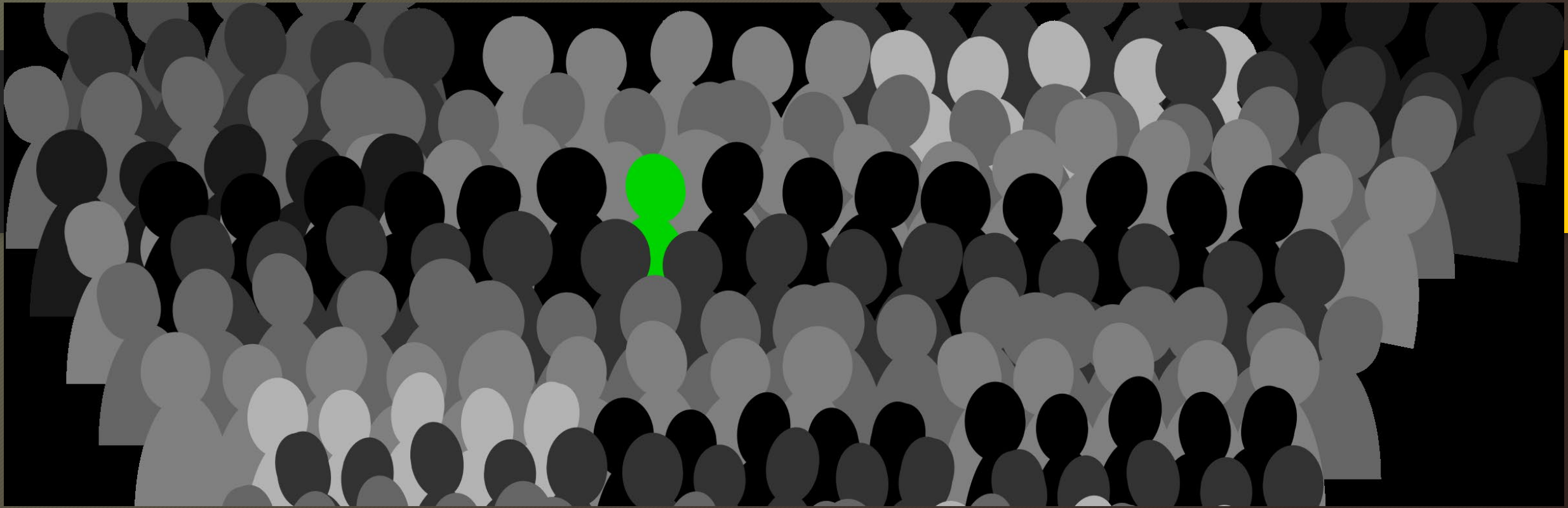


Differences in Clinical Outcomes and Quality of Life of Women Diagnosed With Cancer

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Social Trends / Individual Experiences

Today's talk

This talk will include:

- An overview of differences in morbidity and mortality from cancer across subgroups of women in the population
- Review of cancer side effects and how they vary across subgroups of women
- Ways to conceptualize quality of life after a cancer diagnosis
- What is known on how women cancer survivors experience different outcomes in survivorship depending on their gender, race, ethnicity, spirituality and financial status
- Pathways for advocacy for equitable outcomes for women with cancer

Introduction: A Public Health Perspective on Cancer

Since Richard Nixon declared “A War Against Cancer” in 1971 we have seen extraordinary progress in:

- Our understanding of causes of cancer
- Development of more effective, more targeted, and less destructive cancer treatment modalities

BUT,

Disparities in cancer survival persist in certain subgroups of the population

Health Disparities

Health disparities are significant and systematic differences between certain groups in health care access and health care outcomes including:

Cancer risk

Cancer screening rates

Stage at diagnosis

Types of treatments received

Mortality

Health Equity

Health Equity

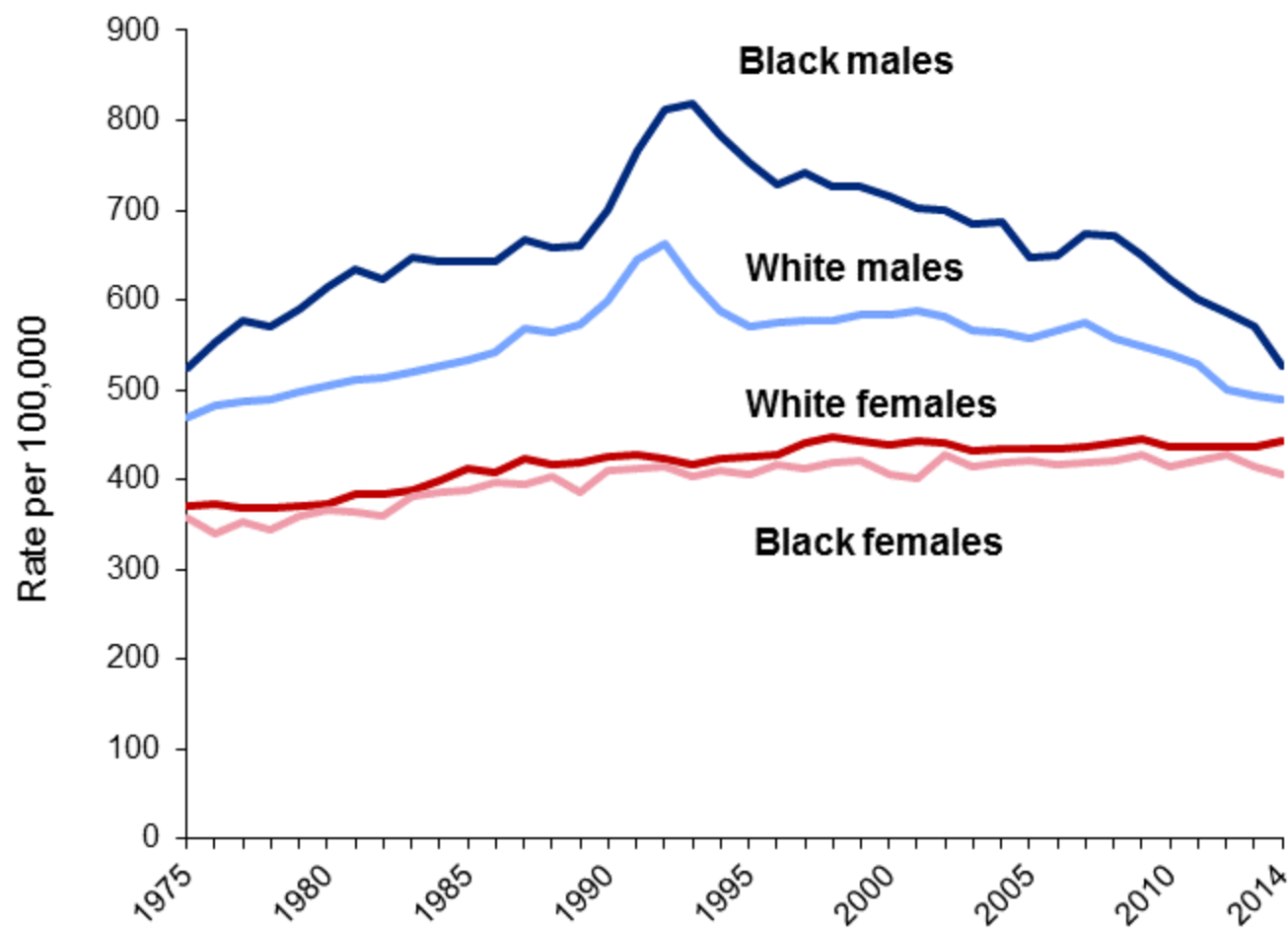
Is the attainment of the highest level of health for all people.

