

# The Role of Advocates in Research and Programs to Address Health Disparities and Contribute to Health Equity

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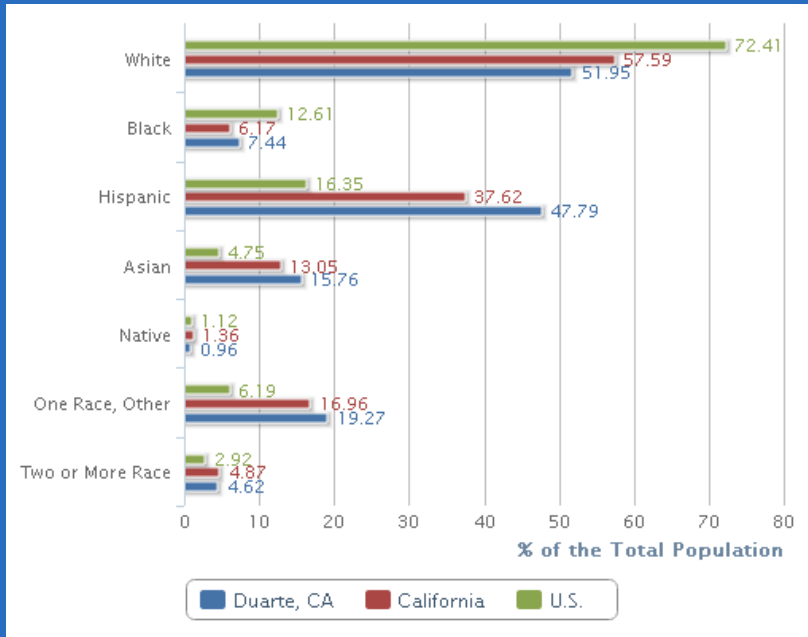
# Eat, Move, Live: Duarte and CCARE-COH Nutrition, Obesity Prevention and Community Opportunities Project

Headstart Parent Policy Council  
Duarte Unified School District  
City of Duarte  
CCARE-City of Hope

Evidenced based, *Peer-to-Peer* strategies to increase adults' and children's nutrition knowledge, consumption of healthy beverages and food, and physical activity (PA).



# Eat, Move, Live: Duarte and CCARE-COH Nutrition, Obesity Prevention and Community Opportunities Project



## Duarte, CA American FactFinder

### Duarte Head Start Report

38% Duarte Head Start students are overweight or obese

### Duarte School District Report

55.1% eligible for free lunch

35% households speak Spanish

### California Healthy Kids Survey

50.6% Duarte students are overweight or obese

42% Duarte's fifth-, seventh-, and ninth-graders are overweight and/or obese

59% do not meet the State standards for physical fitness assessed by the California Physical Fitness Test

### CCARE Community Needs Assessment

11% of adults surveyed in Duarte consuming 5 or more daily servings fruits and vegetables.

