

EPECTM-O

Education in Palliative and End-of-Life Care for Oncology:

Cultural Considerations When Caring for African Americans

Plenary-AA: Cancer and the African American Experience

Abstract

African Americans bear an unequal burden of cancer. This is caused by a complex interplay of socio-economic, cultural, environmental, and biologic factors; the result is the persistence of inequalities in cancer care outcomes. These disparities encompass the entire spectrum of care, from screening and prevention activities, through diagnosis and treatment, to palliative and end of life care. Clinicians should be aware that concepts of race and ethnicity are social and political constructs, without a direct relationship to biology and genetics. The use of patient navigation is discussed, as well as other general strategies for improving access to all aspects of cancer care for African Americans.

Key Words

African American, race, culture, ethnicity, cancer health disparities, health literacy, food deserts, hospice, palliative care, patient navigation

Objectives

At the end of the activity, the participant will be able to:

- Describe African American demographics related to health outcomes.
- Identify trends in cancer incidence, prevalence, and mortality in African Americans.
- Describe sources of disparities in cancer incidence, survival rates, and outcomes of treatment in African Americans compared to other racial-ethnic groups.
- Describe the influence of socio-cultural, environmental, and biologic factors on access, utilization, and outcomes of cancer and palliative care/end-of-life treatment.
- Describe strategies that may be effective both in addressing disparities in cancer screening, diagnosis, treatments and outcomes, and also in improving access to and the quality of hospice and palliative care.

Definitions:

African American: Those self-identifying as belonging to that racial group, most of whom come from a historical, political, and geographic context that is currently reflected in shared lifestyles, behaviors, social, and religious attitudes. Many are descendents of slaves brought over from Sub-Saharan Africa to America during colonial times.^{1,2} This definition also applies to the term “Black” or “Black African American”.

Coping: The process of managing external and/or internal demands that tax or exceed the resources of the person. Coping is a complex and multidimensional process that is sensitive to both the environment and the personality of the individual.³

Types of coping:

- Positive reappraisal: reframing a situation to see it in a positive light.
- Problem-focused or approach coping (also known as planful problem-solving): trying to solve or manage the problem that is causing distress.

- Emotion-focused or avoidant coping: directed at managing or reducing emotional distress using strategies such as “looking on the bright side”, seeking emotional support, distancing, or substance abuse.
- Meaning-focused coping: searching for meaning in adversity and drawing on values, beliefs, and goals to modify the meaning given to—and personal response to—a stressful situation.

Ethnicity: The fact or state of belonging to a social group that has a common national or cultural tradition.⁴

Food deserts: Urban areas where there is a paucity of supermarkets offering healthy foods (for example, fresh fruits and vegetables) and an overabundance of fast-food outlets offering calorie dense/nutritionally-poor meals and small groceries/convenience stores with increased prices and decreased quality and selection of food products.⁵

Health disparities: A particular type of difference in health (or in the most important influences on health that could potentially be shaped by policies); it is a difference in which disadvantaged social groups—such as the poor, racial/ethnic minorities, women, or other groups who have persistently experienced social disadvantage or discrimination—systematically experience worse health or greater health risks than more advantaged social groups.⁶

Health literacy: The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.⁷

Hospice: A program that provides special care for people who are near the end of life and for their families, either at home (which includes nursing home and assisted living facilities), in freestanding facilities, or within hospitals.⁸ Hospice and palliative care are considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury. They bring a team-oriented approach to expert medical care, pain management, and emotional and spiritual support that is expressly tailored to the person’s needs and wishes. Support is provided to the person's loved ones as well.⁹

- The foundation of hospice relies on the belief that each of us has the right to die pain-free and with dignity, and that our loved ones will receive the necessary support to allow us to do so.
- Hospice focuses on caring, not curing; in most cases, care is provided in the person’s home.
- Hospice care also is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities.
- Hospice services are available to patients of any age, religion, race, or illness.
- Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organization.⁹

Palliative Care: Care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of palliative care is to prevent or treat as early as possible the

symptoms of a disease, side effects caused by treatment of a disease, and psychological, social, and spiritual problems related to a disease or its treatment. Also called comfort care, supportive care, and symptom management.¹⁰

Patient Navigators: Trained, culturally competent health care workers who work with patients, families, physicians, and the health care system to ensure that cancer patients' needs are appropriately and effectively addressed.¹¹

Race: The concept of race as used by the U.S. Census Bureau reflects self-identification by people according to the race or races with which they most closely identify. These categories are sociopolitical constructs and should not be interpreted as being scientific or anthropological in nature. Furthermore, the race categories include both racial and national-origin groups.¹²

An alternative definition is: A group or population of humans categorized on the basis of various sets of heritable characteristics (such as color of skin, eyes, and hair).¹³

Video Vignette

A panel of interdisciplinary African American healthcare providers is asked to discuss the socioeconomic, racial, and cultural factors that contribute to disparate outcomes in cancer screening, diagnosis, treatment, and outcomes for African Americans.

While viewing the video, participants are asked to reflect on:

- How they think about racial, ethnic, socioeconomic, and biologic factors that influence access to cancer care.
- Whether they communicate consistently, sensitively, and accurately when talking about race, ethnicity, and culture, and the influence these factors have on various aspects of cancer care.

The panel uses a moderated question and answer format to explore the various issues faced by African American patients and families that are dealing with cancer. The discussion presents population trends in incidence and prevalence of cancer among African Americans, highlights disparities suffered by African Americans along the entire spectrum of cancer care, and explores contributors to the disparities.

The video can be accessed by clicking on the following url:
<http://www.youtube.com/watch?v=wgaZvhW4M5U>

Cancer and the African American Experience

Introduction

African Americans have greater incidence, higher death rates and lower survival rates from cancer than do Whites and other racial/ethnic groups. The unequal burden of cancer experienced by African Americans is related to a complex interplay of social, cultural, environmental and

biological factors; these result in lower rates of screening, later stage of cancer at diagnosis, and diminished access to timely, quality cancer treatment.² For many African Americans, attitudes about disease, cultural values and preferences influence medical decision-making throughout the spectrum of cancer care, and can affect their participation in clinical trials and their utilization of palliative care and hospice services. Health care providers need to have a working knowledge of barriers and facilitators to cancer care experienced by African Americans in order to intervene most effectively in screening and treatment recommendations that will ultimately influence outcomes of care.

For purposes of EPEC-O: Cultural Considerations When Caring for African Americans, the term “African American” is meant to define a population of people who share a similar culture—those who live in similar physical and social environments, and share common beliefs, values, traditions, customs, world views, and communication systems. Most importantly, referring to African Americans as a homogeneous generic group is meant to represent a way of describing a population of people who come from an historical, political, and geographic context that is currently reflected in shared life styles, behaviors, social, and religious attitudes. This is an oversimplification, of course. As defined by United States Census data, the African American population is not a homogenous group. Although a significant proportion are descendents of former slaves brought over from Africa in colonial days, some are descendents of free individuals of African descent from colonial times. More recently, an increasing proportion of the population are recent immigrants from Africa or the Caribbean, with no shared history of slavery, whose languages and cultures differ from the predominant African American population.²

Racial classifications of human populations have no genetic or biological basis, and are social and political constructs. The term “ethnicity” originates from the Greek word, *ethnos*, meaning “people” or “tribe”.¹⁴ Its modern use is often to connote cultural, linguistic, and geographic differences between peoples who share community. In this syllabus, race and ethnicity are used interchangeably.