Health equity exists when all people have the opportunity to achieve their full health potential, regardless of their race, culture, identity or where they live



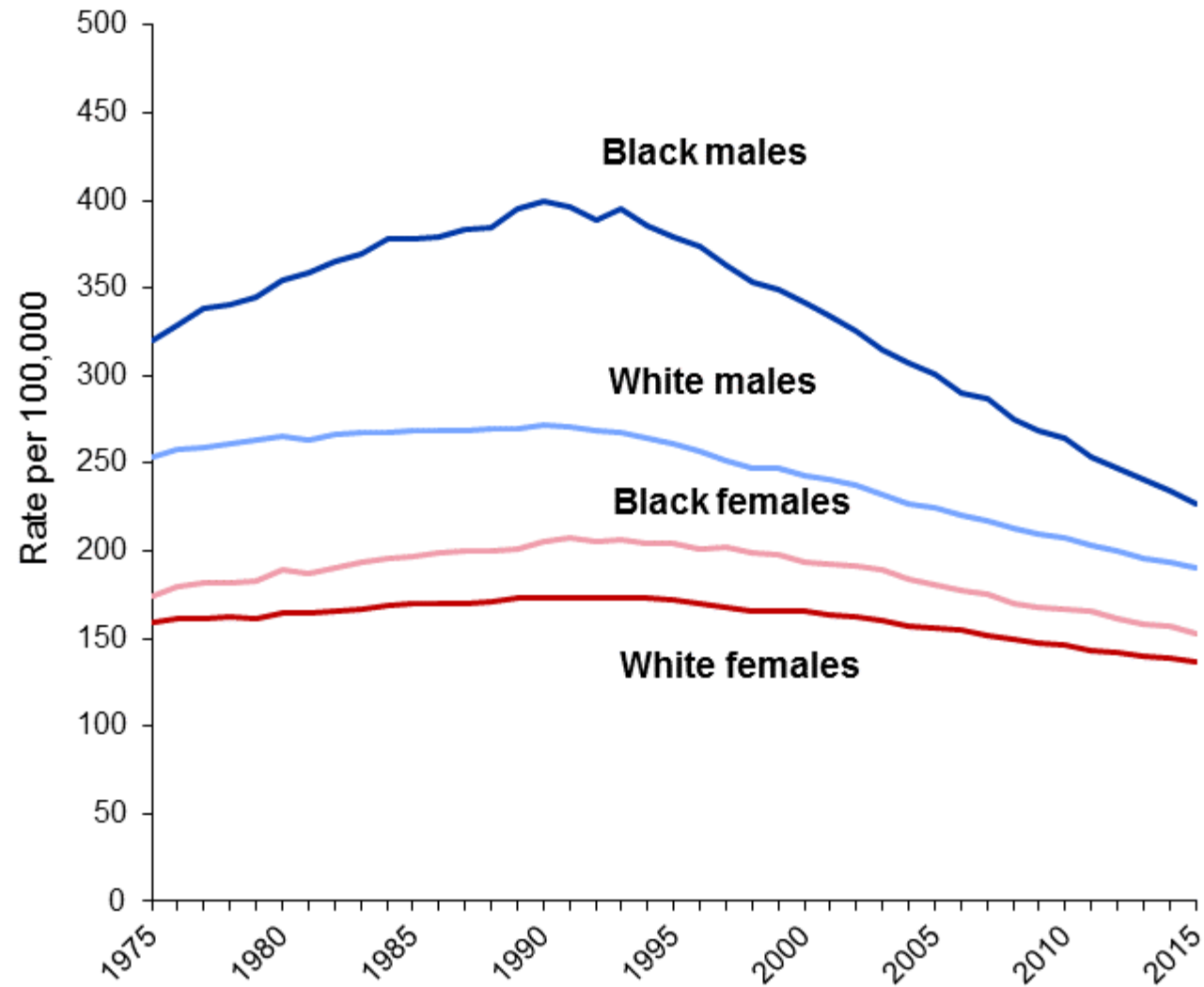
Cancer Disparities by Race and Gender

Trends in Cancer Incidence Rates* by Sex and Race, US, 1975-2014



*Age-adjusted to the 2000 US standard population. Incidence rates are adjusted for delays in reporting.
Source: Surveillance, Epidemiology, and End Results (SEER) Program, National Cancer Institute, 2017.

Trends in Cancer Death Rates* by Sex and Race, US, 1975-2015



*Age-adjusted to the 2000 US standard population.

Source: National Center for Health Statistics, Centers for Disease Control and Prevention, 2017.

The Good News - Race Disparities in New Cancers and Cancer Deaths are Declining

Since the mid-1990s, cancer incidence rates for all sites combined have been declining for black and white males;

Black and white females incidence rates are lower than men, and although increasing slightly, the race difference for women is converging.

Deaths from cancer have declined overall in the last two decades, especially among black men.

The excess risk of cancer death in blacks versus whites dropped from 47% in 1990 to 19% in 2015 among men and from 21% in 1997 to 12% in 2015 among women

The Bad News: African Americans Continue to Have Poorer Cancer Survival Than Whites

While gains in survival have occurred for both whites and blacks, blacks have lower survival rates than whites for most cancer types

Five-year cancer survival rates are lower in the black population than the white population for ALL the major cancers.

Five-year Relative Survival Rates (%) by Race, 2007-2013

Site	White	Black	Absolute Difference
All Sites	70	63	7
Breast (female)	92	83	9
Colorectum	67	59	8
Esophagus	22	12	10
Non-Hodgkin lymphoma	74	67	7
Oral cavity & pharynx	69	49	20
Ovary	46	39	7
Prostate	>99	97	3
Urinary bladder	79	65	14
Uterine cervix	71	58	13
Uterine corpus	85	65	20

Summary of Cancer Disparities in Population Subgroups: Incidence

Cancer Incidence:

- Men, especially black men, have higher rates of new cancers than women
- Rates of new cancers in men of both races have declined in last two decades
- Black and white women are similar in rates of new cancers and incidence rates have remained fairly steady over the last two decades.
- Hispanic, Asian/Pacific Islander and American Native cancer incidence has been consistently lower than black and white women's incidence rates

Summary of Cancer Disparities in Population Subgroups: Mortality

Cancer Mortality:

Deaths from cancer have declined overall in the last two decades, especially among black men.

Five-year cancer survival rates are lower in the black population than the white population for ALL the major cancers.