42% met the guidelines for physical activity

42.3% reported they had difficulty eating healthily

41.7% had difficulty staying physically active, and

50% reported difficulty in healthy meals preparation

# Sister Survivor



## Building the African American Cancer Coalition



# AACC Members



- Kommah Seray Inflammatory Breast Cancer Foundation



- Faith, Hope and Charity Cancer Ministry



- Women of Color



- Healthy Heritage Movement



- Support Sisters African American Breast Cancer Support Group



- Quinn Community Outreach Corporation



- Sisters Breast Cancer Survivors Network

- Women of Essence



- Celebrate Life Cancer Ministry



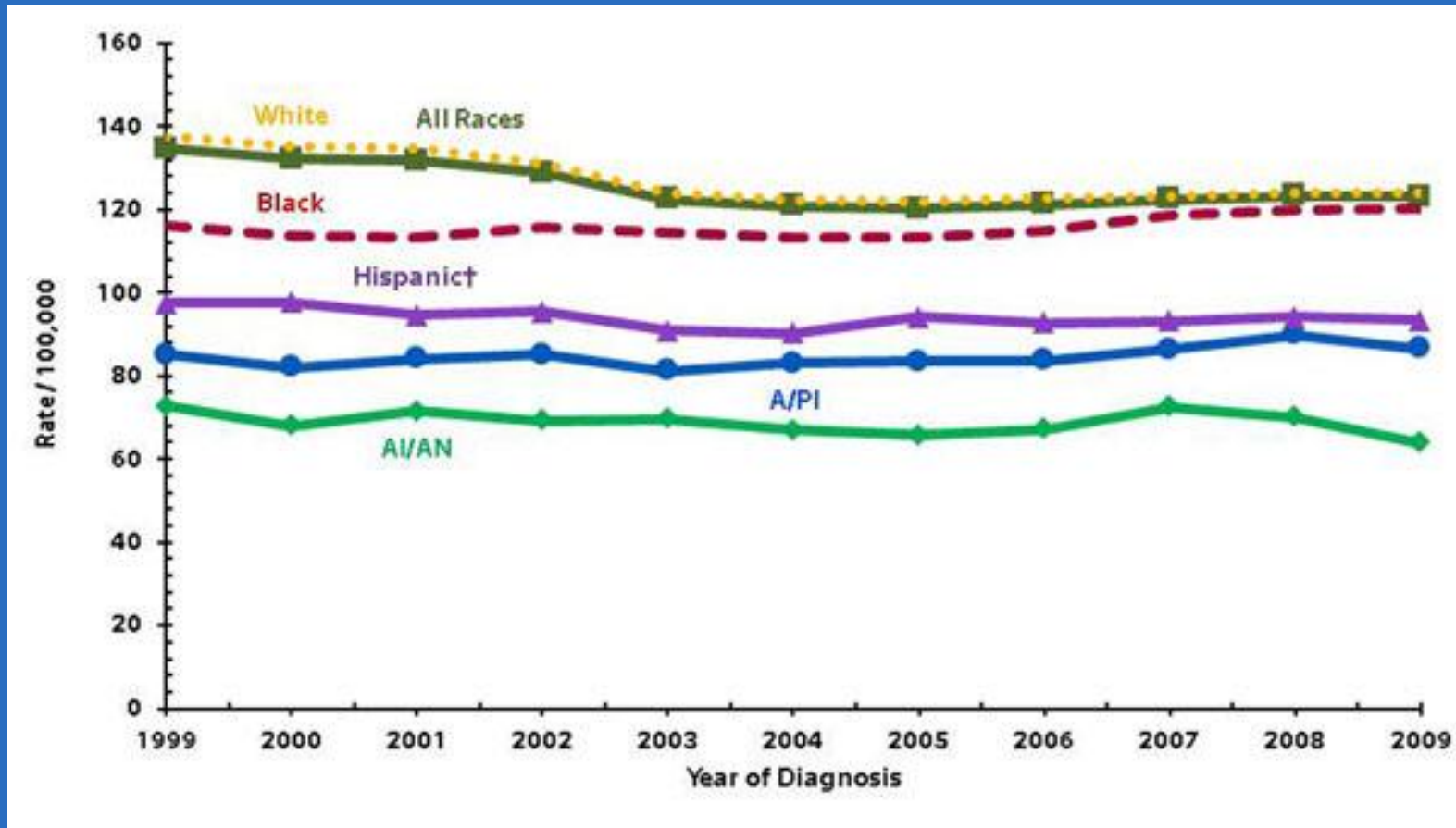
- Sassy Survivor



- Vessels of Hope



## Female Breast Cancer Incidence Rates by Race and Ethnicity, U.S., 1999–2009

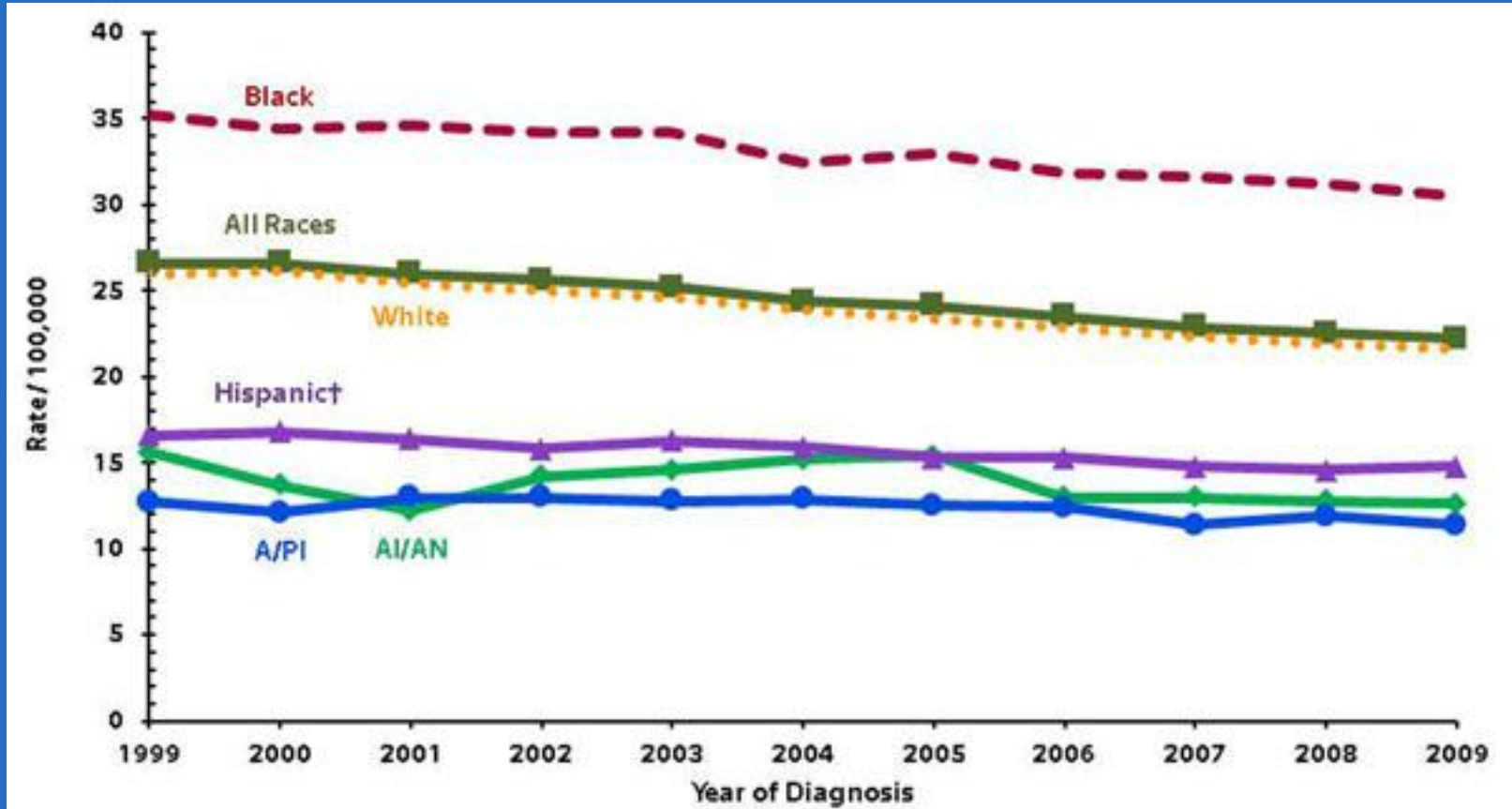


**Incidence source:** Combined data from the National Program of Cancer Registries as submitted to CDC and from the Surveillance, Epidemiology and End Results program as submitted to the National Cancer Institute in November 2011. Additional information available at SEER website.





