similar data, but with mild (0-5%) improvement, from the same information recorded in the 2008-2009 iteration of the survey.⁹⁹ Although the infrastructure is now in place, only 50-65% of women reported being screened for cervical cancer in the last three years, with a disproportionate number of indigenous women reporting never having been screened.¹⁰⁷ Though this number is far below the WHO recommended 80% screening coverage for such programs, it remains significantly higher than the population knowledge regarding breast cancer and breast cancer screening from 2008-2009.⁹⁹ The relative success Guatemala has had in its cervical cancer awareness and screening program demonstrates that the country possesses the resources for a successful nationwide campaign to tackle breast cancer and breast cancer screening inequities.

Given the incredibly prohibitive costs associated with mammography for a lower/middle HDI country, it may not be the most feasible option for Guatemala. A campaign performed in Kenya, a similarly middle HDI country, demonstrated the efficacy of educating women about breast cancer, clinical exams and screening, and diagnostic modalities. By utilizing public radio, multidisciplinary medical teams, educational talks and videos at three different hospital settings, including the area's public hospital, researchers were able to conduct an early diagnosis program with over 1,000 local women. The model demonstrated the potential of launching such a campaign even in the setting of limited resources.¹⁰⁸ By targeting public knowledge and clinical

breast exams, a cost-effective program can be launched in a low to middle HDI country. Though there is debate regarding the efficacy of clinical breast exams compared to mammography, a recent systematic review indicated that a well-performed clinical breast exam may reduce breast cancer mortality equivalent to mammography.¹⁰⁹ Such an organized, low-cost program is something that countries like Guatemala could launch in waves throughout their nation with the appropriate allocation of funding and personnel to increase early detection of breast cancer and thus reduce breast cancer-related morbidity and mortality.

After completion of this exhaustive review, my specific recommendations for the MSPAS and the government of Guatemala to improve its healthcare system and breast cancer screening, treatment, and outcomes are as follows:

1. **Adequately invest in healthcare expenditures.** Additional funds may be secured by following a similar model to that of Costa Rica which levied taxes on tobacco and alcohol products that are then invested into the CCSS.
2. **Strengthen the Primary Health Care System.** The dismantling of the PEC in 2014 left a significant void in the provision of healthcare to rural, largely indigenous areas. Though the PHC system was meant to replace the PEC, without adequate State funding to match what NGOs had provided, the PHC system is ineffective. In theory, the PHC system is similar to the EBAIS developed by Costa Rica, but for it to be successful, significantly more investment into rural care centers must occur and culturally competent healthcare workers need to be graduated and retained.
3. **Centralize the health system.** Though the three-tier systems of Costa Rica and Guatemala are similar, a key difference exists as Guatemala has failed to centralize and integrate the health system tiers. Communication between each tier of the system

- must occur for appropriate referrals to take place from the primary care centers to regional/national centers and for patients to have adequate provider continuity.
4. **Develop a government-funded patient advocacy system.** With nearly half of the population identifying as indigenous, the importance of providing culturally competent and linguistically accessible care cannot be overstated. The implementation of the MIS in 2017 was certainly an important step, but the challenges a rural, indigenous person faces while attempting to access care in a location like Guatemala City are nearly insurmountable – even more so for an indigenous woman. The creation of a government-funded system that provides community patient advocates who speak a patient’s native language would address some of the overwhelming complexity and confusion which makes many rural women reluctant to access care. Such advocates would not only educate and encourage community members to access care, but would physically accompany them to and direct them through a large urban health center.
 5. **Improve transportation infrastructure, especially in rural areas.** A key barrier to accessing health centers for many rural populations is poor road infrastructure and unreliable public transportation. By investing in the repair of existing infrastructure and the creation of new roads throughout rural areas and by providing government-funded transportation to care centers, a physical barrier will be removed for many.
 6. **Develop a national population-based cancer registry.** As previously discussed, Costa Rica’s robust National Tumor Registry has allowed it to accurately quantify and track cancer incidence and mortality throughout the country. Without such a system in place, it is impossible to know the rates of cancer and cancer-related deaths

in Guatemala. Therefore, it is impossible to assess areas in need of funding and resource allocation and to distribute those resources to address cancer prevention and management.

7. **Expand cancer centers past Guatemala City.** Only three cancer centers exist in Guatemala and all three are located in Guatemala City, an urban hub inaccessible to many Guatemalans. Financially incentivizing other regional health centers to develop cancer programs would make cancer screening and treatment more accessible to the whole of Guatemala.
8. **Launch public breast cancer education and awareness campaigns.** As evidenced by the 2008-2009 National Survey of Maternal and Infant Health, rural Guatemalan women are far less educated about breast cancer than their urban counterparts. By implementing teams of public servants and healthcare workers to travel to rural, mountainous areas to provide education, screening, and care center access information, this disparity can be addressed. Some of the mistrust and fatalistic attitudes may also be addressed by increasing education and awareness via the collaboration of such teams with local community leaders. Furthermore, awareness campaigns should be launched on public radio, in city centers, and in markets, all parts of society which Guatemalan women frequently access.

Chapter 7: Conclusion

Costa Rica and Guatemala have similar origins and healthcare system designs, but with key distinctions in each that have led to significant differences in the economic stability, poverty rates, population health, and cancer prevention programs of each country. Costa Rica was

fortunate to have nearly a century of peace through isolationist policy and sound political leadership. This stability allowed it to develop and notably invest in public health and healthcare infrastructure for many decades. For this reason, its population is largely able to equitably access a robust public healthcare system. Unfortunately, Guatemala, devastated by a 36-year civil war that ended only a few decades ago, continues to grapple with instability, racism, and profound poverty on a national-level with its indigenous populations disproportionately affected. Though it also promises universal healthcare to its people, the country falls short on delivering that care to its population due to poor organization and leadership, inadequate funding, and limited healthcare personnel.

As such, Costa Rica has been able to develop and improve a robust national cancer registry over many decades while Guatemala has only recently initiated its own regional registry. Costa Rica has also been able to maintain a stable breast cancer mortality rate despite an increasing incidence, while estimates of breast cancer mortality rates in Guatemala are steadily rising. The key differences in the countries' abilities to manage their health systems and thus prevent and treat cancer may explain the differences in the respective breast cancer mortality trends observed. Both countries face challenges regarding the modernization of cancer management infrastructure, but Guatemala remains decades behind Costa Rica in its ability to track and prevent breast cancer throughout the country. As Guatemala continues to develop, many lessons can be learned from its Central American neighbor, Costa Rica, when it comes to health system management and breast cancer control programs.

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VITAE

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