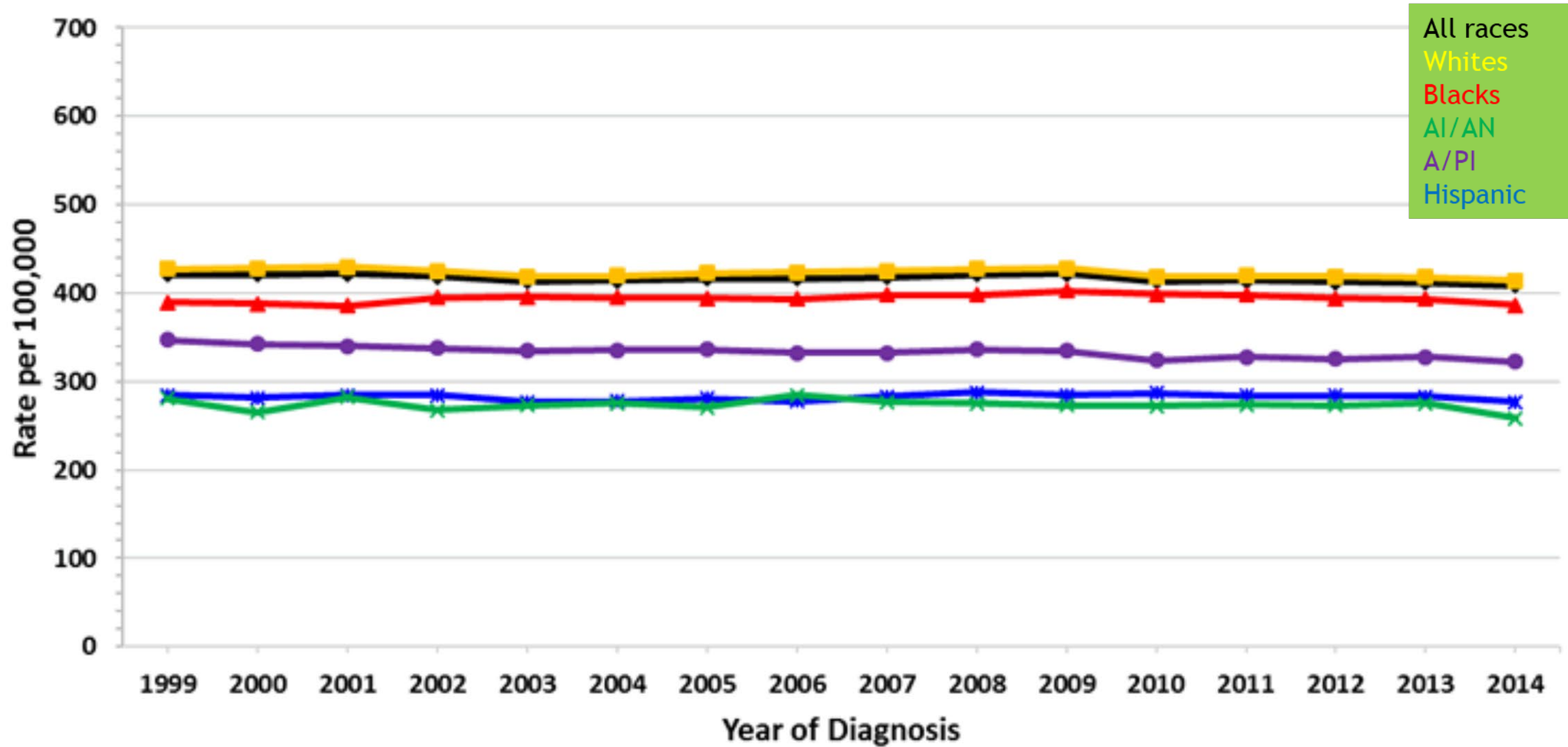
Specific Cancer Disparities by Race/Ethnicity

Documented cancer health disparities include:

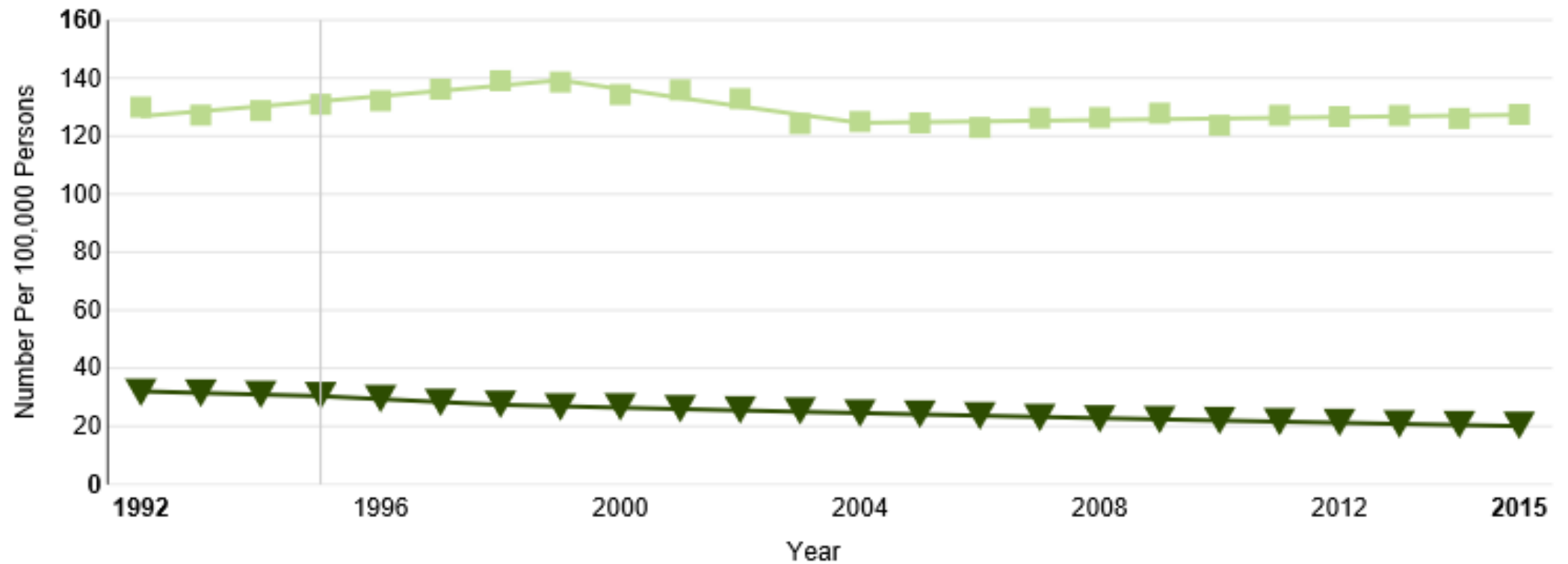
- a higher incidence of a particularly aggressive form of breast cancer (the triple-negative subtype) among African American women than women of other racial/ethnic groups
- substantially higher rates of prostate cancer incidence and death among African American men than men of other racial/ethnic groups
- higher rates of kidney cancer among American Indian and Alaska Natives than other racial/ethnic groups
- higher rates of liver cancer among Asian and Pacific Islanders than other racial/ethnic groups
- higher rates of cervical cancer incidence and death among Hispanic and African American women than women of other racial/ethnic groups

Breast Cancer Disparities

All Cancer Sites Combined
Incidence Rates* by Race and Ethnicity,† Female, United States, 1999–2014^{†§}

