



COMMUNITY PROFILE REPORT

**Susan G. Komen for the Cure®
Tulsa Affiliate**



Disclaimer

The information in this Community Profile Report is based on the work of the Tulsa Affiliate of Susan G. Komen for the Cure® in conjunction with key community partners. The findings of the report are based on a needs assessment public health model but are not necessarily scientific and are provided “as is” for general information only and without warranties of any kind. Susan G. Komen for the Cure and its Affiliates do not recommend, endorse or make any warranties or representations of any kind with regard to the accuracy, completeness, timeliness, quality, efficacy or non-infringement of any of the programs, projects, material, products or other information included or the companies or organizations referred to in this report.

Acknowledgements

Jennifer Barrington, Community Health Programs Coord., Tulsa Affiliate, Susan G. Komen for the Cure
Juell Homco, Senior Research Biostatistician
Julie Sluss, Breast Health Navigator, St. Francis Breast Center
JoAn Camp, St. John Health System
Karen McAhren, Diagnostic Supervisor, Indian Health Care Resource Center of Tulsa
Erma Roquemore
Elian Hurtado
Deborah Stovall
Christy Southard, Executive Director, Tulsa Affiliate, Susan G. Komen for the Cure
Ashley Antle, Board of Directors, Tulsa Affiliate, Susan G. Komen for the Cure
Kristen Turley, Board of Directors, Tulsa Affiliate, Susan G. Komen for the Cure

Table of Contents

Executive Summary	4
Introduction.....	4
Statistics and Demographic Review.....	5
Health Systems Analysis.....	5-6
Qualitative Data Overview.....	6-7
Conclusion.....	7-8
Introduction	9
Affiliate History.....	9
Organizational Structure.....	9
Description of Service Area.....	9
Purpose of Report.....	9-10
Breast Cancer Impact in Tulsa County	11
Methodology.....	11
Overview of Service Area.....	12
Communities of Interest.....	12
Conclusions.....	15
Health Systems Analysis of Target Communities	16
Overview of Continuum of Care.....	16-17
Methodology.....	17-18
Overview of Community Assets.....	18
Legislative Issues in Target Communities.....	18-19
Key Informant Findings.....	19-20
Conclusions.....	21
Breast Cancer Perspectives in Target Communities	21
Methodology.....	21-22
Review of Qualitative Findings.....	22-23
Conclusions.....	23-24
Conclusions: What We Learned, What We Will Do	24
Review of Findings.....	24-25
Conclusions.....	25-26
Action Plan.....	26

Executive Summary

Introduction

Susan G. Komen for the Cure® began as a promise built on the love between Nancy G. Brinker for her dying sister, Susan G. Komen. Nancy promised Susan she would do everything in her power to end breast cancer forever. In 1982 that promise became a reality when Susan G. Komen for the Cure was born. Just 29 years later, it is the world's largest grassroots network of breast cancer survivors and activists fighting to bring Nancy's promise to fruition...to end breast cancer forever.

The Tulsa Affiliate of Susan G. Komen for the Cure was launched in 1997 with Tulsa's first Race for the Cure®. During that first year, \$71,655 was granted to local organizations dedicated to breast health and breast services for the underserved women in Tulsa County Oklahoma. In addition, \$25,551 was granted to fund scientific research. Over the past 14 years the Komen Tulsa Affiliate has grown considerably and in 2010, \$1,100,000 was raised by the Komen Tulsa Race and other fundraising events. Up to 75 percent of the funds raised stay in Tulsa County to fund education, screening and treatment programs and 25 percent is invested in scientific research. Since 1997 the Tulsa Affiliate has granted over \$4 million to local and national organizations in the fight to end breast cancer. Through the Affiliate's funding of community programs in Tulsa County, thousands of women have received mammograms at low or no cost. Komen Tulsa also develops and implements breast health awareness programs for corporations and faith-based organizations. Through these programs women are called to action by educating them on the importance of knowing their bodies and family history, doing the appropriate screening and making healthy lifestyle choices.

The promise of Susan G. Komen for the Cure is to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to find the cures. To better maximize our ability to fulfill this promise, the Komen Tulsa Affiliate conducts a needs assessment every 2 years to assess the breast health needs of women in Tulsa County. This Community Profile determines priorities which direct Komen's work and identifies where efforts and resources will have the most impact within Tulsa County.

In order to accomplish the 2011 Community Profile report, the Community Profile team focused on three main areas. First and foremost, a thorough review of Tulsa County's demographics and breast cancer statistics was conducted in order to find correlations between diagnoses and death rate from breast cancer within the county. The statistical significance of this analysis led the team to identify key target groups based on age, race and ethnicity. Next the team reviewed the breast health system within the Tulsa Affiliate's service area. In this section of the report, conclusions were reached regarding the gaps, needs and barriers faced by women in Tulsa County concerning breast health. The final component of the report focused on data collected from women within the community in relation to their breast cancer understanding, potential barriers to breast health services and education and outreach programs.

Statistics and Demographic Review

A thorough review of Tulsa County's demographic and breast cancer statistics was conducted through the use of many different databases. The four most commonly used sources were: Oklahoma State Department of Health – Ok2Share Database of Vital Statistics; U.S. Census Bureau; Henry J. Kaiser Family Foundation's State Health Facts; and Thomson Reuters © 2007.

The Komen Tulsa Affiliate service area consists of Tulsa County, a predominantly white, fairly affluent urban county. According to Thomson Reuters, approximately 315,765 women resided in the county in 2009 of those, 70% were White, 11.9% were African American, 4.7% were American Indian, 1.8% were Asian, and 3.3% were of other race. Non-exclusive to race categories, the data includes 8.2% who were of Hispanic ethnicity. An analysis of the Thomson Reuters data indicated that age distribution varied by racial/ethnic groups. For instance, Hispanic women are the youngest racial/ethnic group (42% are under 19 years of age) and White women are the oldest racial/ethnic group (52.7% were 40 years and older). For those females aged 18-64 in Tulsa County, Thomson Reuters reported approximately 19.6% (37,640) were estimated to be uninsured in 2009. By cross referencing data available through the Kaiser Family Foundation, it was found that the percentage of uninsured persons in Tulsa County is higher than the national average and significantly higher than top performing states in health care coverage.