Influence of race and socioeconomic status on health and cancer disparities

According to 2010 U.S. Census data in which individuals self-declare membership in a so-called racial group, 39 million people in the United States (12.6 percent) identified themselves as Black/African American alone, rising to 42 million people (13.6 percent) reporting Black/African American alone or in combination.^{15,16} The majority (56 percent) lived in the South and 84 percent had earned at least a high school diploma. The ten states with the largest black populations include New York, Florida, Texas, Georgia, California, North Carolina, Illinois, Maryland, Virginia and Michigan.² The median African American family income was \$32,584, compared to \$54,461 for non-Hispanic White families, and the number of African Americans living in poverty compared to non-Hispanic Whites was over three times as great (26 percent vs. 9 percent respectively).¹⁵

Health disparities reflect socio-economic inequalities. For example, poor people on average live fewer of their days in good health.¹⁷ Racial and ethnic categorizations sometimes function as surrogates for presumed socio-economic status since multicultural populations are

disproportionately represented among the economically disadvantaged. Furthermore, socio-economic status (SES) often predicts health attitudes and behaviors. As SES declines, the prevalence of risk-promoting lifestyles and other unhealthy behaviors (for example, cigarette smoking, physical inactivity, and obesity) increases; people are more likely to reside in inadequate physical and social environments; they are more likely to have inadequate health information and knowledge, and they are more likely to have diminished access to quality health care.²

African Americans are also more likely to be affected by deficiencies in the built environment that impact health. For instance, core inner-city areas, many of which are predominantly African American, rarely have access to supermarkets or Farmer's markets. These "food deserts" are served by an overabundance of fast food outlets, which generally serve nutrition-poor, calorie-dense selections, and small groceries that offer less selection at a higher price. There is also often a lack of safe park and recreation areas, which compounds the problem of physical inactivity for those who live there.⁵ In 2009, the prevalence of obesity in the African American population was 37 percent, compared with 25 percent for non-Hispanic Whites. In non-Hispanic Black women, the rate was 42 percent.¹⁸

Obesity is associated with a number of adverse health outcomes, and contributes to 25-30 percent of cancers, including increased risk of developing breast, colorectal, endometrial, kidney, and esophageal cancer; the evidence is less definitive but still suggestive for cancers of the pancreas, gallbladder, thyroid, ovary, and cervix, as well as myeloma, Hodgkins lymphoma, and aggressive forms of prostate cancer.²

African Americans also have a higher burden of co-morbid illnesses; some of these like diabetes mellitus, are associated with increased incidence of various cancers (for example, breast and colorectal). Co-morbid diseases also influence morbidity and mortality. For instance, postmenopausal women with breast cancer and two or more co-morbid conditions are more than twice as likely to die as those with one or none.¹⁹

Vitamin D deficiency is increasingly being associated with an increased risk of certain cancers, such as colon and breast cancer. African Americans are at higher risk for Vitamin D deficiency—they generally take in less in their diet, and their darker skin inhibits production triggered by sunlight. This deficiency can be compounded for African Americans residing in inner city areas where sunlight is blocked by smog and tall buildings, and where people are less likely to spend recreational time outdoors.^{20, 21, 22, 23, 24}

Many socio-economic and behavioral indices are associated with racial and ethnic factors that contribute to cancer disparities. For example, African American men and women have higher prevalence of cigarette smoking than many other ethnic groups. The Healthy People 2020 goal of 12 percent is significantly lower than the 23 percent smoking rate of African American men and the 18.5 percent rate of African American women due in part to marketing strategies of tobacco companies.²

Level of educational attainment also has a relationship to the experience of cancer. African American and White men with less than a high school education have more than twice the cancer death rate of men who are college educated.² Health literacy is related to, but independent of, educational level. Only slightly more than half of the population of the United States has health literacy adequate to manage their health issues competently. Especially vulnerable populations include the elderly, minorities, and the poor.²⁵

Although no single factor can account for the relationship between low socio-economic status and increased cancer mortality, it is nonetheless true that there is a very strong inverse relationship.

Access to Healthcare

Access barriers to healthcare have a profound impact on rates of cancer screening among African Americans as well as on the timeliness of diagnosis, and the receipt of timely and appropriate cancer treatment. According to the 2010 census data, 21 percent of African Americans are uninsured, compared with 11 percent of the White population. Those between the ages of 18 and 64 have a 28 percent uninsured rate.¹⁵ The African American population has worse access to healthcare, as reflected in the Medical Expenditure Panel Survey (MEPS). According to the MEPS 2008 data:

- 24 percent of African Americans (vs. 18 percent White, non-Hispanic) reported no usual source of care,
- 57 percent (vs. 73 percent White, non-Hispanic) reported office-based care as their usual source of care,
- 18 percent (vs. 8 percent White, non-Hispanic) used hospital-based care (e.g., hospital clinics) as their usual source of care, and
- 1 percent (vs. 0.4 percent White, non-Hispanic) reported that the emergency room is their usual source of care.²⁶

Becker et al²⁷ found several themes in interviews with 60 low and middle income African Americans with chronic illness:

- African Americans in the low income category were more likely to be either uninsured and to access health care in the emergency room or free clinics, or they were Medicaid recipients accessing health care through hospitals and low-income clinics. This contrasts with African Americans in the middle income category who usually had private insurance and utilized private physician's offices or HMOs.
- Low-income African Americans were much more likely to be dissatisfied with their care and to have significant complaints related to the amount of time spent dealing with bureaucracy; they were also more likely to be preoccupied with how to access care, which they were at risk of being turned away from; they noted rapid turnover of physicians and had no continuity of providers, and also perceived the care system as inefficient.

- Middle income African Americans seldom complained or had only mild complaints; they were more likely to see one physician for many years, and felt that their physician knew their health problems.