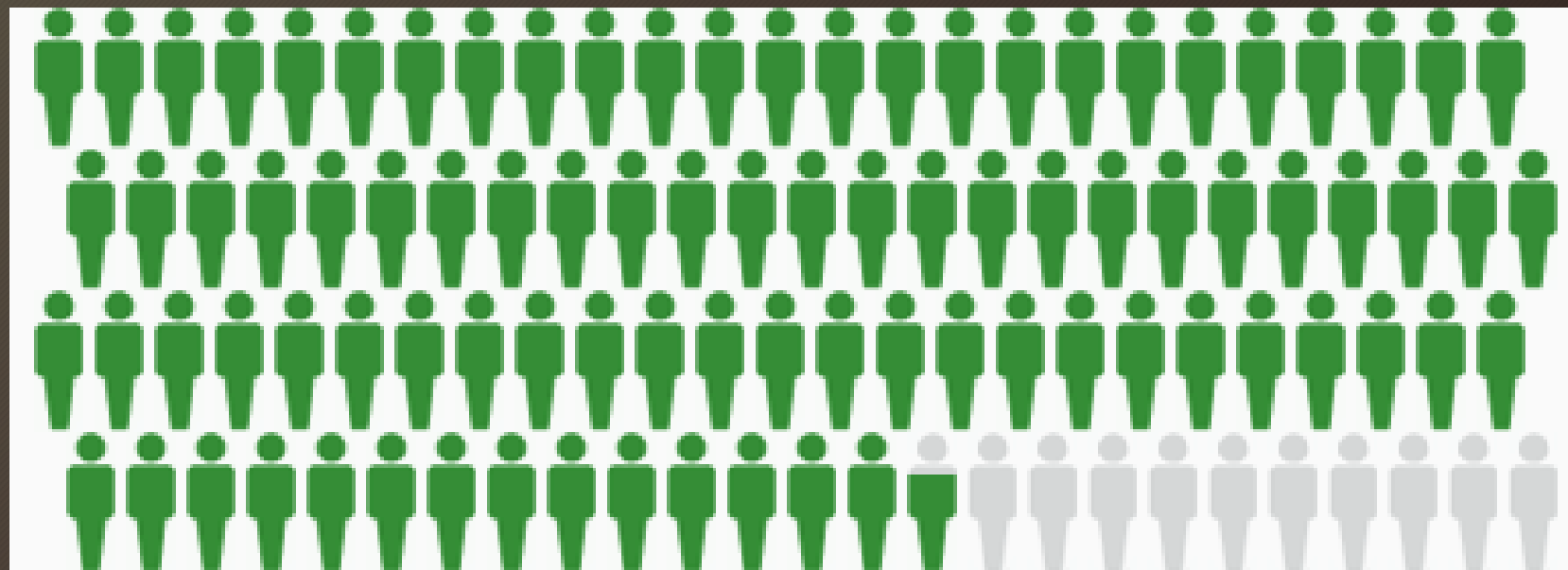


Breast Cancer: New Cases / Deaths

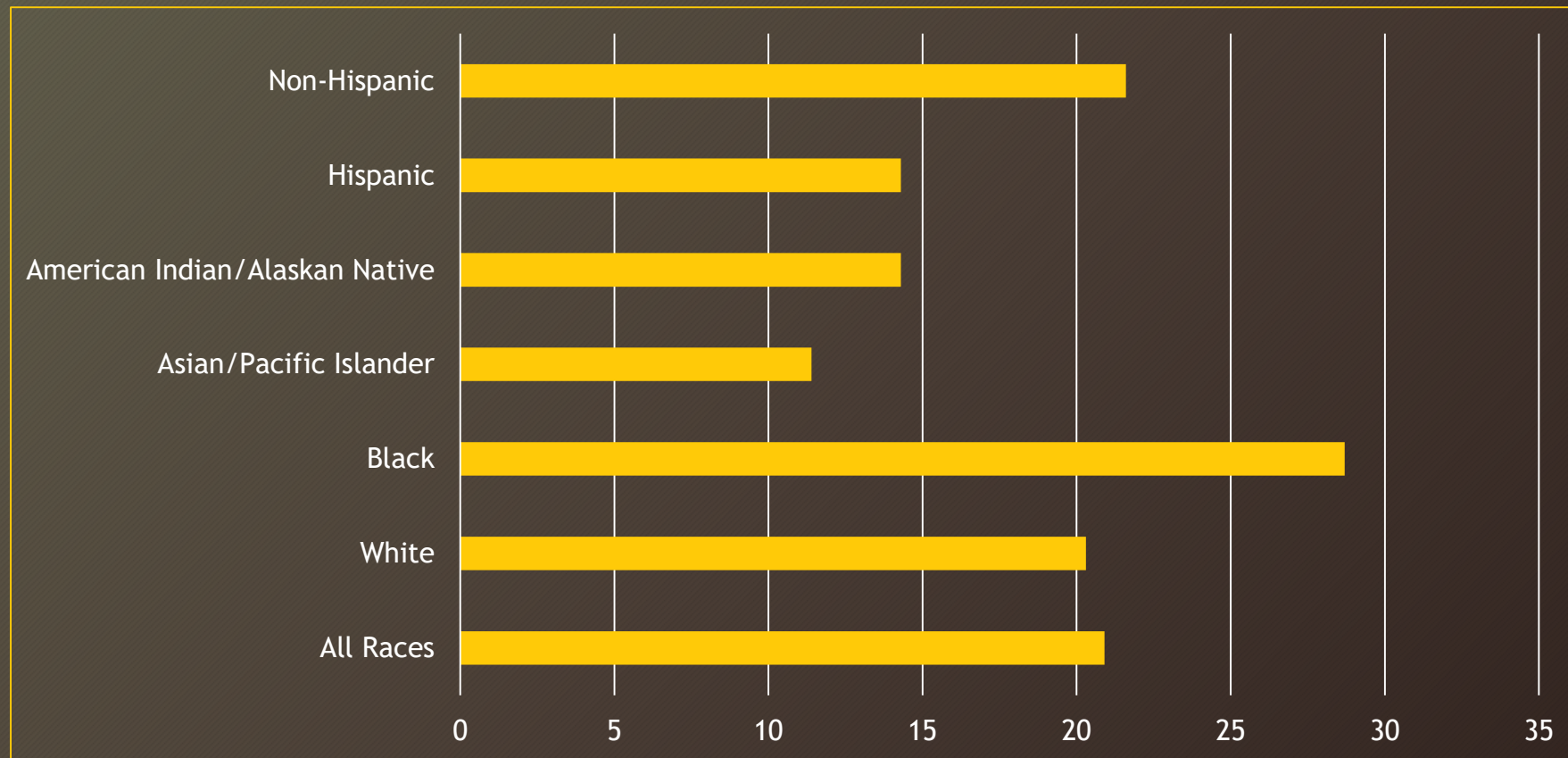


Breast Cancer Five-Year Survival in the Total Population

89.7%

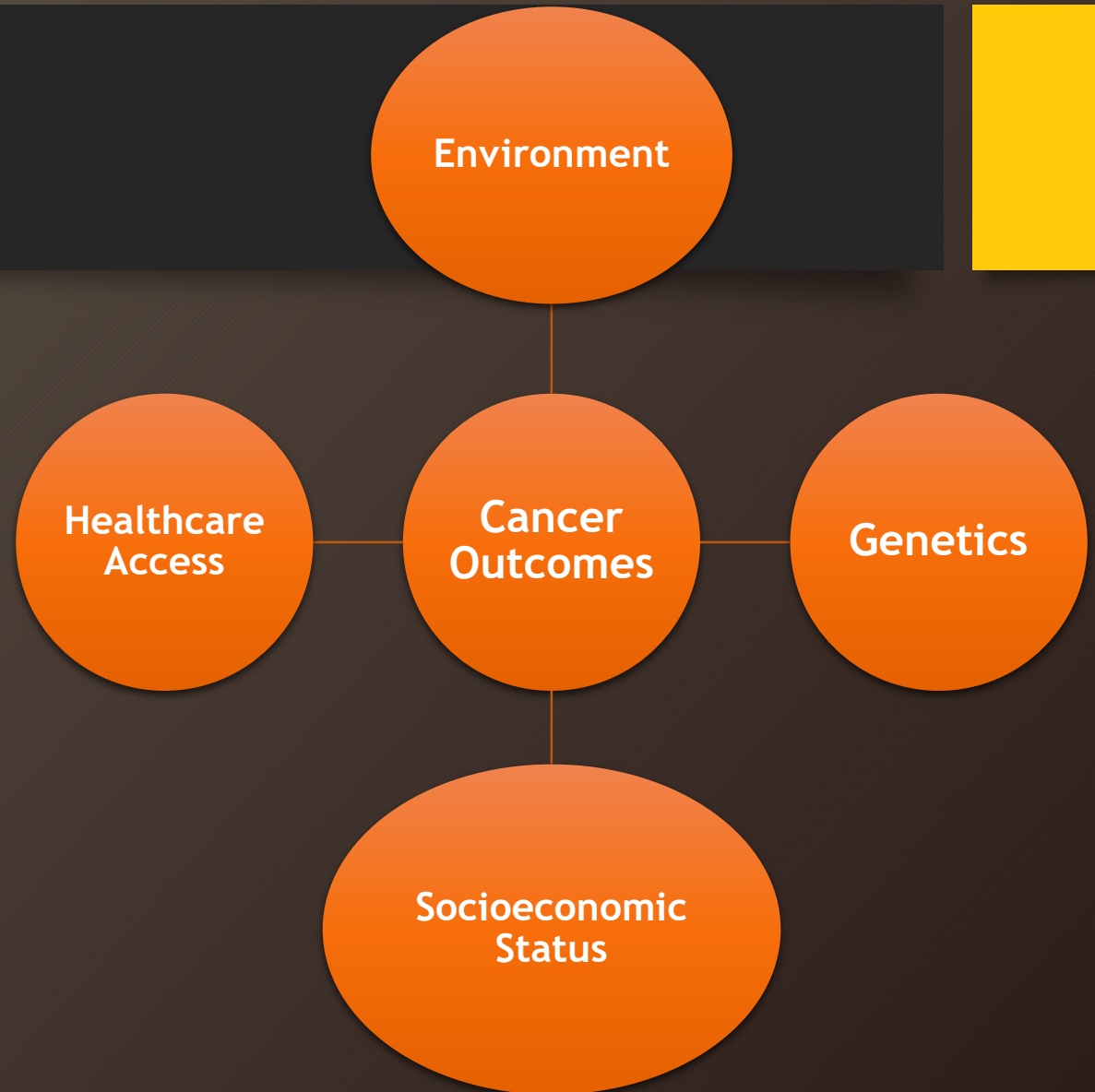


Number of Breast Cancer Deaths By Race per 100,000 Women



Determinants of Health and Cancer Outcomes

-- *Not Always in a Patient's Control*



System of Care and Breast Cancer Disparities

- Some of these disparities relate to:
 - delayed care
 - limited ability to pay for care
 - or inability to complete treatment
- Uninsured women are more likely to have delays in resolution of abnormal mammographic findings
- Black women in Medicaid or Medicare are more likely to experience delays in surgical treatment than Whites
- Surgical delays are more common in states with less generous Medicaid reimbursement for breast surgery
- The quality of surgical therapy also differs by race, and these differences are linked to the institutions where minority patients seek care