With regards to breast health, Ok2Share data indicated from 2003-2007, 2,553 individuals in Tulsa County were diagnosed with breast cancer, and 461 women died from the disease. Thomson Reuters estimated 999 women were living with breast cancer in Tulsa County in 2009. According to the most recent data available from the Kaiser Family Foundation, Tulsa County's breast cancer incidence and mortality rates are higher than the state and national averages. According to the CDC the age-adjusted breast cancer incidence rate for Tulsa County from 2003-2007 was 163.3 women per 100,000, the state of Oklahoma was 151.9 women per 100,000 and the nation was 120.5 per 100,000. Of the female population, OK2Share shows the highest breast cancer incidence and mortality rates were among White, American Indian and African American women. African American women had higher age-adjusted mortality rates than the state and national averages, reports Ok2Share. Another point to note is African American women in Tulsa County have a lower incidence rate in all age groups, but a much higher mortality rate than other races reported by Ok2Share. This lower incidence rate and a trend toward diagnosis at later stages may indicate a shortfall in screening and early detection in African American women.

One of the key factors in surviving breast cancer is early detection. According to Thomson Reuters, 64.4% of women were diagnosed in Stage I; 27.6% in Stage II; 3.5% in Stage III; and 4.5% in Stage IV during 2009. African American women have the highest percentage of late stage (Stage III or IV) diagnoses, which is approximately, double that of Whites and combined other races reports OK2Share. Also, later stage diagnosis trends in American Indian women, in combination with high incidence rates, would suggest an increased underlying risk factor exists for this population. In addition to clinical screening, increased emphasis on behavioral and environmental risk factor screening could be beneficial for this population.

Mammography rates are difficult to qualify due to the fact that the percentage is based on self reporting. However, Thomson Reuters estimated 37.3% of women age 40 and older in Tulsa

County reported they did not have a mammogram within the past 12 months. The most frequent reasons cited were “other reasons” and “didn’t have time.”

The breast cancer statistics for Tulsa County indicate that resources need to be focused on the African American population. With the highest late stage diagnosis rate and the highest mortality rates in the County, special attention needs to be directed to educate, encourage and activate African American women to proactively take charge of their breast health.

Health Systems Analysis

In order to evaluate the systems currently in place in Tulsa County a discussion group was held with key informants from medical organizations within the community. The health care providers agree there are multiple obstacles facing women regarding breast health services, which include a mindset that “going to the doctor means you are sick” and a “survival mentality” among lower-income women who are trying to meet their day-to-day needs. Also there is a general lack of knowledge and education regarding preventive health care. With further discussion it was uncovered that a cultural issue facing women in Tulsa County is a fear of knowing something might be wrong. Having watched friends or family go through breast cancer, women have been paralyzed by fear and are not interested in going through treatment themselves. As a result, they do not seek medical attention because they “do not want to know”. A second cultural barrier is women tend to be too busy taking care of everyone else and do not stop to take care of themselves until it is too late.

All of the barriers mentioned during the key informant focus group led the Komen Tulsa Affiliate to realize there is a huge gap in simply getting a woman into the continuum of care not to mention keeping her there. A larger focus by the Tulsa Affiliate needs to be placed on cultivating partnerships with safety-net health care organizations who can reach the women most at risk in the community. Part of the Affiliate’s involvement in the community needs to be mobilizing women to take action. Many of the key informants mentioned that at their respected facilities patient navigators are going above and beyond to get women into the continuum of care but are finding very little success. The lack of getting the at-risk women in the door for screening is resulting in higher late stage diagnoses and ultimately higher mortality rates.

Qualitative Data Overview

In order to assess the state of breast health through the eyes of the community a community focus group was held with African American women, including breast cancer survivors from Tulsa County. The participants were encouraged to discuss openly their thought and experiences regarding breast health. The key finding from this focus group encompassed education. Women need more comprehensive education to raise their awareness about breast cancer and breast health, in lieu of facts. Komen Tulsa is working diligently with grantees within the community to spearhead a more inclusive education platform for breast health. The goal of this collective effort is to get every woman into the continuum of care by way of knowledge.

Although much information was gleaned from the key informants and focus groups and valuable insight into the needs of the at-risk women in the Tulsa community was gathered there were

limitations to having such a small sampling. The Tulsa Affiliate was unable to reach out to and speak directly with the women most at risk in the community the information and stories shared were from second hand experience. Even though there were limitations with a smaller sampling Komen Tulsa was able to see the correlation between what the key informants and focus group members shared in relation to the data obtained through research.

Conclusion

Findings through the data, key informants and focus group participants indicated that gaps in the continuum of care need to be minimized. Stronger partnerships need to be forged not only with current grantees but also community leaders and safety-net health care organizations (those organizations focused on the at-risk population). For gaps in the continuum of care to be reduced more focus by current grantees needs to be placed on Breast Self Awareness messaging (BSA)

The second theme in Tulsa County pertains to the success of Komen Tulsa's education initiatives. Current education efforts focused on the African American community need to be more comprehensive and direct. The education approach needs to be a call to action for the African American women in Tulsa County rather than simply an awareness message. The Tulsa Affiliate will develop partnerships within the community to encourage and activate African American women in Tulsa County to take a proactive role in their breast health.

The Komen Tulsa board of directors will incorporate the following priorities into the Affiliate's strategic plan and identify tasks and timelines for accomplishing the objectives.

Priority 1

Partner with grantees, community leaders and safety-net health care organizations in Tulsa County to fill the gaps in the continuum of care.

Objective 1

In 2011, Komen Tulsa will begin transitioning grantees to Breast Self Awareness messaging in all awareness and education programs. Beginning in April 2012, 100% of grantees will use BSA messaging.

Objective 2

Of the grantees chosen for 2012 funding, at least 50% will have a priority and/or goal of addressing the breast health needs of African American women.

Action Plan

- a) 100% participation by Komen Tulsa Grantees in annual grant writing workshops.
- b) In 2011 monthly phone conversations conducted with each Komen Tulsa Grantee encouraging the use of Komen material containing BSA messaging in their awareness and education programs.
- c) Identify 2 new potential grant applicants who provide programs designed to address the breast health needs of African American women.

Priority 2

Develop partnerships that encourage and activate African American women in Tulsa County to take a proactive role in their breast health.

Objective 1

By March 2012, identify and establish two new partnerships with African American organizations that will educate young women on Breast Self Awareness messaging.

Objective 2

Develop a faith-based network that includes 10 African American churches who will serve as a distribution point for breast health information by October 2011.

Action Plan

- a) Work with Links through their Knowledge is Power program to identify appropriate avenues to reach young African American women.
- b) Networking through our current Ambassadors to develop relationships with the First Ladies of 10 African American churches in order to grow their commitment to breast health.