In addition to lack of health insurance, patients with low SES experience other practical barriers; these include inadequate financial means to purchase needed health services and treatments (such as medication prescriptions, diagnostic imaging, health provider fees.), transportation difficulties, difficulties taking time off of work to seek health care, difficulties arranging for child care, burdensome intake procedures, inconvenient or limited clinic hours, long waiting times to get appointments, and long waiting times to see the provider once they arrive at the health center.²⁸

A number of access barriers correlate to low educational attainment and low health literacy. People with these characteristic are often not aware of recommended preventive health maintenance or disease management strategies, they may misunderstand directions for care and follow-up, and they are more likely to develop and maintain health beliefs and attitudes at odds with recommended medical treatment, as well as unrealistic fears about recommended therapy.^{28, 29}

Data show that when patients have physicians from their own race or ethnicity, the tenor of the encounter changes. If patient and physician are race-concordant, patients rate their physicians' decision-making style as more participatory and the care they received as more satisfactory, compared to encounters where there is discordance between the patient's and physician's race or ethnicity.³⁰ In concordant encounters, the interaction between the provider and the patient is longer, with more social talk and more positive physician and patient affect.^{30, 31} What is less well studied is whether there are significantly different clinical outcomes between race concordant and race discordant patient-physician encounters. Results differ as to whether the use of patient-centered communication has a mediating effect, with some studies reporting a positive effect, while others report no association.^{30, 31} It is interesting to note that 30 percent of African Americans are cared for by African American physicians when African Americans make up 13.6 percent of the United States population and only 3-4 percent of the physician work force.³²

The US cancer experience in context: race- and ethnically-based disparities

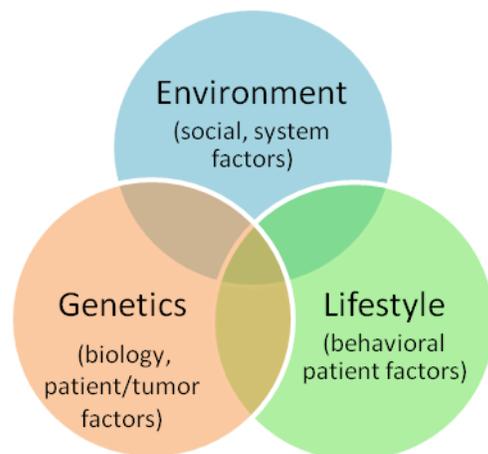
African Americans have higher incidence and death rates from cancer than do Whites and almost all other racial or ethnic groups in the United States.² African American men and Jamaican men of African descent have the highest incidence rate of prostate cancer worldwide.² Prostate, lung and colorectal cancer are the most commonly occurring cancers in African American males, as they are in males of all other racial-ethnic groups. For females, breast, lung and colorectal cancers are the most commonly occurring in all racial-ethnic groups, although colorectal cancer, rather than lung cancer, has the second highest incidence rate in African American females.² African American men and women have higher deaths rates from cancer (all causes), approximately 30 percent and 15 percent higher respectively, than the rates for non-Hispanic White men and women. (See **Appendix**) They also have lower 5-year survival rates at each stage of diagnosis than do Whites.³³

Although lung cancer death rates have trended down in African Americans and are now comparable to rates in Whites, the disparities in colorectal and breast cancer survival are widening.²

According to the Office of Minority Health (OMH) of the Department of Health and Human Services:³³

- In 2006, African American men were more likely to have new cases of lung (1.3 times greater) and prostate cancer (1.4 times greater) compared to non-Hispanic White men.
- African American men were almost twice as likely to have new cases of stomach cancer as were non-Hispanic White men.
- African American men had lower 5-year cancer survival rates for lung, colon and pancreatic cancer, compared to non-Hispanic White men.
- In 2006, African American men were 2.5 times more likely to die from prostate cancer, compared to non-Hispanic White men.
- In 2006, African American women were 10 percent less likely to be diagnosed with breast cancer; however they were almost 40 percent more likely to die from breast cancer, compared to non-Hispanic White women.
- African American women were 2.3 times more likely to have been diagnosed with stomach cancer, and 2.4 times more likely to die from stomach cancer, compared with non-Hispanic White women.
- Cancer disparities are related to the interplay between environmental, genetic, and lifestyle factors. (See Figure 1)³⁴

Figure 1. Reasons for Cancer Disparities



Adapted from Gabram et al³⁴, *Cancer* 2008 © American Cancer Society. This material is reproduced with permission of John Wiley & Sons, Inc.

Specific reasons that contribute to the higher African American cancer incidence and mortality are different for different types (sites) of cancer. Some of the most common factors contributing

to disparities among racial and ethnic groups in cancer incidence, prevalence and survival rates are:

- Exposure to key risk factors (for example, higher rates of smoking in African American men)²
- Lower rates of access to cancer screening, and lower utilization of screening services (for example, historically lower rates of mammography and Pap smears in African American women, and lower rates of colonoscopy in African Americans aged 50 and over, compared with Whites) (see **Appendix**)
- Diagnosis at more advanced stages of illness.² African Americans are more likely than Whites to be diagnosed with metastatic cancer, where the prognosis is generally poorer. Only about half (51 percent) of the breast cancers diagnosed in African American women are diagnosed at a local stage compared with 61 percent in White women.² Some of the disparity may be due to delays in reporting symptoms and seeking treatment. A 2002 study by Falcione et al³⁵ found that factors contributing to a delay in reporting self-discovered breast cancer symptoms among both Latino and African American women included: low income, lack of health insurance, lower education, and poor breast cancer knowledge. The authors concluded that decreasing the delay in reporting symptoms could help reduce breast cancer mortality in minority populations.
- Delays between diagnosis and beginning definitive treatment. Timeliness of treatment also plays an important role in outcomes of cancer therapy. A recent retrospective cohort study of 250,007 patients with breast cancer in the National Cancer Database reported that (independent of age, socio-economic status and stage at diagnosis) African Americans and Hispanics had a higher risk of 30, 60 and 90 day treatment delays compared to Whites.³⁶

Survival rates from most cancers are improving for all racial-ethnic groups, although disparities in mortality persist. Importantly, the differences in survival rates between African Americans and Whites seems to be more closely tied to access to care and the quality of care received, than to basic biological differences in cancer behavior; that is, the different outcomes among races disappear when all patients are diagnosed at similar stages of disease and receive the same quality of treatment.³⁷

Although frequencies of genetic variants related to cancer may differ based on a population's continent of origin, race alone cannot be used to predict which molecular sub-type of cancer an individual has without definitive testing.

A recent study evaluating prognostic markers of breast cancer in African American and White women illustrates the danger of imposing so-called racial factors onto the interpretation of genetic and biological data. Researchers classified breast cancer subtypes using immunohistochemical staining to determine any differences between African American and White women. They found that, while "people of African origin had a higher prevalence of the worst kinds of breast cancer; it also shows that the marker's aggressiveness is more important than race in terms of prognosis. In other words, breast cancer is not a more malignant disease in Black women, but a higher proportion of Black women get the worst kinds of breast cancer."³⁸

In fact, one third of African American women diagnosed with breast cancer are found to have triple negative breast cancer, a more aggressive basal-like form of breast cancer, compared to a 10 percent prevalence in White women.³⁹ African American women under the age of 45 years have a higher incidence of breast cancer than White women in the same age group, and are at particular risk for basal-like breast cancer.² Researchers have also recently found that African American men may have a higher incidence of a particularly aggressive form of prostate cancer than White men.⁴⁰

Studies also have found population differences in how specific drugs are metabolized (processed in the body). For instance, cell lines from individuals of Sub-Saharan African descent are more sensitive to anti-metabolites and are more resistant to platinum agents. In practical terms, this implies that African Americans with a particular genetic signature may do worse with some chemotherapies.⁴¹ However, attempting to predict the response to pharmacologic agents based on race should be avoided, since individual differences abound. In the future, these individual differences are likely to be elucidated by testing each patient's specific genetic makeup.