Contributors to Disparities in Breast Cancer

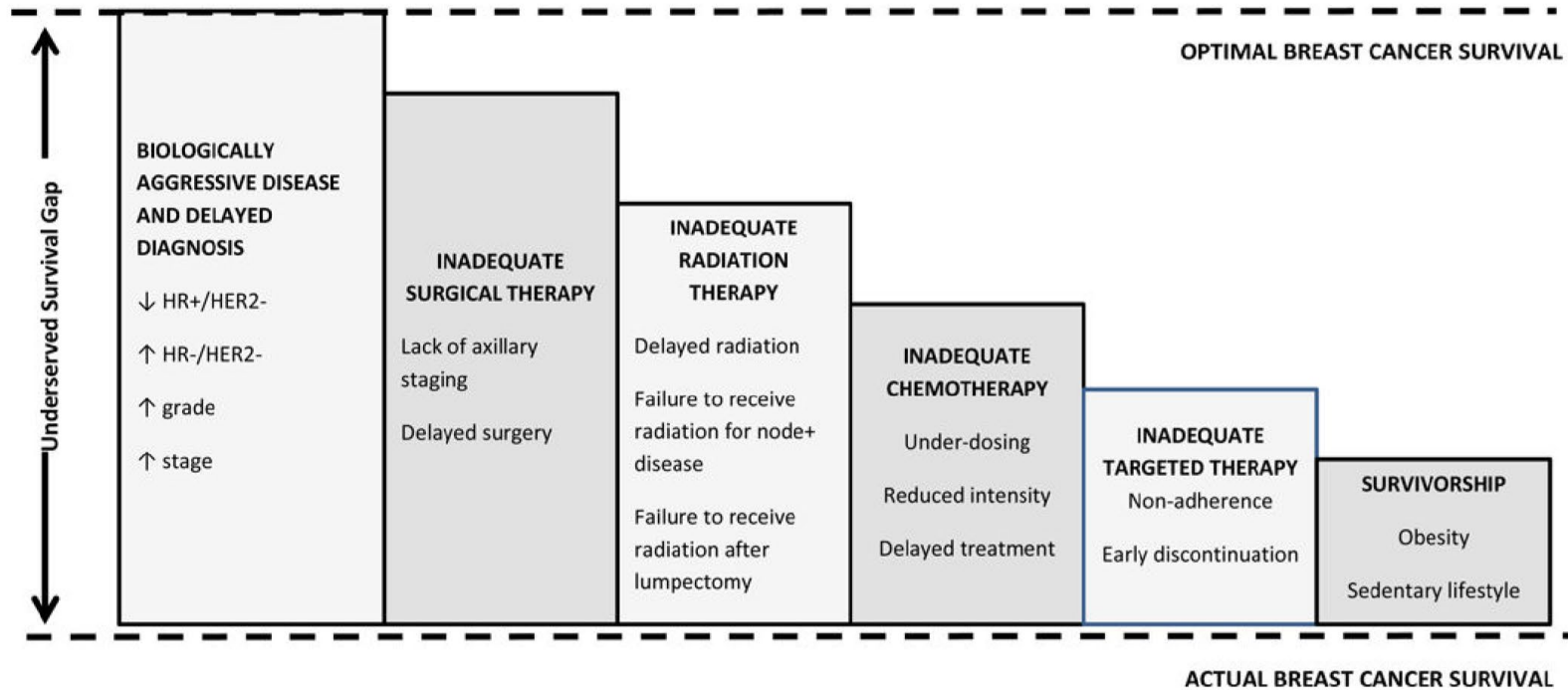
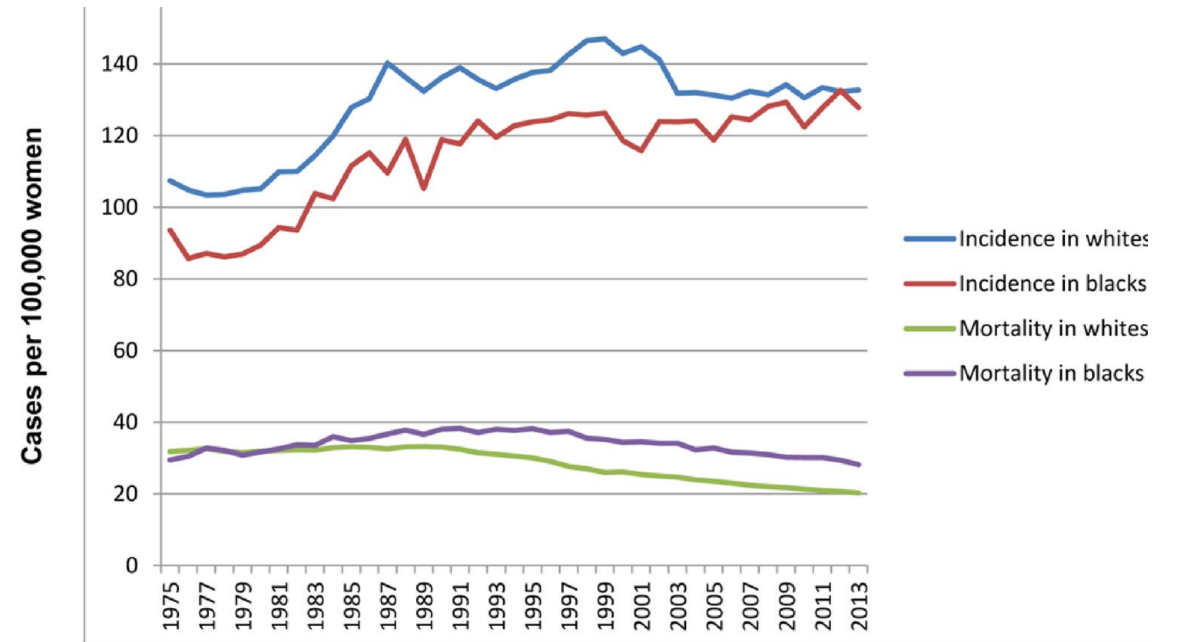


Figure 2. Contributors to US and global outcome disparities in breast cancer across the cancer care continuum. In addition to lack of any treatment (e.g. lack of radiation, lack of chemotherapy), specific treatment gaps are listed in each bar.