Introduction

Affiliate History

Susan G. Komen for the Cure® began as a promise built on the love between Nancy G. Brinker for her dying sister, Susan G. Komen. Nancy promised Susan she would do everything in her power to end breast cancer forever. In 1982 that promise became a reality when Susan G. Komen for the Cure was born. Just 29 years later, it is the world's largest grassroots network of breast cancer survivors and activists fighting to bring Nancy's promise to fruition...to end breast cancer forever.

The Tulsa Affiliate of Susan G. Komen for the Cure was launched in 1997 with Tulsa's first Race for the Cure®. During that first year, \$71,655 was granted to local organizations dedicated to providing breast health and breast cancer services for the underserved women in Tulsa County, Oklahoma. In addition, \$25,551 was granted to fund scientific research. Over the past 14 years the Komen Tulsa Affiliate has grown considerably and in 2010, \$1,100,000 was raised by the Komen Tulsa Race and other fundraising events. Up to 75 percent of the funds raised stay in Tulsa County to fund education, screening and treatment programs and 25 percent is invested in scientific research. Since 1997 the Tulsa Affiliate has granted over \$4 million to local and national organizations in the fight to end breast cancer. Through the Affiliate's funding of community programs in Tulsa County, thousands of women have received mammograms at low or no cost. Komen Tulsa also develops and implements breast health awareness programs for corporations and faith-based organizations. These programs are meant to call women to action by promoting positive breast health and annual clinical breast exams and mammography.

Organizational Structure

The Tulsa Affiliate of Susan G. Komen for the Cure is a nonprofit 501(c)(3) corporation managed by an executive director and staffed by three full-time coordinators who report to a 15-member Affiliate working board of directors. This grassroots organization relies on community activists and partnerships to address the breast cancer needs in our service area.

Description of Service Area

Komen Tulsa's service area encompasses Tulsa County, which had a population of approximately 601,961 individuals in 2009 with 51% being female, according to the U.S. Census Bureau. Whites make up the majority of the population and are the oldest and Hispanics have the youngest population. Tulsa County is fairly affluent with a median income of \$46,857; however, a pocket (13.6%) of households are below the poverty level. According to Thomson Reuters, 19.6% of the females between 18 and 64 in Tulsa County are estimated to be uninsured.

Purpose of Report

The Promise of Susan G. Komen for the Cure is to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to find the cures. To better maximize our ability to fulfill this promise, the Komen Tulsa Affiliate conducts a

Community Profile every two years to assess the breast health needs of women in Tulsa County. The results of this profile direct Komen's work and identify where efforts and resources will have the most impact within Tulsa County. The analysis of data, programs, gaps and needs for this report was conducted by a team of people noted on the Acknowledgements Page and was completed in March, 2011.

In order to accomplish the 2011 report, the Community Profile team focused on three main areas. First and foremost, a thorough review of Tulsa County's demographics and breast cancer statistics was conducted in order to find correlations between diagnoses and death rate from breast cancer within the county. The statistical significance of this analysis led the team to identify key target groups based on age, race and ethnicity. Next the team reviewed the breast health system within the Tulsa Affiliate's service area. In this section of the report, conclusions were reached regarding the gaps, needs and barriers faced by women in Tulsa County concerning breast health. The final component of the report focused on data collected from women within the community in relation to their breast cancer understanding, potential barriers to breast health services and education and outreach programs.

The data for this report was reviewed with the utilization of the resources cited on the next page.

Breast Cancer Impact in Tulsa County

Methodology

A thorough review of Tulsa County's demographic and breast cancer statistics was conducted through the use of multiple databases. The four most commonly used sources were: Oklahoma State Department of Health – Ok2Share Database of Vital Statistics; U.S. Census Bureau; Henry J. Kaiser Family Foundation's State Health Facts; and Thomson Reuters ©2007. While the citations below indicate 2011 documentation we were unable to access data more recent than 2009 from these sources. 2011 census data and state cancer data had not been updated and were unavailable for this report.

U.S. Census Bureau (State & County QuickFacts) ©2011 – Decennial census based on actual counts of persons dwelling in U.S. residential structures.

Oklahoma State Department of Health ©2011 – Oklahoma Central Cancer Registry (OCCR) – Cancer Registry of all cases of cancer from all causes in Oklahoma, ICD-10 code compliant. OCCR data was used to obtain breast cancer incidence data by age, race/ethnicity, and stage at diagnosis at the county and state level for 2000-2005.

Oklahoma State Department of Health – Ok2Share Database of Vital Statistics ©2011 – Vital statistics registry of births, deaths, and other vital statistic initiatives in Oklahoma, 2003-2007.

National Cancer Institute ©2011 – Surveillance, Epidemiology and End Results Program (SEER) – A premier source for cancer statistics in the United States representing 26 percent of the U.S. population with information on incidence, survival, and prevalence.

American Cancer Society ©2011 – Statistical tracking of cancer occurrence, including the number of deaths, cases, and how long people survive after diagnosis. ACS also tracks data regarding behaviors that influence the risk of developing cancer and the use of screening tests.

Thomson Reuters © 2009: Susan G. Komen Data Pack (SGK) – An independent analysis of demographic and vital statistics specific to breast cancer in geographic populations.

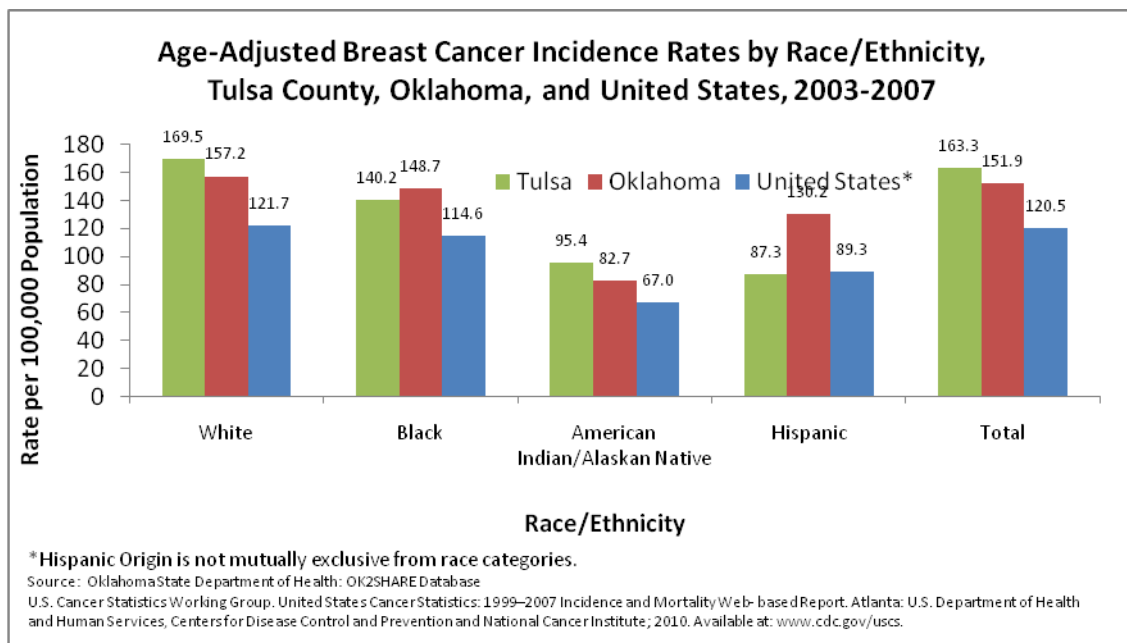
Center for Disease Control and Prevention – National Program of Cancer Registries (NPCR) ©2011 – Provides data collected by state cancer registries that enable public health professionals to understand and address the cancer burden more effectively.