While these differences in incidence of aggressive cancers and in pharmacokinetics of drug metabolism may explain a small percent of the cancer disparities among African Americans, the predominant contributors to health disparities remain related to impaired access to, inconsistent quality of, and delays in diagnosis and treatment of cancer.

Cancer Survivorship and the African American Experience

A 2006 Institute of Medicine report reviewed the needs of cancer survivors.⁴² This report emphasizes that cancer survivors require a written care plan from their healthcare providers that covers the following essential components: 1) prevention of recurrent and new cancers, and other late effects of cancer, 2) surveillance for cancer spread, recurrent or second cancers, 3) intervention for consequences of cancer and its treatment and, finally 4) coordination between the cancer care providers and primary care providers, particularly if the patient is being transferred back to the primary care provider. The American Society for Clinical Oncology (ASCO) has developed templates to help develop a survivorship care plan, but studies are ongoing to examine the effectiveness of these plans in improving continuity of care for cancer survivors.⁴³

Economic hardship often follows in the footsteps of a cancer diagnosis. In a national sample of 2,314 bankruptcy filers in 2007, Himmelstein et al found 62.1 percent of bankruptcies were related to the costs of medical care with 92 percent owing over \$5000, or 10 percent of pre-tax family income. Three quarters of these bankruptcy filers had health insurance.⁴⁴ Ramsey and coauthors at the 2011 ASCO Annual Meeting reported that the risk of bankruptcy in cancer patients increases with increased survival time, and is highest in those diagnosed with lung cancer, thyroid cancer, and leukemia/lymphoma and in those younger than age 65.⁴⁵ Cancer survivors face loss of health insurance, increased out-of-pocket costs for medical care, and unemployment or underemployment because of effects of the cancer or its treatment, and these issues are exacerbated in those with limited means prior to a cancer diagnosis.⁴⁶

African Americans make up only 8 percent of the cancer survivor population and are less likely to survive long-term (that is, more than 10 years) than are Whites.³¹ The National Cancer Institute (NCI) estimated that approximately 942,400 African Americans with a history of cancer were alive in January of 2007.²

A National Action Plan for Cancer Survivorship: African American Priorities was released in 2006.⁴⁷ The report built on previous recommendations from *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies*.⁴⁸ Co-sponsored by the Centers for Disease Control and Prevention and the Lance Armstrong Foundation, and supported by the National Black Leadership Initiative on Cancer, the newer report prioritizes the cancer survivorship needs of the African American community which, if met, would improve quality of life and survival rates for African Americans with cancer. The most important issue was access to services, followed by culturally competent patient and provider education. Patient navigation was a top crosscutting issue in all areas of need.⁴⁷ (See Table 1.)

Table 1. Main Cancer Survivorship Topics and Crosscutting Issues

Main Cancer Survivorship Topics in order of importance	Crosscutting Issues
Access to quality care and services: Access to quality treatment, pain and symptom management, End-of-life care	1. Develop and promote patient navigation systems for cancer survivors
Education, training and communication: Survivor education, provider training, public communication	2. Develop and disseminate public education programs on informed decision making for cancer survivors
Infrastructure, programs, and policies	3. Develop and disseminate clinical practice guidelines for each stage of cancer survivorship
Applied research and surveillance	4. Develop a comprehensive database on cancer survivorship
	5. Develop comprehensive evaluation systems that monitor cancer survivorship issues and services

The survivorship needs of African Americans are often greater than those reported by Whites. For instance, African American breast cancer survivors report more frequent treatment complications and greater difficulty in social functioning, employment and other issues related to cancer survivorship, compared to White breast cancer survivors.^{49, 50}

A recent focus group of 28 African Americans (15 women breast cancer survivors and 13 men prostate cancer survivors) in North Carolina reported that spirituality and a personal relationship with God were critical coping aids for cancer survivorship.⁵¹ Similarly, in a qualitative analysis of how African American women cope with breast cancer, Henderson et al. found that spirituality played a major role in coping, as did supportive networks. African Americans were

more likely than a mixed sample of primarily Caucasian women to use positive reappraisal, social support, planful problem solving, distancing, and escape avoidance.

Participants also discussed the need for culturally sensitive breast cancer support groups.⁵² In focus groups of African American survivors of breast cancer conducted by the non-profit educational agency Living Beyond Breast Cancer, a central theme to emerge was “getting connected.” To navigate their breast cancer experience successfully, African American women used positive coping through connection to self, God and nature, family and friends, other survivors, and the health care team.⁵³

Palliative and End of Life Care: Issues in African American Cancer Patients and Survivors

Palliative care should be a component of quality cancer care, from the time of diagnosis through end of life care.⁵⁴

Palliative care is specialized medical care for people with serious illnesses, delivered by an interdisciplinary team of healthcare providers. This type of care is focused on providing patients with relief from the symptoms, pain, and distress of a serious illness and its treatment—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who coordinate care with a patient's other healthcare providers to provide an extra layer of support. Palliative care is appropriate at any age, and at any stage in a serious illness, and can be provided together with curative treatment.⁵⁵

Although the goals of palliative care and hospice are the same, palliative care does not require a terminal prognosis of six months or less. Since 2001, the number of palliative care programs in U.S. hospitals with 50 or more beds increased from 658 (in 24.5 percent of all such hospitals) to 1,486 (58.5 percent), an increase of more than a 125 percent.⁵⁶ Fifty three percent of hospitals with more than 50 beds reported the presence of a palliative care program in 2006.⁵⁷

Healthcare providers use the following strategies to provide quality palliative care to their patients, in the context of delivering optimal cancer care:

- Assessment of physical, emotional and spiritual needs of patients.
- Information sharing and empathic listening and communication skills.
- Practice of shared decision-making that emphasizes discussion of goals of care, advance care planning, identification and communication with surrogates, and conflict resolution.

Care planning and care coordination.⁵⁴

The Institute of Medicine (IOM)⁵⁸ has identified six essential criteria that define quality care, including palliative care: Is the care patient-centered? Beneficial? Timely? Safe? Efficient? Equitable?

Palliative care outcomes meet these tests of quality care in all measures, with the possible exception of equitable access to care.

Several studies found cultural barriers to palliative and hospice care for African Americans. Among these are:

- the emphasis in African American culture on living and prolonging life, even in the face of suffering;
- cultural mistrust of the healthcare system, based on the experience of past injustices;
- the perception that hospice does not place an emphasis on the importance of spirituality and religious practices at the end of life that is so basic to many African Americans;
- the lack of diversity among the hospice healthcare workforce; and
- the perception that hospice values individual autonomy and devalues the importance of family in decision-making.^{59, 60, 61, 62, 63}

There is little empirical data concerning racial-ethnic differences in utilization of hospital-based palliative care services.⁶⁴

End of life decision-making—racial and ethnic comparisons. (see also Module 13, Advance Care Planning)

Studies have consistently demonstrated differences between African American and White populations in their preferences for palliative and end-of-life care. These differences extend across all disease categories, including cancer and also apply to the rates of completing Advance Directives. In a general survey of 1,178 Californians assessing cultural attitudes about end of life care, 68 percent of African Americans thought it “was very important to have their wishes in writing”, although only 33 percent actually had done so. By comparison, 63 percent of Whites thought it was very important to have their wishes in writing, and 47 percent had done so. Participants in an African American focus group identified an attitude of fatalism associated with African American culture, which led to people avoiding discussions or planning for their death.⁶¹ Is it appropriate to allow terminally ill patients to die? Sixty-nine percent of Whites said “yes”, but only 38 percent of African Americans did so, and 44 percent of African Americans in this survey said that one should “always do everything.”⁶⁵

These trends were also seen among those who are seriously ill. Studies among cancer patients have found that African Americans were more likely than Whites to desire aggressive interventions such as cardio-pulmonary resuscitation, tube feeding, or mechanical ventilation even when death is imminent, and were less likely to have formal advance directives.^{66, 67, 68, 69} However, a recent report looking at medical records in the Veterans Administration (VA) health system noted that “African Americans were more likely than Whites to have do-not-resuscitate orders (DNR) and advance directive discussions documented.”