Disparities Have Persisted Over Time

- Black women in the United States are more likely to die of their disease than Whites
- A survival gap that has persisted for more than three decades even as overall mortality rates have improved by 36%
- There is a higher incidence of hormone receptor (HR) and HER2 receptornegative or “triple negative” tumor subtype in young Black women
- Black women have a more advanced stage at presentation
- *The widening of the racial disparity in mortality over time suggests an influence of post-diagnosis factors on differences in outcome*



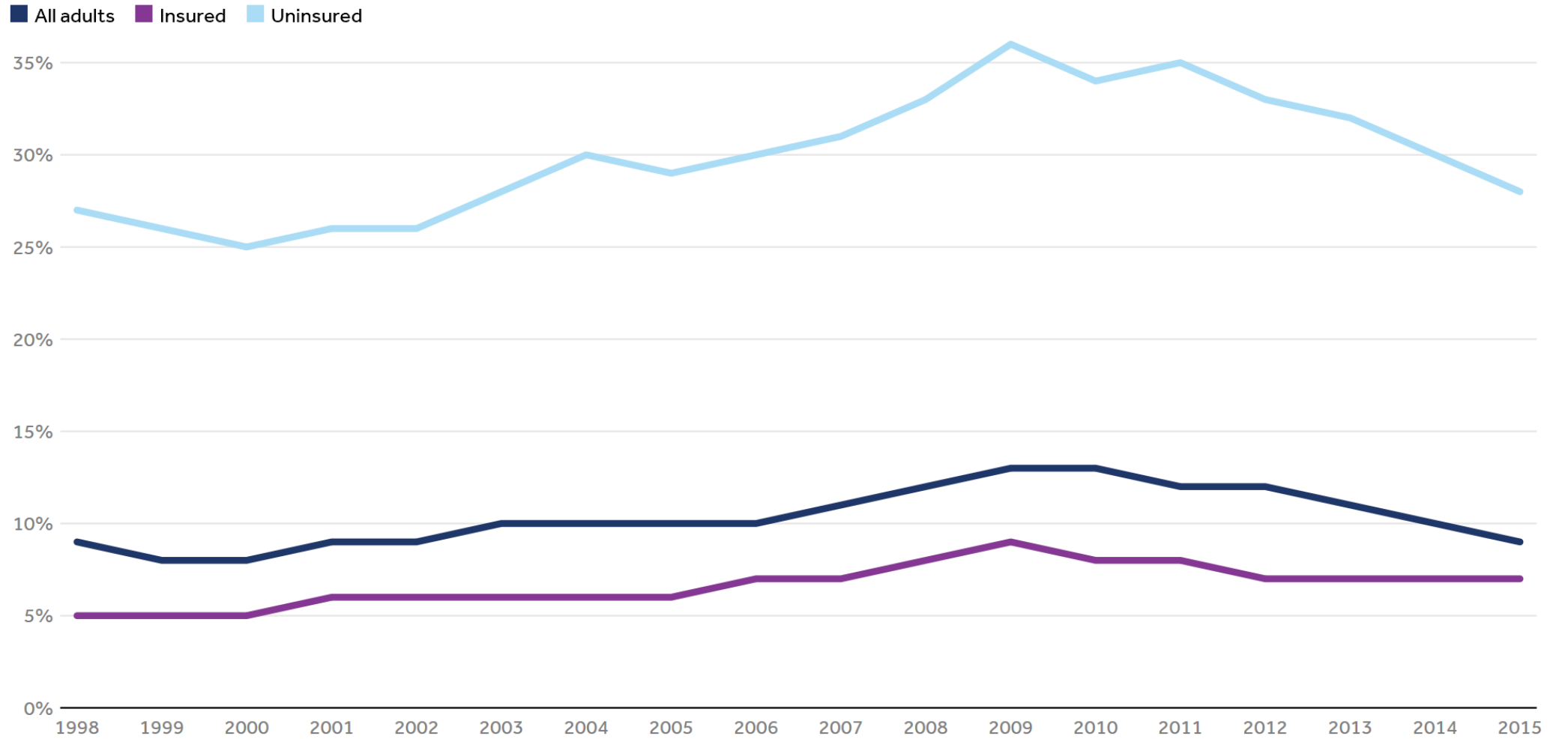
Other Factors Associated With Cancer Disparities

1. Food insecurity
2. Poor access to quality health care
3. Smoking
4. Physical inactivity
5. Availability of affordable health care
6. Smoke free policies
7. Payments to states from Medicaid
8. Obesity

Financial Factors Affecting Cancer Outcomes

- Individuals from medically underserved populations are more likely to be diagnosed with late-stage diseases that might have been treated more effectively or cured if diagnosed earlier.
- People with lower socioeconomic status (SES) have disproportionately higher cancer death rates than those with higher SES, regardless of demographic factors such as race/ethnicity

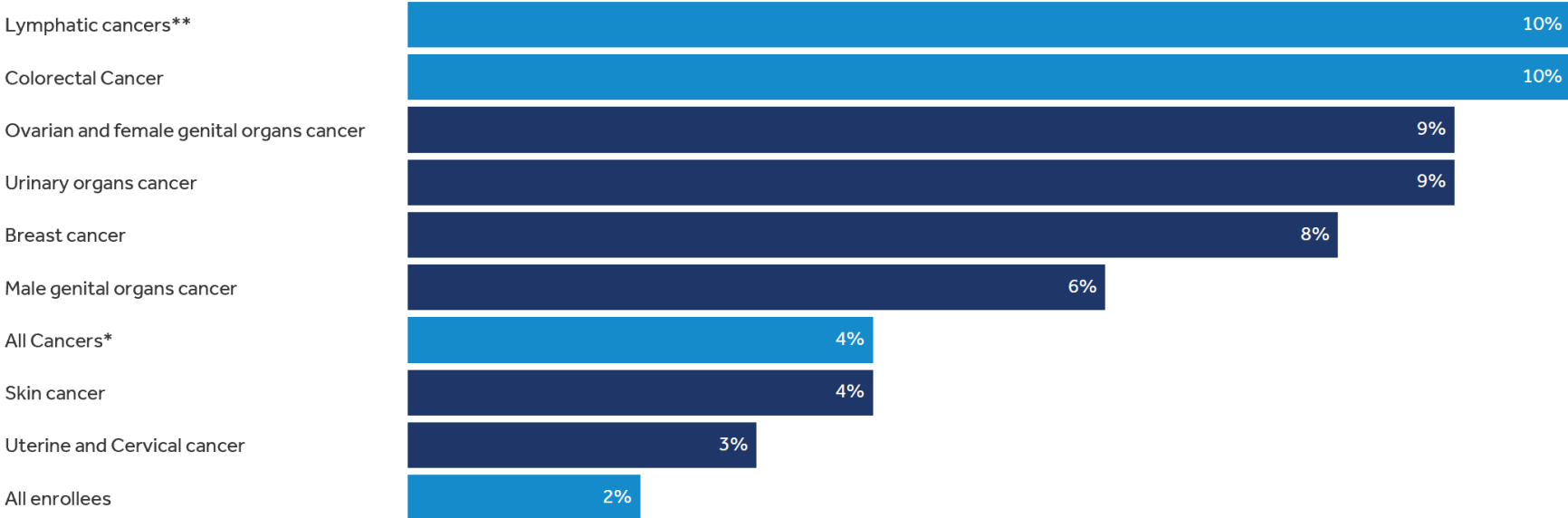
Percent of adults who report delaying and/or going without medical care due to costs, 1998 - 2015



Source: Kaiser Family Foundation analysis of National Health Interview Survey • [Get the data](#) • [PNG](#)

Enrollees with cancer diagnoses are much more likely to have out-of-pocket spending over \$5,000