The Henry J. Kaiser Family Foundation: State Health Facts ©2011 – a non-profit, private operating foundation focusing on major health care issues facing the nation.

Overview of Service Area

The Komen Tulsa Affiliate service area consists of Tulsa County, a predominantly white, fairly affluent urban county. According to Thomson Reuters, approximately 315,765 women resided in the county in 2009 of those, 70% were White, 11.9% were African American, 4.7% were American Indian, 1.8% were Asian and 3.3% were of other races. Non-exclusive to race categories, the data includes 8.2% who were of Hispanic ethnicity. The largest proportion for all races/ethnicities was in the 0-19 year old age group. Age distribution varied by racial/ethnic group, such that Hispanic women were the youngest (42% under 19 years of age) and White women were the oldest (52.7% were 40 years of age) reported Thomson Reuters. An estimated 601,961 people lived in Tulsa County during 2009 according to the US Census Bureau. The estimated median income for the county was \$46,857 and 13.6% of the people lived below the poverty line. In addition to poverty Thomson Reuters reported that 19.6% of the females in Tulsa County, age 18-64, did not have health insurance.

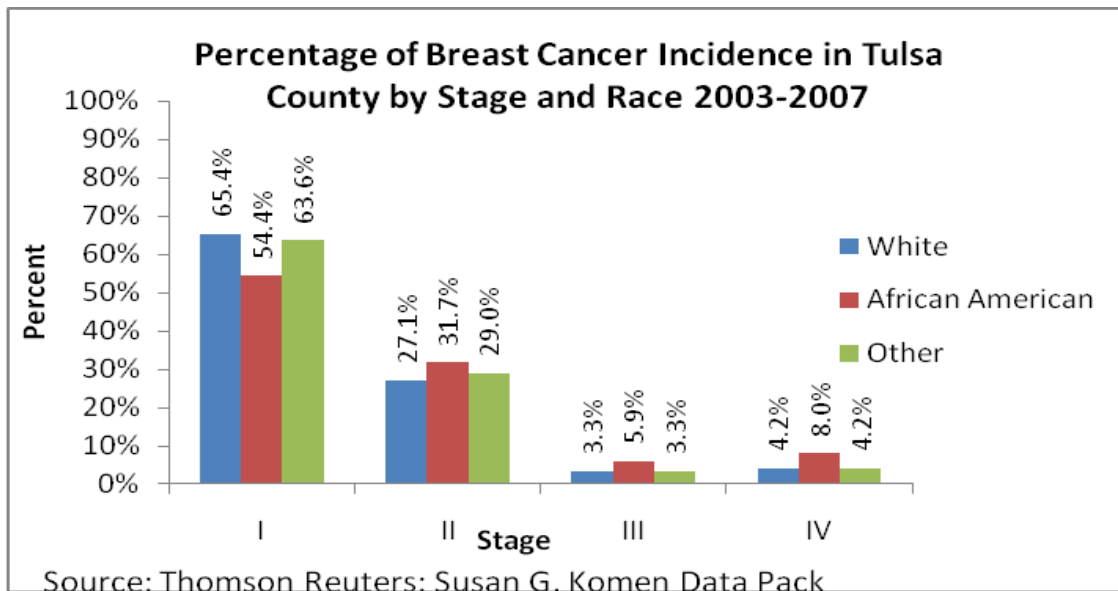
With regards to breast cancer, the incidence is defined as the number of new cases within a population divided by the number of individuals within that population per year. In figures where comparisons are made between different populations, age adjusting allows for meaningful comparisons across groups with different age compositions. According to the CDC the age-adjusted incidence rate for all Tulsa County between 2003 and 2007 (163.3 per 100,000) was higher than the state of Oklahoma, (151.9 per 100,000) and the nation (120.5 per 100,000). The graph below compares Tulsa County's incidence rates by race and ethnicity with the state and U.S. rates.



Breast cancer stage of diagnosis is an important predictor of survival. Women who are diagnosed in less advanced stages are less likely to die from the disease than women who are diagnosed in more advanced stages. Thomson Reuters reported that between 2003 and 2007 there were 2,553