This finding contrasts to several previous studies that indicated African Americans are less likely to complete advance directives. The authors attribute the change to the fact that the VA is an

“equal access” health system where African Americans do not experience the access barriers that are prevalent in the healthcare system as a whole. Each is assigned a primary care physician. There may be inherently more trust in the system among African Americans as well.⁷⁰ As a closed integrated health system, the VA also has the capacity to institute system-wide initiatives to improve quality of care, and did just that by initiating a strategic initiative in 1997 to improve end-of-life care for veterans. Part of this initiative focused on the development of the Palliative Care Index, a performance measure that includes discussion of advance directives.⁷¹

There also appear to be significant differences in attitudes between African American and White physicians about care at the end of their patients’ lives as well as their own.⁷² For example, White physicians more often view tube feedings as “heroic” measures in terminally ill patients than do African American physicians (58 percent vs. 25 percent). In this same study, 36 percent of White physicians accept physician-assisted suicide (PAS) as a treatment alternative, while only 26.5 percent of African American physicians do so. When asked about how they preferred care for themselves at the end of life, this study also observed startling differences between White and African American physicians. For example, if they were to be in a persistent vegetative state, African American physicians were six times more likely than White physicians to request aggressive treatment. In a scenario in which the physicians might be brain damaged but not terminally ill, the majority of both groups did not want aggressive treatment, but African American physicians were five times more likely than Whites to request specific aggressive treatment (23 percent vs. 5 percent) and White physicians were twice as likely to request PAS than African American physicians (22.5 percent vs. 9 percent).⁷²

Satisfaction with end of life care and hospice utilization patterns among African Americans (see also Plenary 3: Models of Comprehensive Care)

In a cross-sectional follow-back survey of family members of decedents (from hospitals, nursing homes, and home-based medical services, including hospice and home health) Welch et al. found that family members of African American decedents were less likely than those of White decedents to rate their care as excellent or very good, were more likely to report absent or problematic physician communication, and more often reported concerns with being informed and with receiving family support. Family members of African American decedents were also more likely to report financial hardships related to the care of their loved one.⁷³

Statistically, as a percentage of the population, fewer African Americans (8.7 percent of hospice enrollees nationally in 2009) utilize hospice compared to Whites (80.5 percent).⁷⁴ Fishman et al. studied 283 patients in oncology clinics and found that African Americans had a stronger preference for continuing their cancer treatments than Whites, and this may exclude them from earlier hospice access.⁷⁵

Although the rates of hospice use among both African Americans and Whites have been rising over the years, the rate of increase among African Americans continues to lag behind that of the White population. From 2000 Medicare data, approximately 17 percent of African American decedents and 24 percent of white decedents used hospice services prior to death. The data on decedents in 2009 were 33 percent of African Americans using hospice and 44 percent of White

decedents.⁷⁶ Of note, Greiner et al. studied the records of 23,000 deceased individuals in the National Mortality Followback Survey and observed that hospice use by African Americans was less likely than in Whites (odds ratio =0 .59), particularly when there was not a cancer diagnosis and when there was no living will.⁷⁷

To summarize findings on palliative care and end of life practices, compared to Whites African Americans are:

- Less likely to complete advance directives, enroll in hospice, receive appropriate symptom management at the end-of-life, or be satisfied with the quality of end-of-life care and communication.
- More likely to receive aggressive treatment at the end-of-life, stop hospice care to seek life-prolonging treatment, and die in the hospital⁷⁸

Some of the reasons for these differences are related to preferences and values, including strong religious and spiritual views held by African Americans, and concerns about the trustworthiness of the health care system rooted in the experiences of historic and current health care inequalities.

In a survey of 205 older adults, Johnson et al. found that African Americans had less favorable beliefs about hospice care than did Whites. They: were more likely to express discomfort discussing death; wanted aggressive care at the end of life; had spiritual beliefs which they perceived to conflict with the goals of palliative care; and were most likely to distrust the health care system—although none of these factors alone completely explained the differences in attitudes about advance care planning or beliefs about hospice care.⁷⁹

As do other Americans, African Americans have many misconceptions about hospice care, and know little about the practice of palliative care. This lack of knowledge may play a role in the observed disparities in access to palliative end-of-life care. For instance, Taxis et al. found that pervasive lack of information about hospice led to numerous erroneous assumptions about hospice care among African Americans, such as the belief that care would be inadequate; that people would die lonely, painful deaths in a nursing-home like setting; or that hospice was inaccessible because of cost.⁶¹

Another barrier to accessing hospice and palliative care is not knowing it is an option. Physicians are the main referrers to hospice and palliative care, and investigators have found that they often neglect to fully inform patients, including African American patients, of options for care at the end of life. For instance, Rhodes et al. found that African Americans often were not even informed of the option of hospice care, yet those who *were* informed about hospice, only 8.9 percent refused enrollment.⁸⁰ Yancu, in a study examining the barriers to hospice and palliative care, found that almost all of the 314 African American participants expressed willingness to use hospice services, especially if the hospice team were diverse.⁸¹

Health literacy may also play a role. Volandes et al. found that differences in preferences for care at the end-of-life evident after verbal descriptions disappeared after both African Americans and

Whites viewed a video about the final stages of dementia. The authors concluded that health literacy and not race was an independent predictor of end-of-life preferences. The preference for comfort care when using an educational video was born out by further studies undertaken by Volandes involving urban and suburban patients (56 percent of whom were African American) as well as rural patients with advanced dementia, where nearly 50 percent of the study participants were black or African American.^{82, 83, 84}

Recommendations for Improvement—best practices to impact disparities in cancer care

The “cancer experience” spans from participation in recommended screening interventions, through diagnosis and treatment, to palliative and end-of-life care. This experience is often emotionally and physically challenging for all patients regardless of race or ethnicity. African American patients may face more challenges from disparities in access to screening and treatment options throughout this spectrum.