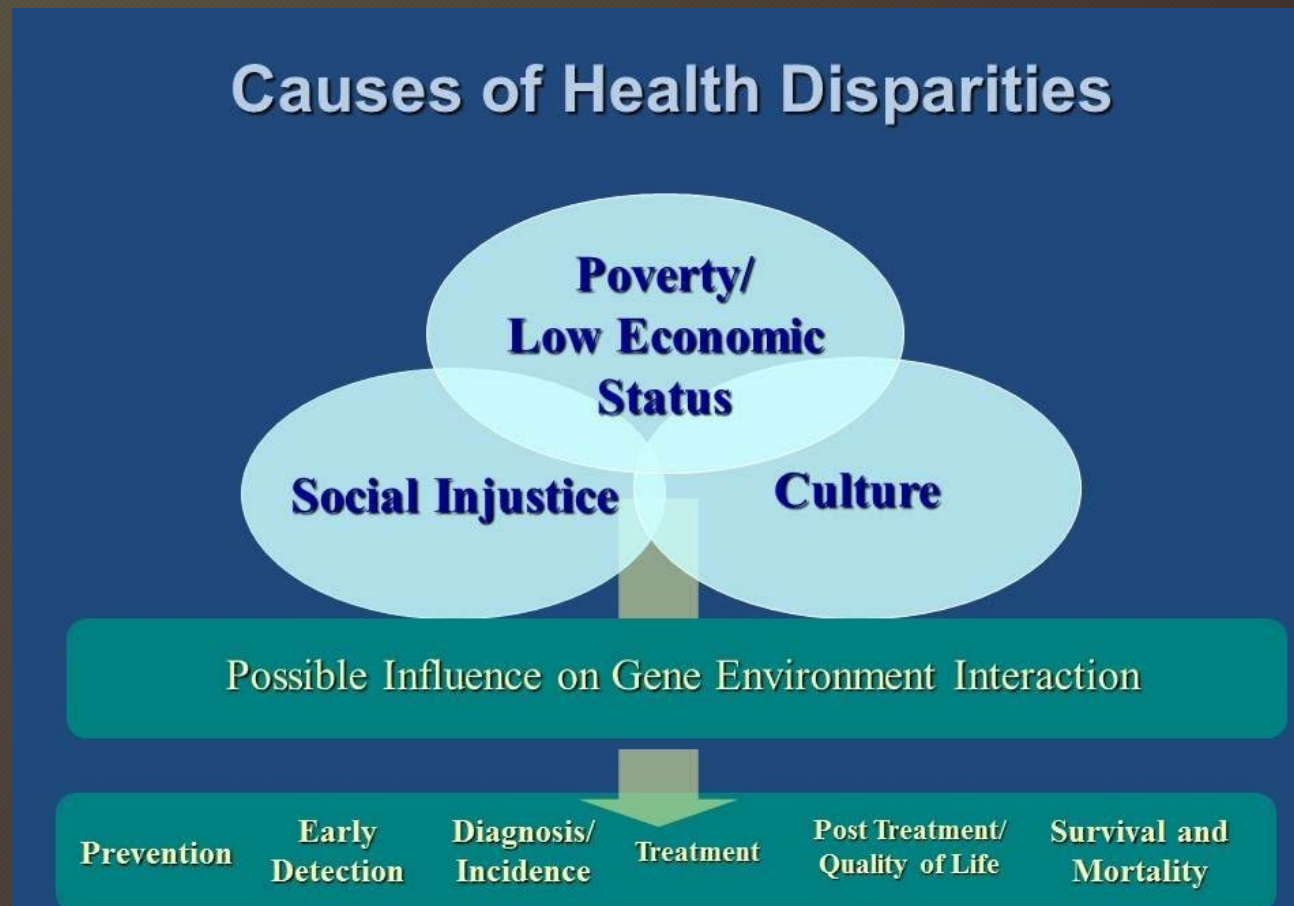
Percent of people with health coverage from a large employer and out-of-pocket spending above \$5,000, by cancer diagnosis, 2015



*including benign tumors **including cancers of lymphatic and hematopoietic tissue

Source: Kaiser Family Foundation analysis of Truven Health Analytics MarketScan Commercial Claims and Encounters Database, 2015 • [Get the data](#) • [PNG](#)

Upstream Causes of Cancer Disparities



Social Factors and Cancer Disparities

- Increased risk of ER- breast cancer incidence among women born in states with Jim Crow laws (post-slavery laws in place in the US from the 1870s to 1964 that limited Black advancements and freedoms)
- Early childhood abuse and neglect, which is more common among Black children than White [8], have been associated with elevated markers of inflammation among breast cancer survivors completing primary breast cancer treatment

Krieger N, Jahn JL, Waterman PD (2017) Jim Crow and estrogenreceptor-negative breast cancer: US-born black and white nonHispanic women, 1992-2012. *Cancer Causes Control* 28:49-59.

Crosswell AD, Bower JE, Ganz PA. (2014) Childhood adversity and inflammation in breast cancer survivors. *Psychosom Med* 76:208-214

Social Isolation and Cancer Outcomes

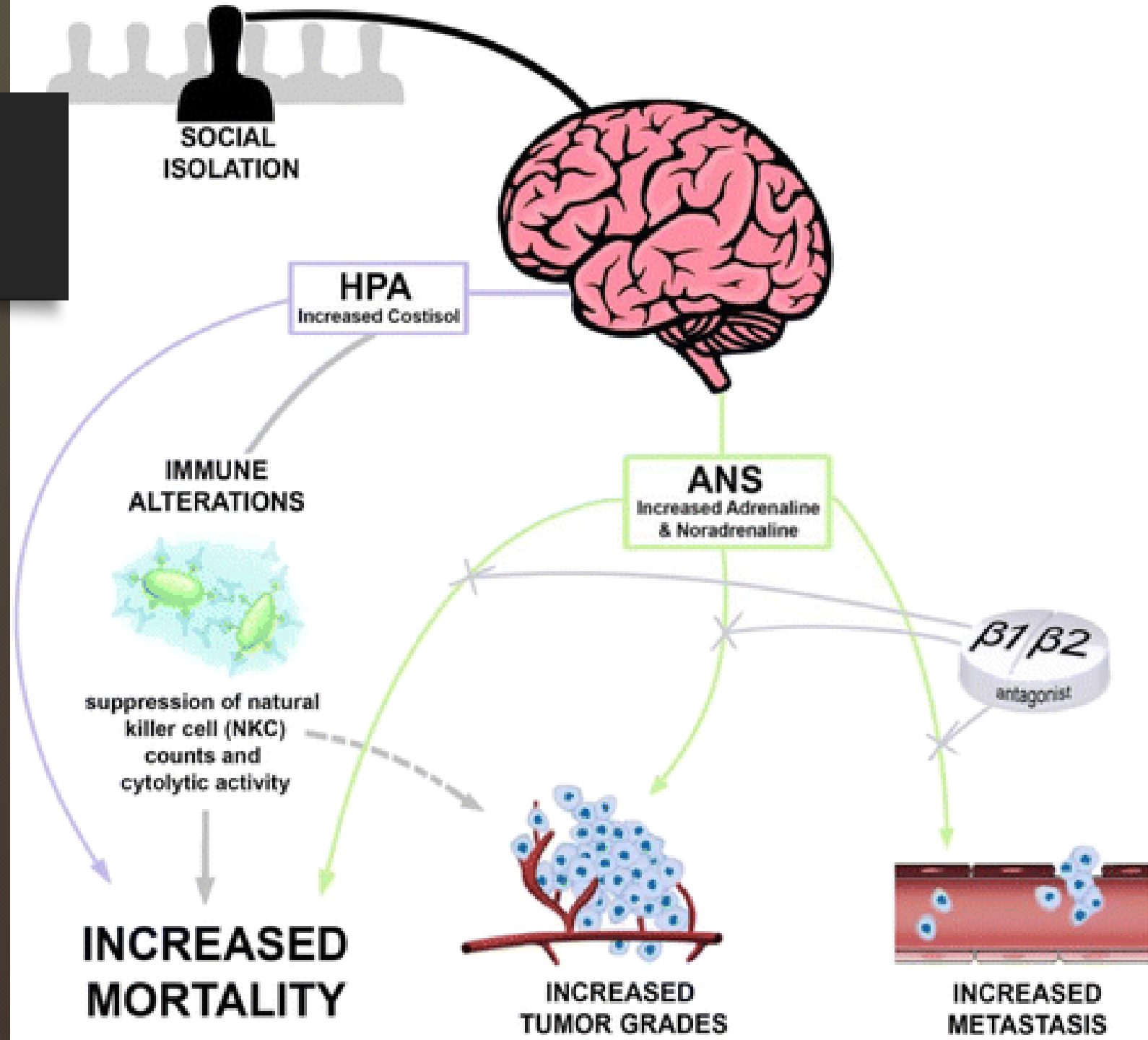
- Women who experience pre-diagnosis social isolation have both a 66 % increase in risk of all-cause mortality and a two-fold increase in risk of BC-related mortality compared to a socially integrated cohort

Minority Stress Theory of Cancer Disparities

Minority stress theory postulates that there is a great deal of stress associated with being oppressed and/or victimized, both personally and by policies.