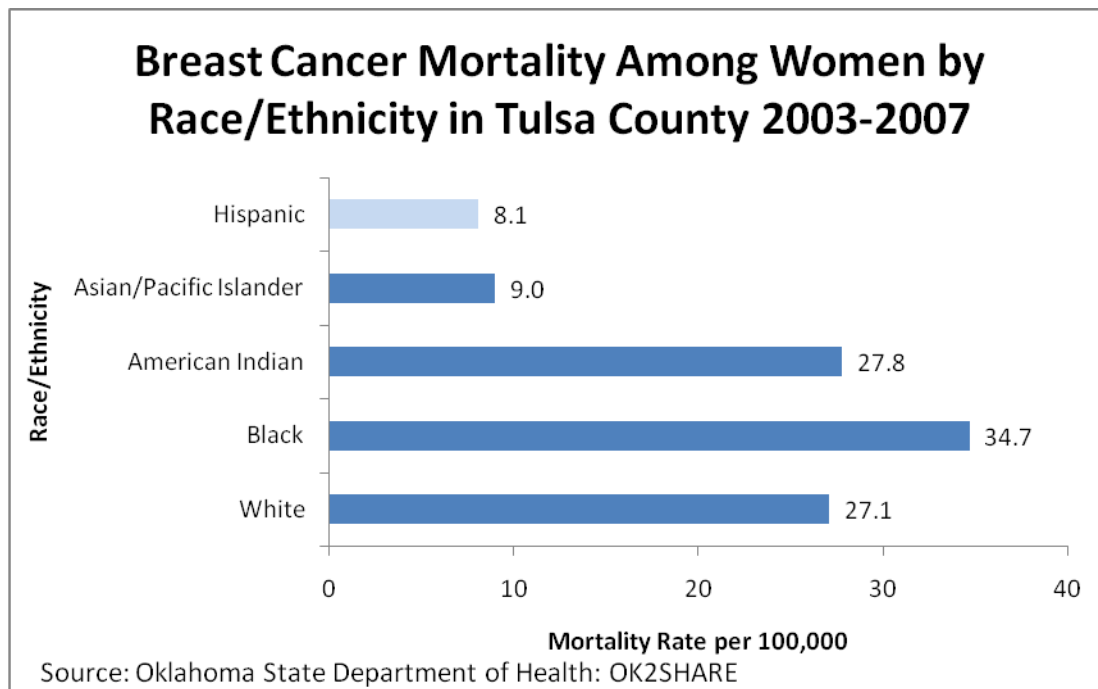
incidences of breast cancer. According to Thomson Reuters in 2009, 64.4% of women were diagnosed in Stage I, 27.6% in Stage II, 3.5% in Stage III, and 4.5% in Stage IV.

African American women have the highest percentage presenting with initial diagnosis at late stages (III and IV), approximately double that of White and combined other races reports Thomson Reuters. Behavioral and environmental risk factor screening, in addition to clinical screening, would be beneficial in all breast cancer cases. However evidence here indicates that increased emphasis of screening could be particularly beneficial for this population.



Breast cancer mortality is defined as the number of deaths due to breast cancer divided by the number of individuals within that population per year. In figures where comparisons are made between different populations, age adjusting allows for meaningful comparisons across groups with different age compositions. The most recent data available from OK2Share reported that from 2003-2007 there were 457 confirmed deaths from breast cancer in Tulsa County, an age-adjusted mortality rate of 27.5 deaths per 100,000 females. Mortality from breast cancer, as expected, is highest in the oldest age groups.

Of emphasis, African American women had a high mortality rate from breast cancer in Tulsa County. In consideration of the higher mortality rate and trends toward diagnosis at later stages, this may indeed indicate a shortfall in screening and early detection in African American women.



The goal of screening for breast cancer by mammography is to improve survival through early identification of disease. Mammography rates are difficult to qualify due to the fact the percentage is based on self reporting. That said, Thomson Reuters shows an estimated 37.3% of women age 40 and older in Tulsa County did not have a mammogram within the past 12 months. The most frequent reasons cited were “other reasons” and “didn’t have time”.

Communities of Interest

Through data analysis we have seen that incidence rates are highest among White women who comprise 70% of the population according to the U.S. Census Bureau. OK2Share reports African Americans make up the largest minority race at 11.9% of the total population, and reside primarily in the city of Tulsa. Two neighborhoods north of downtown can be considered racially isolated because three-fourths or more of their residents are African American. Racial isolation within neighborhoods increases the likelihood of disparities in health and quality of life. This disparity in health is also related to breast health as OK2Share reported African American women in Tulsa County have a higher mortality rate than the state and national averages.

The U.S. Census Bureau shows that nearly 33% of the African American population lives below the poverty level, a rate almost three times that of the White population. The highest percentage of people living below poverty was in downtown Tulsa, where there are a number of shelters. The next highest were generally the neighborhoods with the highest percentage of African American residents, north of downtown. The unemployment rate is highest in the northwestern part of Tulsa. With a low unemployment rate the area of Tulsa County north of downtown was home to the largest number of Medicaid enrollees. Lack of income and lack of health insurance are two factors contributing to African American women having the highest percentage of late stage (Stage III or IV) diagnoses, approximately double that of White and combined other races,

due to the fact they are not able to get into the continuum of care early enough to have their lives saved.

Conclusions

The Komen Tulsa Affiliate service area contains only one county however; breast cancer statistics for Tulsa County indicates distinct differences among certain demographic and geographic groups for breast cancer incidence, late stage diagnoses and cancer mortality. It became immediately evident that resources need to be focused on the African American population. With the highest late stage diagnosis rate and the highest mortality rates in the County, special attention needs to be directed to educate African American women and help them understand the correlation between early detection and survival. In addition an emphasis needs to be placed on screening as the key to early detection.

Health Systems Analysis of Tulsa County

Overview of Continuum of Care

The Continuum of Care is the manner by which the Komen Tulsa Affiliate gauges how a woman typically moves through the health care system. It is critical that all women enter the Continuum of Care for screening and if necessary receives diagnostic tests, treatment and as a result of treatment, follow up care.

Komen Tulsa is working on ways to better maximize the Continuum of Care by utilizing partnerships with health care service providers, in order to assess the state of breast health programs and services in Tulsa County. As noted earlier in this report, the targeted community is African American women due to late stage diagnosis and high mortality rates. The geographic locations for these groups have been identified and we know the number of physicians practicing in the areas where health care is needed most, mainly north and west Tulsa is not sufficient for the population. In addition, the mobile mammography van used to provide services to the County and its underserved women was shutdown. All of these factors cause gaps in the Continuum of Care and result in women falling out of the continuum.

Helping to address these gaps and provide medical options for the uninsured in Tulsa County, are free clinics, mobile clinics and medical facilities that offer outpatient services. In October, 2010, Morton Comprehensive Health Center, located in north Tulsa, began providing screening mammograms to uninsured, low-income women from the targeted communities in Tulsa County. Free clinics, such as Xavier, Good Samaritan, Bedlam and Dream Center are physically located or highly accessible through a mobile unit to low-income, uninsured Tulsans making it convenient for citizens to have their basic medical needs met. All of these clinics serve minority uninsured and Medicaid patients and they are staffed with volunteer physicians and nurses. They conduct clinical breast exams but refer out mammography to Oklahoma Project Women who utilizes their partnerships with breast health care institutions to provide no-cost or low-cost mammograms. In addition, the Tulsa Affiliate created a Breast Health Directory as a helpful resource to those low-income, uninsured women who are unaware that breast health services

exist. The Breast Health Directories can be found at local libraries, salons, Laundromats and doctors offices.