Improving prevention, treatment, and survivorship activities for African Americans

Kin Keepersm Cancer Prevention Intervention

The Kin Keepersm Cancer Prevention Intervention is a program to help African American women receive potentially life-saving preventative health care information in the comfort of their own homes and with family support. Designed by Dr. Karen Williams, this program has shown that African American women’s strong family bonds help reinforce information-sharing to increase cancer literacy, and also encourages participants to follow through with mammograms and other cancer screening procedures. The Kin KeeperSM program has been so successful that Dr. Williams has translated the curriculum into Spanish and Arabic, bringing this preventative health care information and support system to other populations in the U.S. who frequently experience health disparities.^{85, 86}

Patient navigation programs

Patient navigation was introduced by Dr. Harold Freeman in 1990 as a strategy to facilitate access to cancer screening and care for poor individuals living in medically underserved communities.⁸⁷ The role of a patient navigator is to provide individual guidance for patients as they interact with the health care system by identifying and eliminating barriers to screening, diagnosis and treatment, and supportive and palliative care. Many different models of patient navigation programs are sporadically available in health settings of all types—community health programs, hospitals, physician practices, and health insurers. They usually focus on a specific disease, and often on one part of the trajectory of care—for example, breast cancer screening or colon cancer screening—though some include navigation through treatment as well.

Patient navigators vary from professional case managers to lay community persons, and organizational structures that support them vary from those connected closely to (and employed by) specific oncology practices to those more generally supported by hospitals and other institutional settings. Early evaluation of navigation programs indicates they are superior to conventional approaches to cancer screening and treatment, clinical trials participation, and

patient satisfaction.⁸⁷ For example, after utilizing patient navigation, Freeman showed in 1990 that presentations of late-stage breast cancer dropped from 50 percent to 21 percent and 5-year survival rates improved from 39 percent to 70 percent.⁸⁸

Patient navigator activities include:

- Identifying the patient's unique logistical and emotional needs.
- Coordinating with staff to anticipate and develop effective solutions to present and unforeseen barriers.
- Facilitating communication between patient and providers.
- Helping patients get to appointments and prepare them for appointments.
- Connecting the patient to community and social services.
- Providing health education to patients.
- Assisting with information about clinical trials and recruitment into trials.

Fischer et al. describe patient navigation used as an approach to reduce disparities in palliative care. In the intervention they are testing, patient navigators would be compared to usual care to determine whether advance care planning and hospice utilization increase, pain management improves, and satisfaction with care improves.⁸⁹ The study was ongoing at the time of publication of this curriculum.

Lessons from large integrated health systems

Keating et al. reviewed the records of 3,805 members of the Kaiser Permanente of Northern California Health Plan who were diagnosed with lung, colorectal, breast or prostate cancer and found a 65 percent rate of enrollment in hospice care that did not vary by race or ethnicity. They concluded that a large integrated delivery system had the potential to eliminate racial disparities in hospice use, although they did note "substantial" local variation in use.⁹⁰

Advanced Illness Management Paradigms and Community-Based Palliative Care

Ciemins et al. described the impact of an Advanced Illness Management (AIM) program on hospice utilization in the Sutter Health Care System. AIM is a home-based intervention that provides access to simultaneous "curative and comfort care" for seriously ill patients. Over a two-year period, 435 patients with a life expectancy of 6 months or less were evaluated; African American patients received higher rates of hospice referral after participation in the AIM program, compared to those in usual care (47 percent vs. 18 percent).⁹¹

Palliative Care Consultation

Temel et al. found that patients receiving early concurrent palliative care during cancer treatment for metastatic non-small cell lung cancer had better quality of life, fewer depressive symptoms, earlier hospice referral, and longer median survival by about 2 months (in spite of receiving less aggressive care at the end of life) than did patients who received standard care.⁹² Unfortunately,

the study population was predominantly White, so whether these results would be found in an African American population is not known.

Deamont et al. conducted a retrospective cohort study of all (173) African American cancer patients referred for palliative care consultation at a public hospital during 2007. In contrast to other data on the preferences of African Americans, they found that, palliative consultation for cancer patients resulted in a high rate of hospice enrollment post-discharge (90 percent), and a willingness among competent patients to complete advance directives, as 89 percent appointed a Durable Power of Attorney for Health Care.⁹³

African American participation in cancer clinical trials

Patients who join clinical trials may gain access to promising new treatments and receive more regular and careful attention from a medical research team than might otherwise be available. Despite these advantages, only about 3 percent of adult cancer patients participate in clinical trials. And participation in palliative care clinical trials may pose further barriers; for example, concerns that individuals participating in Phase I trials might not benefit; also experimental interventions could place additional burdens on very ill and vulnerable patients.

On the other hand, some patients find it rewarding to participate in studies that could potentially benefit others, if not themselves.⁹⁴ Of all cancer patients who join clinical trials, White men and women make up approximately 36 percent and 46 percent, respectively. African American men provide 4 percent and African American women 5 percent.⁹⁵ The most commonly cited reasons for this disparity are persistent concerns about the history of unethical medical research performed on African Americans, which has profoundly shaped attitudes about the basic trustworthiness of medical institutions in these communities.⁹⁶

The most effective means to enhance recruitment to clinical trials, regardless of race or ethnicity, has been shown to be physicians recommending the idea to their patients.^{97, 98, 99} Mainous et al. surveyed physicians from clinics with ≥ 40 percent African Americans or Latinos, and found that the Trust in Medical Researchers Scale (TIMRS) score was lower in both African American physicians and physicians with a high proportion of minority patients who mirrored the trust-related issues among their minority patients.¹⁰⁰

A meta-analysis evaluating the effectiveness of strategies to recruit African Americans and other under-represented minorities into cancer clinical trials showed there is a paucity of data on this topic, but media campaigns and church-based projects did have a small effect on improving accrual and recruitment of African Americans.¹⁰¹

Wujcik and Wolff employed a successful intervention at Nashville General Hospital at Meharry Medical College to recruit minorities to cancer clinical trials using a clinical trials shared resource (CTSR). The approach was proactive and used multiple interventions to eliminate barriers to recruitment and enrollment. They were successful in recruiting patients to cancer clinical trials at twice the national average.¹⁰²

See Table 2 for strategies to improve the rate of minority participation in clinical trials.¹⁰³

Table 2. Strategies employed to improve the rate of minority participation in clinical trials

Strategy	How to accomplish
Improve communication about clinical trials between doctor and patient	<ul style="list-style-type: none"> • Establish trustworthy relationships • Understand patient fears about research and past experiences • Provide information about clinical trials appropriate for the literacy level of the patient and family • Understand the patient’s concerns about the benefits and burdens of clinical trial participation • Discuss potential financial costs of clinical trials participation • Involve the patient’s family in the discussion
Change oncology practice patterns	<ul style="list-style-type: none"> • Incentivize and educate entire staff to the goal of increased clinical trials participation • Diversify the staff • Select appropriate clinical trials
Improve outreach and relationships with the community	<ul style="list-style-type: none"> • Foster relationships and network with key community opinion leaders • Form partnerships with local community organizations such as churches, libraries, barber and beauty shops, etc. • Make educational presentations to the community, emphasizing the benefits of clinical trials • Connect with primary care physicians in the community • Share research findings with the community

Park¹⁰³

Summary

African Americans suffer a disproportionate burden of cancer. As health providers, we must continually strive to reduce the disparities in cancer care, and improve the cancer treatment experience of African Americans throughout the spectrum of cancer care from prevention through survivorship and palliative and end-of-life care.