## Female Breast Cancer Mortality Rates by Race and Ethnicity, U.S., 1999–2009



# Breast Cancer (BCA) in African-American Women



## African-Americans bear some of the heaviest burden due to BCA :

- Diagnosed with more advanced, pre-menopausal; endocrine distinct subtypes (i.e., estrogen-, progesterone- and HER2-negative, and triple negative); more aggressive and therapeutically unresponsive cancers<sup>4-6</sup>
- Greater Mortality (77.5% vs 88.8% 5-yr survival )<sup>7</sup>
- Experience >60 days delays in diagnostic and therapeutic care<sup>8-9</sup>
- 15% report not receiving annual mammogram post BCA<sup>10</sup>
- Documented treatment dissatisfaction, poor communication<sup>11-12</sup>; uncoordinated care<sup>13</sup>; and inadequate knowledge of surveillance and follow-up care guidelines<sup>14</sup>





## Support Group Impact on Life Domains

Impact on:	Positive Impact	Somewhat Positive Impact	No impact
Feeling hopeful	50 (82%)	7 (12%)	4 (6%)
Family life	38 (66%)	8 (13%)	12 (21%)
Intimate relationship	20 (47%)	4 (9%)	19 (44%)
Spirituality/religious practices	49 (82%)	3 (5%)	8 (13%)
Express feelings about cancer	46 (79%)	8 (14%)	4 (7%)
Outlook on life	49 (85%)	3 (5%)	6 (10%)
Quality of doctor-patient relationship	37 (65%)	7 (12%)	13 (23%)
Quality of healthcare	29 (50%)	9 (15%)	20 (35%)
Treatment decision making	24 (42%)	10 (18%)	23 (40%)
Symptom management	37 (62%)	11 (18%)	12 (20%)
Health habits	37 (61%)	20 (33%)	4 (6%)



Article

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## Peer-Based Models of Supportive Care: The Impact of Peer Support Groups in African American Breast Cancer Survivors

Kimlin Ashing-Giwa, PhD, Carolyn Tapp, BA, Monica Rosales, PhD, Kommah McDowell, MSLM, Virginia Martin, MA, Rhonda Holbert Santifer, MMin, Phyllis Clark, MA, Joy Steward, BA, Leah Lewis, MA, and Eudora Mitchell, MAEd, BA

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## Are survivorship care plans responsive to African-American breast cancer survivors?: voices of survivors and advocates

Kimlin Ashing-Giwa • Carolyn Tapp • Shirley Brown • Gingi Fulcher • June Smith • Eudora Mitchell • Rhonda H. Santifer • Kommah McDowell • Virginia Martin • Betty Betts-Turner • DeBorrah Carter • Monica Rosales • Paris Adkins Jackson

Ashing-Giwa, K., et al. (2012). "Peer-Based Models of Supportive Care: The Impact of Peer Support Groups in African American Breast Cancer Survivors." *Oncol Nurs Forum* **39(6)**: 585-591.

Ashing-Giwa, K., et al. (2013). "Are survivorship care plans responsive to African-American breast cancer survivors?: voices of survivors and advocates." *Journal of Cancer Survivorship*: 1-9.



# Embracing Hope

*Hopeful Living After Breast Cancer*





**Did You Know?** The American College of Surgeons' Commission on Cancer mandated the implementation of the survivorship care plan by 2015. A survivorship care plan may improve survival and reduce morbidity via coordinated clinical care informed by documenting and following surveillance care and recommended tests, late effects and symptom management, and healthy lifestyle promotion.

*African-American women have a five year survival rate of 78 percent after diagnosis as compared to 90 percent for white women. Early detection, appropriate treatment, post-treatment tests and follow-up care save lives.*



*Kimlin Tam Ashing-Giwa, Ph.D., director of City of Hope's Center of Community Alliance for Research & Education (CCARE), and the National African American Cancer Coalition are joining forces to educate and navigate survivors to get the best information and resources to improve follow-up care.*

**After** being diagnosed with breast cancer, many experience some fear and anxiety and may worry about what to do to gain the best outcomes through the phases of treatments, after active treatment ends and during the next stages of life. Most breast cancer survivors recover to normal well-being and functioning within one to two years. The survivorship care plan is your roadmap to follow-up care and well-being.