There are medical options for the uninsured in Tulsa County through free clinics, mobile clinics and medical facilities that offer outpatient services. The free clinics, such as Xavier, Good Samaritan, Bedlam, and Dream Center are physically located or through a mobile unit highly accessible, to the low-income uninsured Tulsans making it convenient for citizens to have their basic medical needs met. All of these clinics serve minority, uninsured and Medicaid patients. Many are staffed with volunteer physicians and nurses. They conduct clinical breast exams but refer out mammography to Oklahoma Project Woman who utilizes their partnerships with breast health care institutions to provide no-cost, mammograms. In addition to the free clinics available to the low-income and uninsured the Tulsa Affiliate created a Breast Health Directory as a helpful resource to those who are unaware that breast health services exist.

Programs and services that are lacking and keeping women from accessing the continuum of care include:

- Full-service medical facilities and physicians in geographically convenient locations.
- Mobile mammography vans in combination with mobile clinics to bring mammography services to underserved women in their own neighborhood
- Transportation to the mammography centers

Methodology

In order to evaluate the systems currently in place in Tulsa County a discussion group was held with key informants from medical organizations within the community. As the Komen Tulsa staff began the search for ideal participants for the key informant discussion group they reached out to breast centers, grantees, hospitals and board members that were located in or familiar with the area of Tulsa County most at risk. A small sampling from Breast Health Navigators to diagnostic specialists to health department employees volunteered their time to sit down in a round table discussion to focus their attention on the state of breast cancer in Tulsa.

More representation from the diagnostic and treatment aspects from the continuum of care could have added value to the discussion regarding barriers and mindsets of women in our target communities.

Overview of Community Assets

The promise of Susan G. Komen for the Cure is to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to find the cures. One of the most important ways the Komen Tulsa Affiliate works to reach this goal is through the funding of quality community programs that address the breast health and breast cancer needs of our community.

The Affiliate's grant review process is based upon the peer-review formula that is used by Susan G. Komen for the Cure® and Research Grant Program; it is also recognized by the National Cancer Institute (NCI). The grant approval process is comprehensive and includes an analysis of

the applicant's impact on breast cancer disparities, the feasibility of achieving objectives, the capacity of the organization to carry out their program, and the sustainability of a long-term impact. The 2010-2011 grantees are Indian Health Care Resource Center, Morton Comprehensive Health Services, Tulsa Project Woman, Inc. and Y-Me Breast Cancer Organization.

Indian Health Care Resource Center with funding provided by Komen Tulsa will continue operations of its breast cancer screening and education programs for Native American women. For 2011-2012, their goal is to provide baseline and screening mammograms to 1,200 uninsured, low- and moderate-income Native American women. They also intend to provide clinical breast exams and educational instruction on how to conduct a self-breast exam to 1,650 Native American women, ages 20-64. They have successfully promoted the message that "Knowledge is Power" by encouraging women to bring a friend, mother, daughter or sister when they make their annual mammogram appointment. Supporting the development of social "buddy" networks helps overcome patient fears and strengthens the ability of patients to receive information and solve problems.

Morton Comprehensive Health Center is committed to women's health; this is reflected in the recent addition of two part-time midwives, one family practice doctor and the acquisition of a mammography machine. Through granting from Komen Tulsa, Morton will be able to provide complete components to their circle of care program for breast health to at-risk African American and Hispanic women who have cultural and economic barriers, preventing them from seeking primary and preventative breast health screenings. The circle of care program encompasses outreach, education and awareness, free breast examinations, transportation to mammography appointments, and assists women with paperwork to access in-hospital services. Morton currently refers patients to another Komen Tulsa grantee, Tulsa Project Woman for mammography.

Tulsa Project Woman, Inc., (TPW) offers a comprehensive program providing free breast health education, mammography, diagnostic procedures and surgical services for women with no health insurance and limited financial resources. The organization fills a unique niche in the community by integrating a breast health education program with a comprehensive clinical program. Through funding provided by Komen Tulsa, TPW is able to ensure an individual can attend a Breast Health Education class and learn about proper breast health care and then move seamlessly into an appointment for a Clinical Breast Exam, a free mammogram and if necessary a diagnostic procedure and/or surgery.

Y-Me Breast Cancer Organization (Y-Me) provides ongoing emotional support and information for those touched by breast cancer within Tulsa County. With funding provided by Komen Tulsa Y-Me will offer three monthly support groups with trained facilitators and at least four Open Door programs to provide the public and breast cancer survivors with opportunities to hear from speakers on important breast cancer topics. Y-Me is focused on strengthening its presence in the African-American community by facilitating at least two Open Door programs and meeting with new contacts within the community each month. Their main focus is to help move individuals through the breast cancer Continuum of Care cycle.

The Community Profile assessment revealed aspects of the Continuum of Care which do not exist within critical areas in Tulsa County. Women are falling out of the continuum based on financial, transportation, geographical and cultural factors. The Tulsa Affiliate is seeking opportunities to fund grants related to breast health and breast cancer in order to address these barriers and to keep all women in the Continuum of Care.

Komen Tulsa, along with those who generously support the Affiliate with their talent, time and resources, are working to better the lives of those facing breast cancer in our community. There are many partnerships and programs in the Tulsa community that do not meet the requirements needed to obtain a large grant. However these partnerships and programs are as equally as important to eradicating breast cancer. As a result the Komen Tulsa Affiliate offers small grants up to \$5,000 to support education projects, conference and travel scholarships related to breast health and breast cancer.

According to the National Cancer Institute, “although age-adjusted breast cancer rates are higher in white women than in black women, mortality rates are higher in black women”. Several explanations for these findings have been proposed, including lower socioeconomic status, lower level of education, and less access to screening and treatment services. Population-based studies demonstrate that, compared with other groups, Medicaid recipients and uninsured patients of all races have later-stage breast cancer diagnosis, and survival from the time of diagnosis is shorter. This difference is associated with socioeconomic status and may reflect lack of participation in screening activities.

Research provided by the National Cancer Institute’s Research-tested Intervention Programs (RTIPs) shows key evidence-based programs that have the potential to positively impact the underserved women in Tulsa County. RTIPs describe evidence-based cancer prevention and control programs that have been implemented in community or clinical settings for specific populations, were developed and tested by researchers, include free program materials that can be previewed, downloaded or ordered on CD-ROM, and include program materials that can be previewed and ordered directly from the developer. RTIPs include only programs that meet the following criteria: were developed and tested through a peer-reviewed research grant, research findings were published in a peer-reviewed journal, and include messages, materials and other intervention components that can be used in community or clinical settings.