Prejudice and stigma directed toward individuals from oppressed groups brings about unique stressors that cause adverse health conditions and may predispose one to certain cancers.

Getting By With the Help of our Friends: Psychoneuroimmunology



Hinzey, A., Gaudier-Diaz, M. M., Lustberg, M. B., & DeVries, A. C. (2016). Breast cancer and social environment: getting by with a little help from our friends. *Breast Cancer Research*, 18(1), 54.

Cancer Survival is Relative

Because survival statistics are based on large groups of people, they cannot be used to predict exactly what will happen to an individual patient.

No two patients are entirely alike, and treatment and responses to treatment can vary greatly.

Quality of Life (QOL) and Cancer Survival

Quality of life (QOL) has become a focus of research and therapy in cancer care

QOL is a subjective phenomenon affected by objective circumstances

QOL can be defined as *the difference between an individual's hope and expectations and his/her current life experiences*

4 primary domains of QOL:
Physical, Psychological, Spiritual, Social

Calman K. Definition and dimensions of quality of life. In Aaronson NK, Beckman J, eds., *Quality of Life of Cancer Patients*. New York:Raven Press, 1987:1-10.

Ferrell BR, Grant M, Funk B, Otis-Green S, Schaffner ML. Quality of life in breast cancer. *Cancer Pract.* 1996; 4:331-340.

Exploring QOL Among Cancer Survivors

“Current unmet needs of cancer survivors: Analysis of open-ended responses to the American Cancer Society Study of Cancer Survivors II.”

Burg, M. A., Adorno, G., Lopez, E. D., Loerzel, V., Stein, K., Wallace, C., & Sharma, D. K. B.

Cancer 2015, 121(4), 623-630.

Top Five Continuing Problems of Cancer Survivors

Problem	Percent of survivors	Description
1. Physical	38.2 %	pain, symptoms, sexual dysfunction, and care of body (such as diet, exercise, and rest)
2. Financial	20.3 %	money, insurance, and the affordability of needed services and products
3. Information needs	19.5 %	unanswered questions and the lack of knowledge regarding what to expect as a cancer survivor, follow-up care, self-care
4. Personal control	16.4 %	ability to maintain autonomy in terms of the physical self (sexual function, evacuation, and ambulation) and the social self (disclosure about cancer and ability to make plans and socialize)
5. Health care system	15.5 %	Health care system flaws that affect early detection, diagnosis, treatment, follow-up care, continuity of care, and inadequate response from health care providers

Subgroup Differences in Continuing Problems

Type of Problem	Who is most likely to have this problem?
Physical	Men, older survivors
Financial	Women, younger survivors, black and Hispanic survivors
Information	All groups
Personal control	Men, older survivors
Health care system	Women

Exploring QOL: Positive Outcomes of Cancer

“Positive aspects of having had cancer: A mixed-methods analysis of responses from the American Cancer Society Study of Cancer Survivors-II (SCS-II).”

Adorno, G., Lopez, E., Burg, M. A., Loerzel, V., Killian, M., Dailey, A. B., & Stein, K.

(2018). *Psycho-oncology*, 27(5), 1412-1425.

Top Five Benefits Endorsed	Percent of survivors (n=5,149)	Description	Endorsing Survivors
1. Gratitude/pleasantly surprised	24.6 %	Specific to the diagnostic and treatment phase of cancer. Involves how the cancer. Went better than expected, or there was a silver lining in the experience in terms of early detection, diagnosis/staging, available treatment(s), side effects of treatment, surviving, feeling cured	Men
2. Appreciate/value	24.0 %	Positive awareness, expressions of, realizations, or insights about aspects of one's life, in terms of family, friends, church nature, beauty, one's time remaining, one's emotional/physical health, intangible things in life	Women White survivors
3. Spirituality/existential	15.4 %	Finding, strengthening or affirming one's sense of spirituality, finding positive meaning in having had cancer, finding a new life purpose, becoming more spiritually focused in one's daily life, feeling blessed, receiving spiritual support	Women Black survivors
4 Relationships	15.1 %	Positive reflections on beginning, continuing, strengthening, renewing, or ending relationships with important others (such as spouse, family members, friends, pets, etc	
5 Support/Medical	13.1 %	Experiencing how medical professionals, medical treatments,	Black

What Predicts QOL in Breast Cancer Survivors? The Research

- High levels of social support
- Good patient/physician communication
- Self-efficacy in interacting with physicians
- Level of information given to patients by physicians
- Low levels of co-morbidity
- Being Hispanic (less acculturated) & Asian/Pacific Islanders
- Low levels of cancer-related financial burden

Maly RC, Liu Y, Liang LJ & Ganz PA (2015) Quality of life over 5 years after a breast cancer diagnosis among low-income women: effects of race/ethnicity and patient-physician communication. *Cancer*, 121(6), 916-926.

Kale HP & Carroll NV. (2016). Self-reported financial burden of cancer care and its effect on physical and mental health-related quality of life among US cancer survivors. *Cancer* 122(8), 283-289.



PATHWAYS to CANCER EQUITY

Pathways for Reducing Cancer Disparities

Increase access to the entire continuum of cancer care

- The Center for Disease Control and Prevention's (CDC) National Breast and Cervical Cancer Early Detection Program (NBCCEDP) provides uninsured and underinsured women access to no-cost screening, diagnostic, navigation, and education/outreach services, as well as a pathway to cancer treatment care

Patient navigation

Reduce risk factors for cancer

- Increase research into environmental exposures and breast cancer
- Increase access to healthy foods
- Increase low cost options for physical activity

System-Level Actions to Reduce US Breast Cancer Disparities

- Improve access to mammography and timely surgical care after mammography
- Allow for Medicaid expansion and other provisions of the Affordable Care Act that lower uninsured rates and close disparities in access to breast screening and surgical treatment
- Support patient navigation programs that benefit minority patients by mitigating differences in health literacy, access to resources, and self-advocacy, and by increasing access and follow-through in cancer care, entry into clinical trials and follow-up care
- Engage clinical practices in collaborative quality improvement work and promote adoption of guideline-concordant care by providers

Reduce the Cost Barriers To Care

For people undergoing treatment for cancer, out-of-pocket expenses are nearly double that of the average enrollee (\$1,510 compared to \$778).

Additionally, out-of-pocket costs for treatment for many common forms of cancer - such as colorectal, breast, and urinary cancers - are well above the average for cancer patients

Florida's Challenge in Reducing Disparities

- Florida has the second highest cancer burden in the nation.
- As of 2011, cancer is now the leading cause of death for Floridians, surpassing heart disease
- Florida has the nation's second-highest rate of uninsured residents younger than 65 — a total of about 3.8 million people, or about 25 percent of the state's population
- Florida did not pass Medicaid expansion

ADVOCATE FOR CHANGE



Barriers *to* Patient Enrollment in Therapeutic Clinical Trials for Cancer

A Landscape Report



The Henrietta Lacks Enhancing Cancer Research Act of 2019 was [introduced](#) in Congress at the end of March. This legislation aims to identify the reasons for the considerable disparities in access to cancer clinical trials that persist in underrepresented communities.



[American Cancer Society Cancer
Action Network](#)

Breast Cancer Action



Breast Cancer Action is the watchdog for the breast cancer movement. We are able to tell the truth about the epidemic because we are the only national breast cancer organization that does not accept funding from entities that profit from or contribute to cancer, including the pharmaceutical industry.

Current Campaigns:

Lymphedema Treatment Act
Cosmetics: Philanthropy or Hypocrisy?
Environmental Justice: Don't Frack With My Health

*THANK YOU FOR YOUR
ATTENTION*