Key Take Home Points

1. African Americans experience an unequal burden of cancer.
2. Disparities exist in all aspects of the cancer experience for African Americans, from screening, to diagnosis and treatment of cancer and its complications, to palliative and end-of-life care.
3. Social and economic determinants of health (including cultural and religious values and preferences) impact care for African Americans.
4. There needs to be better utilization of identified best practices and strategies in communication and community outreach to achieve better outcomes in cancer treatment and palliative care for African Americans.
5. Patient navigation is emerging as a key strategy to reduce disparities in cancer care, particularly for many African Americans and other medically underserved patient populations.
6. Other promising interventions include peer counseling, palliative consults, and effective systems of integrating care.
7. There is an urgent need to include African American participants in research studies, and successful models of increasing accrual of African Americans to clinical trials exist.

Resources: Professional and/or Patient & Family

Coping With Cancer: Supportive and Palliative Care

<http://www.cancer.gov/cancertopics/coping> accessed 6/6/12

Home Page for Supportive and Palliative Care on Cancer.gov, with links to patient and professional resources on:

- Managing Physical effects
- Managing emotional effects
- For caregivers, family and friends
- About children with cancer
- Finding healthcare services
- Financial, insurance, and legal information
- Survivorship-Living beyond cancer
- Supportive and palliative care clinical trials

NCI Fact Sheets

- Palliative Care in Cancer: NCI Fact Sheet (patient resource)
<http://www.cancer.gov/cancertopics/factsheet/Support/palliative-care> accessed 6/6/12
- Hospice: NCI Fact Sheet (patient resource)
<http://www.cancer.gov/cancertopics/factsheet/Support/hospice> accessed 6/6/12

National Institute of Nursing Research

Palliative Care: The Relief You Need When You Are Experiencing Serious Illness (patient brochure) http://www.ninr.nih.gov/NR/rdonlyres/01CC45F1-048B-468A-BD9F-3AB727A381D2/0/NINR_PalliativeCare_Brochure_508C.pdf accessed 6/6/12

The Duke Institute on Care at the End of Life (ICEOL) www.iceol.duke.edu accessed 6/6/12

End of life topics for the public and health professionals

- APPEAL Curriculum—available through Duke ICEOL
- *Key Topics in End of Life Care for African Americans*

The National Hospice and Palliative Care Organization

African American Outreach Guide. Caring Connections (NHPCO) in collaboration with Duke Institute on Care at the End of Life, 2008. (for hospice and palliative programs)
http://www.caringinfo.org/files/public/outreach/African_American_Outreach_Guide.pdf
Accessed 6/12/12

Intercultural Cancer Council

<http://www.iccnetwork.org> Accessed 6/6/12

- Resources for health professionals

Center to Advance Palliative Care

- Palliative care resources: <http://www.getpalliativecare.org/resources> Accessed 6/6/12

Patient Navigation Resources

- Center to Reduce Cancer Health Disparities: Patient Navigation Research Program
<http://crchd.cancer.gov/pnp/pnrp-index.html> Accessed 8/8/12. (for health professionals)
- Harold P Freeman Patient Navigation Institute. www.hpfreemanpni.org (for lay public)
Accessed 6/6/12

Clinical Trials Resources

- Including Clinical Trials in Your Practice: An Overview [NCI training-professional]
<http://www.cancer.gov/clinicaltrials/conducting/clinicaltrialscourse> Accessed 6/6/12
- Minority recruitment into clinical trials. Education Network to Advance Cancer Clinical Trials (ENACCT). www.enacct.org (for health professionals) Accessed 6/6/12

Survivorship Resources

- American Society of Clinical Oncology Treatment Plan and Summary Resources: <http://www.asco.org/ascov2/Practice+&+Guidelines/Quality+Care/Quality+Measurement+&+Improvement/Chemotherapy+Treatment+and+Summary/Cancer+Treatment+Plan+and+Summary+Resources> Accessed 6/6/12
- A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies. <http://www.cdc.gov/cancer/survivorship/pdf/plan.pdf> Accessed 6/6/12
- A National Action Plan for Cancer Survivorship: African American Priorities http://www.livestrong.org/App_Themes/Livestrong/pdfs/NAP%20African%20American%20Priorities.pdf Accessed 6/6/12
- After Treatment Ends: Tools for the Adult Cancer Survivor http://media.cancercare.org/publications/original/25-ccc_survivor.pdf?1302556249 Accessed 6/6/12
- Lance Armstrong Foundation Survivorship Worksheets http://www.kintera.org/site/c.khLXK1PxHmF/b.2662847/k.72C3/Survivorship_Worksheets.htm 1-866-673-7205 Accessed 6/12/12
- CancerCare® www.cancercare.org 1-800-813-HOPE(4673) accessed 6/6/12
- Patient Advocate Foundation www.patientadvocate.org 1-800-532-5274 Accessed 6/6/12

Appendix

From Tables listed in Reference 23, based on CDC/SEER statistics

New Cancer Cases in African Americans:

New Cancer Cases per 100,000 – Men (2006)				
Cancer	All Men	African American Men	Non-Hispanic White Men	African American/Non-Hispanic White Ratio
All Sites	506.9	572.8	535.0	1.1
Colon and Rectum	51.1	61.4	51.1	1.2
Lung	66.6	92.3	70.1	1.3
Pancreas	12.9	16.1	13.4	1.2
Prostate	155.1	217.1	155.3	1.4
Stomach	10.9	15.3	8.5	1.8

New Cancer Cases per 100,000 – Women (2006)				
Cancer	All Women	African American Women	Non-Hispanic White Women	African American/Non-Hispanic White Ratio
All Sites	393.6	390.4	427.9	0.9

New Cancer Cases per 100,000 – Women (2006)				
Breast	119.6	118.7	130.3	0.9
Cervical	7.3	8.7	6.4	1.4
Colon and Rectum	40.2	51.9	40.5	1.3
Pancreas	10.4	14.6	10.2	1.4
Stomach	5.7	9.0	4.0	2.3

Source: CDC 2010. Health United States, 2009. Table 49. <http://www.cdc.gov/nchs/data/hus/hus09.pdf>

Cancer Incidence Rates:

Cancer Incidence Rates per 100,000 – Men				
Cancer	All Men	African American Men	Non-Hispanic White Men	African American/Non-Hispanic White Ratio
All Sites	538.9	624.0	564.3	1.1
Colon & Rectum	38.9	50.8	39.7	1.3
Esophagus	7.8	8.9	8.4	1.2
Kidney & Renal Pelvis	19.2	21.8	20.1	1.1
Liver & IBD	10.7	14.0	8.0	1.8
Lung & Bronchus	76.2	101.2	81.1	1.2
Oral Cavity & Pharynx	15.4	16.1	16.9	1.0
Pancreas	13.3	16.7	13.5	1.3
Prostate	156.9	234.6	154.4	1.5
Stomach	10.9	16.7	8.8	1.9