Examples of these RTIPs programs are “Prevention Care Management”, “Maximizing Mammography Participation”, “Reducing Barriers to the Use of Breast Cancer Screening”, “Breast Cancer Screening Among Non-adherent Women” and the “Witness Project”. “Prevention Care Management” is designed to increase cancer screening among medically underserved women through awareness building and behavior modification. “Maximizing Mammography Participation” is designed to increase breast cancer screening by encouraging women to schedule and keep mammography appointments for un- and under-screened individuals. “Reducing Barriers to the Use of Breast Cancer Screening” involves physician intervention aims to increase the breast cancer screening practices of community-based physicians. “Breast Cancer Screening Among Non-adherent Women” is designed to address barriers to mammography screening and to identify strategies for motivating women to have regular mammograms. “The Witness Project” is a community-based program designed to

increase breast cancer screening and promote the practice of mammography among underserved African American women.

Legislative Issues in Target Communities

Health insurance coverage is a critical factor in making health care accessible to women. Women with health coverage are more likely to obtain needed preventive, primary, and specialty care services, and have better access to many of the new advances in women's health.

Uninsured women are more likely to lack adequate access to care, get a lower standard of care when they are in the health system, and have poorer health outcomes. They are more likely to postpone care and often delay or go without important preventive care such as mammograms.

Medicaid is an option for many uninsured women who do not have access to employer-sponsored plans, or cannot afford individual policies. Medicaid covers a broad range of services that are important for women including Pap smears and mammograms. In recent years, states have expanded Medicaid eligibility to assist certain low-income uninsured women with the costs of breast and cervical cancer treatment called the "Breast and Cervical Cancer Early Detection Program" (BCCEDP) but these programs are in jeopardy of budget cuts. If programs are cut, women have nowhere else to go, leading to later diagnoses, larger tumors and lower survival rates. When breast cancer is detected at later stages, treatment becomes more expensive, putting greater pressure on state and federal budgets down the road.

Susan G. Komen for the Cure is leading the fight nationwide to protect this vital program. The Tulsa Affiliate has built relationships with Oklahoma's elected officials at all levels to ensure there is continued funding of the state's BCCEDP program. Starting in 2011 our advocacy efforts will need to be diligent to ensure that program funding is preserved within the state budget.

As the debate on health care reform continues, Susan G. Komen for the Cure and the Tulsa Affiliate will seek inclusion of the following points:

- Protect cancer patients who have health insurance from excessive out-of-pocket costs that may lead to severe financial hardship and even bankruptcy.
- Ensure access to affordable, high-quality health insurance for all, including people with "pre-existing" conditions like cancer – so everyone can have health insurance, even if they lose or change jobs.
- Enhance the quality and value of health care by focusing on prevention, wellness and chronic disease management.
- Address the chronic shortage of cancer care specialists, particularly in underserved areas.

To improve access to screening, Congress passed the Breast and Cervical Cancer Mortality Prevention Act of 1990 which guided the Centers for Disease Control (CDC) in creating the NBCCEDP. The program helps low-income, uninsured, and underinsured women gain access to breast and cervical cancer screening and diagnostic services. In 2000, Congress passed the Breast and Cervical cancer Prevention and Treatment Act which gives states the option to offer

women in the NBCCEDP access to treatment through Medicaid. To date, all 50 states and the District of Columbia have approved this Medicaid option.

Take Charge! is Oklahoma's Breast and Cervical Cancer Early Detection program which is provided through a grant from the Centers for Disease Control and Prevention. The mission of Take Charge! is to provide women with information and access to screening services in order to reduce morbidity and mortality from breast and cervical cancer.

Oklahoma women get access to Medicaid for breast/cervical cancer treatment by meeting the guidelines of the program and going through a certified screener. The basic guidelines for the program include: Oklahoma resident, woman, 185% of current federal poverty level, no insurance, US citizen or qualified alien with an abnormal breast and/or cervical finding that needs further diagnostic or treatment. To find out if a woman is eligible and to locate a certified screener, she should call 866-550-5585.

The number of women age 50-65 at or below 185% of poverty level who are eligible for Take Charge! services is approximately 33,782. This number is an estimate based on BRFSS data that changes very little from year to year. In FY'10, over 5,000 screening mammograms and over 6,500 clinical breast exams were provided.

The working relationship between the state screening program and Medicaid is very strong. There are five agencies that make the Oklahoma Cares program work. OSDH, OHCA, DHS, Kaw Nation BCCEDP, and Cherokee Nation BCCEDP. The five agencies worked together to design and implement the program and the team works together to evaluate the program and to suggest policy changes.

Komen Tulsa has built relationships with members of the Oklahoma State Department of Health (OSDH) in order to better work together to fill the needs of the underserved women in Tulsa County. Our plan is to partner with the OSDH to ensure they have all the resources they need to provide the best access to care and fill the needs of the underserved women in Tulsa County.

In 2009 the Tulsa Affiliate's Executive Director was appointed to the BCCEDP program's advisory committee. This appointment allows Komen Tulsa to partner with other breast cancer advocates and organizations and provide valued input for program decision-making and future direction.

Key Informant Findings

The health care providers agree there are multiple obstacles facing women regarding breast health services, which include a mindset that "going to the doctor means you are sick" and a "survival mentality" among lower-income women who are trying to meet their day-to-day needs. Also there is a general lack of knowledge and education regarding preventive health care. With further discussion it was uncovered that a cultural issue facing African American women in Tulsa County is a fear of knowing something might be wrong. Having watched friends or family go through breast cancer, women have been paralyzed by fear and are not interested in going through treatment themselves. As a result, they do not seek medical attention because they "do

not want to know”. A second cultural barrier is women tend to be too busy taking care of everyone else and do not stop to take care of themselves until it is too late.

Conclusions

Many of the key informants mentioned that at their respected facilities patient navigators are going above and beyond to try to get women into the continuum of care but are finding very little success when the woman is not motivated to take action. The barriers mentioned during the key informant focus group led the Komen Tulsa Affiliate to realize there is a huge disconnect in simply getting a woman into the continuum of care not to mention keeping her there. A larger focus by the Tulsa Affiliate will be placed on cultivating partnerships with safety-net health care organizations who can reach the women most at risk in the community. These organizations are better prepared to service these women in a way to get them into the continuum of care, part of the Affiliate’s involvement with these organizations needs to be mobilizing women to take action through breast health education and awareness.

