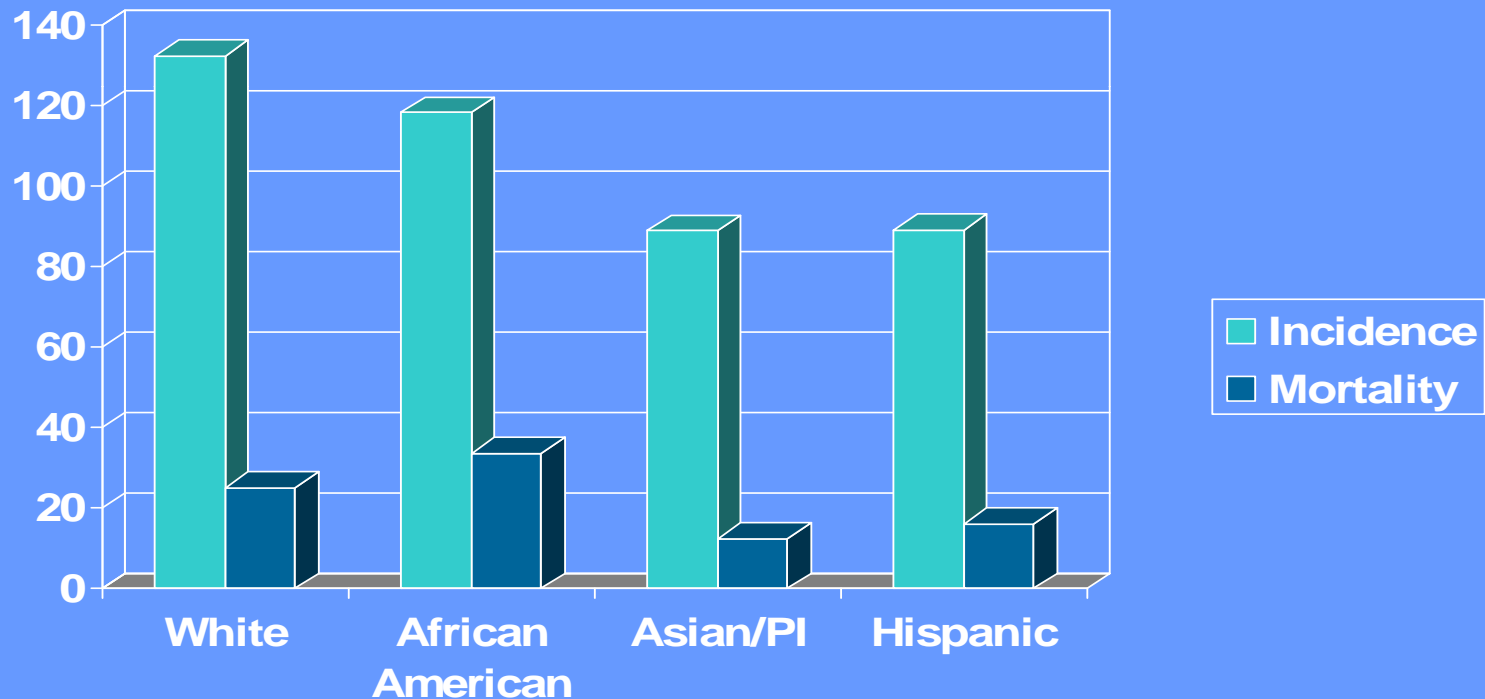


MAKING THE BEST DECISIONS FOR YOUR CARE

Karen Schmitt, MA, RN
Director,
Columbia University Cancer
Screening Partnership



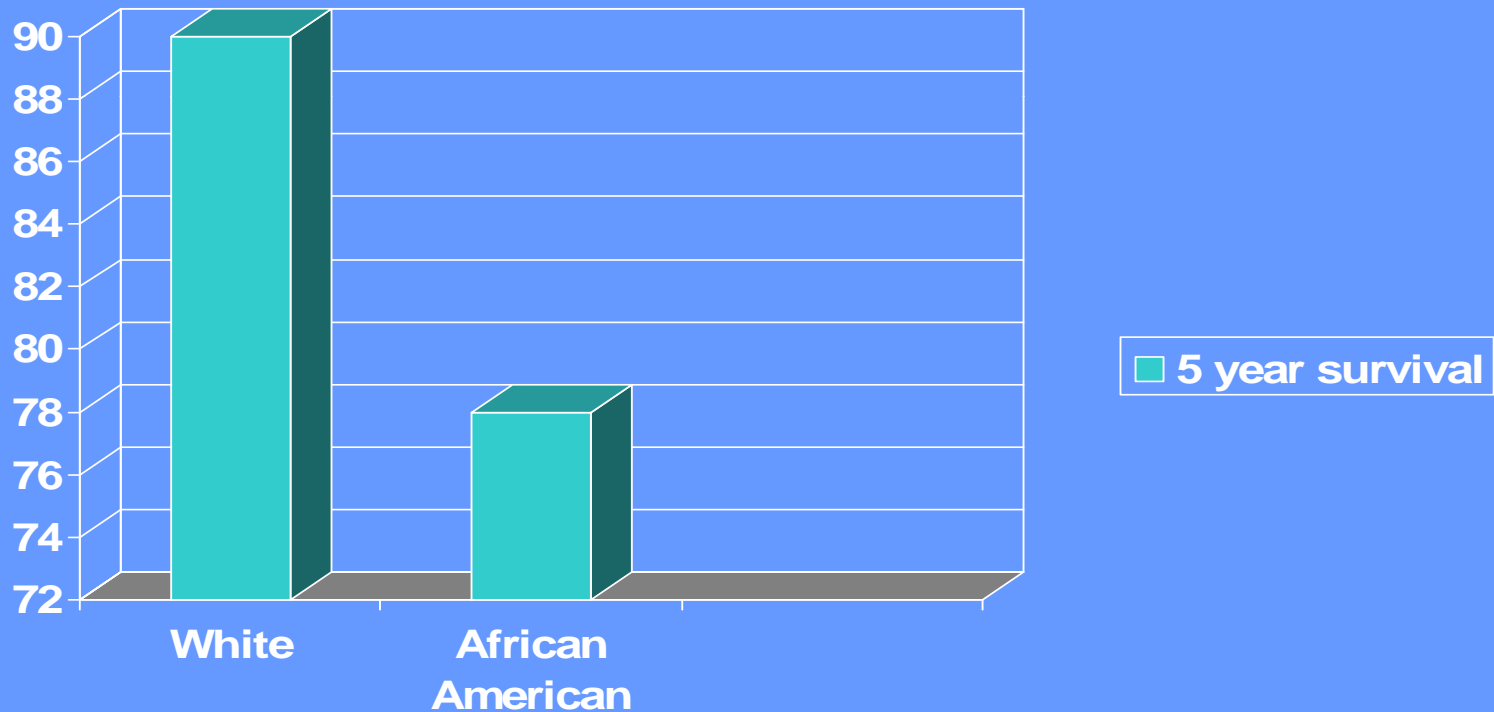
Breast Cancer Incidence and Mortality By Race



Per 100,000

American Cancer Society, Surveillance Research, 2008

Breast Cancer Five Year Survival by Race



Per 100,000

American Cancer Society, Surveillance Research, 2008

Influences on Cancer Survival

“Blacks are less likely to have their diseases detected early, and when it is detected, they are less likely to receive adequate treatment. If we are to decrease disparities in these diseases, we must work to get all people adequate treatment, and an important question for health disparities researchers is ‘how do we get adequate care including preventative services to all who deserve it?’”

Otis W. Brawley, “Is race really a negative prognostic factor for cancer?” JNCI, vol.101, Issue 14/ July 15,2009

Influences on Cancer Survival

- Socioeconomic
 - Access to health insurance
 - Access to preventative care
 - Access to early detection
 - Access to high quality treatment
- Cultural
 - Language
 - Beliefs and Values
 - Traditions



How To Assure Access To Affordable Early Detection, Appropriate Diagnostic Services And High Quality Treatment

GET YOURSELF EDUCATED!



- Learn the American Cancer Society Screening Guidelines
- Women of average risk should receive annual Clinical Breast Exams and Mammograms beginning at age 40
- Make sure your insurance covers screening
- If you are uninsured, enroll in you State Free Cancer Screening Program

Keep Your Own Records



- If you are changing mammogram providers, bring your previous films with you
- If you have had a breast biopsy, get a copy of your pathology report and give your breast screening provider a copy

Expect Timely Access to Quality Treatment

- If you need to have a breast biopsy, ask why you need it and what it will entail
- Be sure your insurance will pay for the biopsy, if not, ask to speak with a Social Worker
- If you are uninsured, the diagnostic process will be covered if you are enrolled in a State Free Screening Program

Navigating Breast Cancer



If you are diagnosed with breast cancer, you will most likely meet with a breast surgeon first.