Cancer Incidence Rates per 100,000 – Women				
Cancer	All Women	African American Women	Non-Hispanic White Women	African American/Non-Hispanic White Ratio
All Sites	408.0	399.1	438.0	0.9
Breast	122.9	118.3	133.2	0.9
Cervical	8.1	10.1	7.0	1.4
Colon & Rectum	31.2	41.0	31.5	1.3
Kidney	9.9	10.7	10.2	1.0
Liver & IBD	3.7	4.4	2.7	1.6
Lung & Bronchus	52.4	54.8	59.0	0.9
Pancreas	10.5	14.4	10.3	1.4
Stomach	5.5	8.6	3.9	2.2

Source: NCI 2010. Seer Cancer Statistics Review, 1975-2007. Tables 2.15 through 24.15

Cancer 5 Year Survival Rates for men and women:

Percent of Patients, Men (1999-2005)			
Cancer	African American Men	White Men	African American/White Ratio
All Sites	62.2	69.3	0.9
Colon	55.0	67.9	0.8
Lung	11.1	14.4	0.8
Pancreas	3.6	6.0	0.6
Prostate	97.9	99.9	1.0
Stomach	25.1	23.4	1.1

Percent of Patients – Women (1999-2005)			
Cancer	African American Women	White Women	African American/White Ratio
All Sites	56.2	68.9	0.8
Breast	78.9	91.3	0.9
Cervical	64.8	73.1	0.9
Colon	55.9	66.9	0.8
Pancreas	6.6	5.3	1.2

Source: CDC, 2010. Health United States, 2009. Table 50

<http://www.cdc.gov/nchs/data/hus/hus09.pdf>

Cancer Death Rates:

Cancer Death Rates per 100,000 – Men (2003-2007)			
Cancer	African American Men	Non-Hispanic White Men	African American/Non-Hispanic White Ratio
All Sites	296.5	227.5	1.3
Colon & Rectum	30.5	20.9	1.5
Lung	87.5	71.1	1.2
Pancreas	15.4	12.4	1.3
Prostate	54.2	22.9	2.4
Stomach	10.7	4.3	2.5

Cancer Death Rates per 100,000 – Women (2003-2007)			
Cancer	African American Women	Non-Hispanic White Women	African American/Non-Hispanic White Ratio
All Sites	180.6	158.8	1.1
Breast	32.4	23.9	1.4
Cervical	4.4	2.1	2.1
Colon and Rectum	21.0	14.6	1.4
Pancreas	12.4	9.2	1.3
Stomach	5.0	2.1	2.4

Source: NCI 2010. Seer Cancer Statistics Review, 1975-2007. Table 1.20.
http://seer.cancer.gov/csr/1975_2007/results_single/sect_01_table.20_2pgs.pdf

Breast Cancer Screening Facts:

Percent of women age 40 and over who had a mammogram within the past 2 years, 2008 (crude)		
Non-Hispanic Black Women	Non-Hispanic White Women	Non-Hispanic Black/Non-Hispanic White Ratio
68.3	68.7	1.0

Source: CDC, 2010. Health United States, 2009. Table 86. <http://www.cdc.gov/nchs/data/hus/hus09.pdf>

Cervical Cancer Screening Facts:

Percent of women age 18 and over who had a Pap smear within the past 3 years, 2008 (crude)		
Non-Hispanic Black Women	Non-Hispanic White Women	Non-Hispanic Black/Non-Hispanic White Ratio
80.0	74.9	1.1

Source: CDC, 2010. Health United States, 2009. Table 87.
<http://www.cdc.gov/nchs/data/hus/hus09.pdf>

Colon Cancer Screening Facts:

Adults age 50 and over who reported they ever had a colonoscopy, sigmoidoscopy, or proctoscopy, or had a fecal occult blood test within the past 2 years, United States, 2005

Non-Hispanic Black	Non-Hispanic White	Non-Hispanic Black/Non-Hispanic White Ratio
48.5	58.5	0.8

Source: 2009 National Healthcare Disparities Report. Table 1_3_1.2b.

<http://www.ahrq.gov/qual/qdr09/index.html>

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Self-Assessment Questions

Plenary AA: Cancer and the African American Experience

1. Which of the following contributes to increased risk of death due to cancer for African-Americans?
 - a). Increased poverty rate among African-Americans
 - b). Increase in onset of treatment delays after diagnosis for African-Americans compared with non-Hispanic Whites
 - c). Diminished access to cancer screening
 - d). Diagnosis at more advanced stages of cancer compared with non-Hispanic Whites
 - e). All of the above.

2. Which of the following are true concerning cancer among African-Americans?
 - a). African American women have a higher incidence of breast cancer than non-Hispanic White women.
 - b). Although African-American men have a lower incidence of prostate cancer than non-Hispanic White men, they have 3 times the mortality rate.
 - c). African-American men and Black men from the Caribbean have the highest incidence of prostate cancer worldwide.
 - d). African-Americans have the same risk of death due to pancreatic cancer as do non-Hispanic White men.

3. African American and White men with less than a high school education, compared with men who are college educated,
 - a). Have the same cancer death rate.
 - b). Have 1.5 times the cancer death rate.
 - c). Have more than twice the cancer death rate.
 - d). Have a 50% higher cancer death rate.

4. In a recent study by Temel et al, patients with metastatic non-small cell cancer who received early concurrent palliative care during cancer treatment of metastatic non-small cell lung cancer experienced the following:
 - a). Better quality of life and fewer depressive symptoms, but shorter life-expectancy.
 - b). Better quality of life, shorter median survival, and delayed hospice referral.
 - c). Earlier hospice referral and better quality of life, with shorter median survival.
 - d). Better quality of life, earlier hospice referral, and longer median survival.

5. Which of the following has been shown to improve access to quality cancer care for African-Americans at various points along the cancer trajectory?

- a). Kin KeeperSM Cancer Prevention Intervention
- b). Cancer patient navigation programs
- c). Advanced Illness Management Program
- d). Palliative Consultation
- e). All of the above

Self-Assessment Answers

Question 1. The correct answer is: e)

All of the options play a role in the increased burden of cancer among the African-American population.

Question 2. The correct answer is: c)

African-American men and Black men from the Caribbean have the highest incidence of prostate cancer worldwide. The incidence is nearly one and a half times the incidence in non-Hispanic White (NHW) men, and the death rate is two and a half times that in NHW men. African-American women have about a 10% lower incidence of breast cancer than NHW women, but 40% higher death rate due to breast cancer. African-Americans have a higher risk of death due to pancreatic cancer.

Question 3. The correct answer is: c)

Lower educational attainment is an independent risk factor for death due to cancer.

Question 4. The correct answer is: d)

The study found that patients receiving early concurrent palliative care during cancer treatment of metastatic non-small cell cancer had better quality of life, fewer depressive symptoms, earlier hospice referral, and longer median survival by about 2 months.

Question 5. The correct answer is: e)

The Kin KeeperSM Program has been found to be useful in prevention and screening activities, the patient navigation programs have a role in screening and follow-through with treatment of those diagnosed with cancer, and the AIM program and palliative consultation increase access to

improved symptom management and psychosocial support for those with advanced cancer undergoing active anti-cancer therapy, and result in increased rate of, and earlier referrals to hospice care.