**A survivorship care plan answers three main questions:**

- *What treatments are most effective for me and what are the possible side effects?*
- *What follow-up care do I need from my oncology and primary care team?*
- *What actions and behaviors should I practice to improve my health and well-being?*

Ashing-Giwa, K. ; Tapp, C., Brown, S.; Smith, J.; Fulcher, G; Mitchell, E.; Santifer, R.H.; McDowell, K.; Martin, V.; Betts-Turner, B.; Carter, D.; Adkins-Jackson, P.; & **Rosales, M.** (In press). Are Survivorship Care Plans Responsive to African American Breast Cancer Survivors?: Voices of Survivors and Advocates. Journal of Cancer Survivorship.

Ashing-Giwa, K; Brown, S; Lai, L; Fulcher, G; Tapp, C; Smith, J; Mitchell, E; Santifer, R; McDowell, K; Martin V; Betts-Turner, B; Carter, D; Rosales, M. (Under review). Developing a Treatment Summary and Survivorship Care Plan Responsive to African-American Breast Cancer Survivors

### What is a Survivorship Care Plan?

A survivorship care plan (SCP) is a blueprint for quality cancer care. The SCP is completed by you, your oncology team and may include your primary care team. It is uniquely suited to you and your needs with information on your:

- Health history and breast cancer, including type and stage
- Treatments and possible side effects
- Follow-up treatments, medical exams and ongoing care
- Contacts and referrals for cancer and other health-care providers
- Recommendations and resources for healthy lifestyle

# Conclusions



- By designing CBPR projects that equitably include the community and research components, we are building infrastructure and capacity among community partners
- The level of community involvement allows for community-by-in through the maintenance of their activities and through alignment with their organizations' mission and goals
- Creating new partnerships
  - Kommah McDowell from Kommah Seray Inflammatory Breast Cancer Foundation partnered with Dr. Monica Rosales from CCARE to submit Pilot Award Proposal to CBCRP “Examining Follow-up Care among Young Breast Cancer Survivors”
  - Eudora Mitchell –Komen OC Funding
  - Eudora Mitchell and Phyllis Clark partnering with Loma Linda Medical Center- CBCRP Pilot Funding
  - Lily Lai partnering with AVCC – Komen LAC Funding
  - CCARE-COH Partnering on Building City



# Conclusions



- The Sister Survivor studies are based on sound scientific and CBPR principles, and designed to expand and deepen community involvement and benefit from science
- Sustained participation may speak to the desire of AABCS to take leadership and direct their own support organizations
- The AACC demonstrates the potential of community-research partnerships to address health disparities through coalition building, prioritizing direct community benefit, training/capacity building among community members and infusing cultural and socio-ecological dimensions into the process
- As a coalition we continuously working, supporting and dialoguing together about gaps and ways to reduce cancer disparities and bring cancer equity



# Together We Stand



# Together We Stand



## TOGETHER WE STAND

“Two heads are better than one”, we have heard  
And, *two hearts care better than one*, is inferred.  
We’re gather today to join heads and hearts  
For those whose lives cancer is ripping apart.

From our dialoguing today,  
Some pearls of wisdom, may open the way  
To research that could, in the end, find a cure  
Or, at least, make life better for others, I’m sure.

Let’s roll up our sleeves, don our thinking caps  
Each one may provide what the other lacks.  
Let’s listen and hear the concerns of each other  
For the community needs what researchers offer.

We must engender mutual trust and respect  
For community and researchers to interact.  
Then together we’ll stand with one common aim  
We will stand up to cancer and end all this pain.



Joy E. Walker Steward ©2008



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