- The breast surgeon will discuss your surgical options with you based on your age, tumor size and type, and general health condition
- It is a good idea to bring someone with you who can take notes for you to refer back to after the appointment

Navigating Breast Cancer

If you are diagnosed with breast cancer, depending on your tumor characteristics and surgical treatment you will likely:

- Meet with a Radiation Oncologist to determine need for radiation therapy
- Meet with a Medical Oncologist to determine your need for chemotherapy, chemo prevention or hormonal therapy

Informed Decision Making

At any point in this process, you should:

- Expect culturally appropriate, clear patient education
- Make sure all your questions are answered – keep notes
- Consider speaking with other women who have been treated for breast cancer
- Access evidence-based information
- Feel free to seek a second opinion,
 - you will need your reports, films and slides, and those can be arranged through the surgery, pathology, and radiology departments

Ask For Needed Services

Other professional services include Case Managers and Social workers, they can assist with:

- counseling of patients and families dealing with breast cancer, hospitalization, and disability.
- navigation through health care system
- coordination of transportation, home care services and equipment.
- information and referrals to appropriate support groups and other cancer specific resources
- referrals to community agencies for services to patients and their families - food services, child care, financial, housing
- referral for legal assistance

Ask For Your Care Plan



Once initial treatment is complete, you will be given a plan for on-going surveillance. This includes how often you will see your physicians, what testing you will need and at what intervals.

Cancer Survivorship Care Plan

Record of Care

Each patient should be given a record of all care received including diagnostic tests, tumor characteristics, dates and types of treatment, support services, contact information of treating institutions and providers and contact information of key personnel such as coordinator of care.

Cancer Survivorship Care Plan

Standards of Care

Upon discharge from treatment, patients and their primary provider should receive a written follow-up care plan that includes; ongoing health maintenance, screening intervals and periodic testing, signs of recurrence, physical and emotional effects of treatment, recommendations for health behaviors, information on genetic counseling and testing as appropriate, information on chemoprevention, referral to specific care providers ,and list of cancer related resources,

Cancer Survivorship Care Plan

Questions to ask:

- List of medications and treatments
- Detailed plan of follow-up care
- Risk of recurrence or secondary cancers
- How to maintain health
- Possibility of short-term and long term side effects
- Resources for potential employment and insurance discrimination
- List of support groups
- Who will be monitoring care

“Cancer Patient to Cancer Survivor: Lost in Transition”, 2006, Institute of Medicine



Lifetime Considerations

Who Are Cancer Survivors?



Those Diagnosed with cancer and the people in their lives who are affected by the diagnosis.

Stages of Survivorship

Cancer survivors and doctors have attempted to describe the stages that cancer survivors typically experience. [The CDC National Action Plan for Cancer Survivors](#) describes three stages:

Stages of Survivorship

Stage One:

Living with cancer refers to the experiences of receiving a cancer diagnosis and treatment. Patients may be asked to enroll in clinical trials, and they and their caregivers may be offered services to help cope with emotional, psychological and financial concerns.

Stages of Survivorship

Stage Two:

Living through cancer describes the period in which initial treatment is complete and the risk of recurrence is high. Many patients experience anxiety that they are no longer active receiving treatment, and they visiting their physician less frequently, often a few times per year.

Stages of Survivorship

Stage Three:

Living beyond cancer describes the post treatment long term survival period. While most patients report that they 'return to normal', many experience continuing physical, psychological or financial consequences. Their long term medical plan may be transferred to their general medical doctor.

Long Term Impact of Cancer

Fear of Recurrence

Can cause unnecessary worry and anxiety.

Relearning to know your body in order to distinguish 'normal changes' from serious symptoms is an important step in reducing fear.

Grief

Grief is a natural result of loss. Such losses can include, diminished health or mobility, loss of sexual desire or fertility. Support groups and counseling can help women work through these important issues.

Long Term Impact of Cancer

Depression

Depression is experienced by 70% of cancer survivors at some point in time. Symptoms of depression can mimic side effects of cancer treatment such as weight loss, fatigue, insomnia and inability to concentrate. Cancer survivors experiencing depression should seek treatment as symptoms of depression are associated with shorter survival

Long Term Impact of Cancer

Body Image

Physical changes due to treatment can impact ability for intimacy, negatively impacting quality of life. Couples counseling and support groups for women and their partners that focus on intimacy are available.

Long Term Impact of Cancer

Spirituality

Some survivors report a renewed meaning of life after cancer, others felt they have been abandoned by God.

Relationships

Family, friends and co-workers may not know how to react to your cancer diagnosis, and may not give you what you need. Asking for help with specific tasks, emailing updates to a list of close friends and family, and/or keeping a journal can help communicate your feelings and needs.



RESOURCE GUIDE

**“When I use my strength in the service of my vision
it makes no difference whether or not I am afraid”**

**Audre Lorde
1934-1992**

