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

Kimlin Tam Ashing, PhD, Director, Center Community Alliance for Research & Education (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).
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
Building the African American Cancer Coalition
AACC Members

- Kommah Seray Inflammatory Breast Cancer Foundation
- Women of Color
- Support Sisters African American Breast Cancer Support Group
- Sisters Breast Cancer Survivors Network
- Celebrate Life Cancer Ministry
- Faith, Hope and Charity Cancer Ministry
- Healthy Heritage Movement
- Quinn Community Outreach Corporation
- Women of Essence
- Sassy Survivor
- Vessels of Hope

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.
Breast Cancer in African-American Women


Mortality source: U.S. Mortality Files, National Center for Health Statistics, CDC. Additional information available at SEER website.
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

- Greater Mortality (77.5% vs 88.8% 5-yr survival)

- Experience >60 days delays in diagnostic and therapeutic care

- 15% report not receiving annual mammogram post BCA

- Documented treatment dissatisfaction, poor communication; uncoordinated care; and inadequate knowledge of surveillance and follow-up care guidelines

## Pilot Study - Research Outcomes

### Support Group Impact on Life Domains

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


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

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.

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?**

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

CCARE - City of Hope Breast Cancer Treatment Summary and Survivorship Care Plan SCP
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

“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
References

1. U.S. Census Bureau; American Community Survey, 2010 American Community Survey; using American FactFinder; <http://factfinder2.census.gov>; (July 8, 2013).
2. Los Angeles County Department of Public Health Office of Health Assessment and Epidemiology. Key Indicators of Health by Service Planning Area, March, 2013.