Breast Cancer Perspectives in Tulsa County

Methodology

A community focus group was held with African American women including breast cancer survivors from Tulsa County. Two months before the focus groups were to meet an email was sent out to volunteers, race participants and grantees asking for individuals interested in participating in a discussion group regarding their thoughts and feelings concerning the state of breast cancer in Tulsa County. One focus group of 7 participants from the African American community was held and dinner was served. The focus group was conducted in a discussion format led by the Tulsa Komen staff. This format proved to be advantageous in that it provided a platform for the participants to openly discuss their thoughts and experiences regarding breast health and the ease of moving through the continuum of care.

A discussion guide was developed for each session and covered key topics focused on the entire continuum of care. Topics ranged from where sources of education information for breast health can be found, frequency of self breast exams, mammography history and attitudes, mammography service providers, breast cancer diagnoses, ideas for encouraging women to seek regular breast health services, and what support groups were available. The group was facilitated by a Komen Tulsa employee and transcribed by additional Komen Tulsa personnel. The information obtained through the group was utilized for report writing purposes.

Review of Qualitative Findings

The need for education was echoed continuously through the focus group. Women need more comprehensive education to raise their awareness about breast cancer and breast health, in lieu of facts. Komen Tulsa is working diligently with grantees within the community to spearhead a more inclusive education platform for breast health. The goal of this collective effort is to get every woman into the continuum of care by way of knowledge. As the education discussion moved forward it was discovered that women in Tulsa County clearly require education

concerning breast health, but more specifically, information related to mammograms such as it may be uncomfortable but it is not painful. It was surprising to learn that many uncertainties and misinformation still remain regarding breast health – especially as the population ages. It was mentioned that physicians are advising patients that mammograms are no longer needed after a certain age or every five years after age 65. Learning that education provided to the younger generations may help them embrace a healthy concept of breast health was encouraging and has helped to focus the education efforts of Komen Tulsa and their grantee. Education, if provided at the right time can help prevent the younger generation from having the same attitudes as their parents and grandparents.

The majority of the focus group participants indicated that they receive information regarding breast health from their doctors as well as television ads, brochures and other women. They have found that not all of the doctors they see routinely conduct clinical breast exams with their well woman exam. It was found to be helpful when a mammography technician utilized a prototype breast to demonstrate breast self-exam so a woman will know what to look for and how to distinguish between lumps. Most of the women conduct breast self-exam but many do not do so regularly. T-shirts or other free items are an enticement for women to get an annual mammogram.

Conclusions

As the data from the key informants and the focus groups was reviewed a common thread appeared which was education. Education would not only provide the information women need to move into action of positive breast health, it will also help to break down some of the barriers the key informants saw as obstacles in getting women, especially at-risk women into the continuum of care. Many fears faced by uninsured, low-income women can be addressed by providing information on breast health services available to them through free clinics and other programs. In addition, utilizing Komen's BSA messaging to encourage women to know their risk and what is normal for them, to get screened and to make healthy lifestyle choices can begin to empower women to take responsibility for their breast health.

In order to address education needs, which will in turn prompt women to action, Komen Tulsa is working diligently to implement an Ambassador program that spans the scope of the Tulsa community. By definition an ambassador is an authorized messenger or representative. Komen Tulsa will seek ambassadors within different facets of the community to represent Komen's promise and mission. Faith-based Ambassadors, geared to our target community will lead the charge to reach out and educate women and men alike within their faith-based organizations regarding breast health and the importance of early detection. Community-based Ambassadors will work hand in hand with community and corporate leaders in order to organize a strategy that works within the community (schools, neighborhood associations, local businesses, Tulsa-based corporate offices, etc.) to not only build individual's awareness of breast cancer but to encourage them to take a proactive approach with their breast health. Medical-based Ambassadors will play a key role in the development and execution of a breast health coalition in order to address major needs in Tulsa County relating to mobile mammography, barriers to health care and gaps in the continuum of care.

What We Learned, What We Will Do

Review of the Findings

Breast cancer remains a large concern in Tulsa County just as it does globally. As the most recent data from the Kaiser Family Foundation showed, Tulsa County's breast cancer incidence and mortality rates are higher than the state and national averages. According to OK2Share, the highest incidence and mortality rates were among White, American Indian and African American women, with African American women showing higher age-adjusted mortality rates than the state and national averages. Also reported, the percentage of African American women being diagnosed in later stages (III or IV) is approximately double that of Whites and combined other races. This trend toward later-stage diagnosis combined with a higher mortality rate may indeed indicate a shortfall in screening and early detection in African American women in Tulsa County.

To understand reasons behind this shortfall, an analysis of Tulsa County's breast health continuum of care was conducted. This process identified multiple obstacles which contribute to a woman's lack of care, including cultural issues and accessibility of mammography services, as well as education. Another contributing factor is the geographic location of most low-income, uninsured African American women who reside where there is an insufficient number of physicians for the population and lack of facilities that provide mammography services.

While challenges exist, the greatest opportunity to address service gaps among African American women is through breast health and breast cancer education. Additional opportunities exist through Komen Tulsa's community grant dollars and partnerships with safety-net health care organizations with the goal of increasing screening rates by providing better accessibility to underserved women.

Conclusion

As Komen Tulsa looks to the future and what can be done to continue the journey in decreasing the mortality rate the gaps in the continuum of care need to be minimized. The partnership with current grantees needs to be strengthened and additional partnerships with safety-net health care organizations need to be forged. Strengthened and increased partnerships will bridge the gaps within the continuum of care and provide the accessibility for all women to enter the continuum and get the treatment they need without fall out.

In addition to developing stronger partnerships Komen Tulsa needs to continue to grow education initiatives. As brought to the attention of the Affiliate, education platforms need to be a motivating call to action not simply an awareness message. Utilizing Komen's BSA program to encourage women to know their risks and what is normal for them, get screened and to make healthy lifestyle choices will play a critical role in educating the at-risk women of Tulsa. In correlation with the BSA program, Komen Tulsa will implement an Ambassador program through churches, schools, neighborhood associations, local business and Tulsa-based corporations as a call to action education platform. These Ambassadors will be voices in the community sharing Komen's promise and mission.

With a large focus being placed on the African American community the Tulsa Affiliate will work to implement, in conjunction with the Ambassador program, the Witness Project. As explained earlier in this report, the Witness Project is not only about building awareness but more importantly about behavior modification resulting in increased screening rates. With the implementation of the Witness Project the desire is to see a new attitude towards the practice of mammography among the underserved African American women in Tulsa County.

Action Plan

The Tulsa Affiliate priorities for 2011-2012 are to:

- 1) Partner with grantees, community leaders and safety-net health care organizations in Tulsa County to fill the gaps in the continuum of care.
- 2) Develop partnerships that encourage and activate African American women in Tulsa County to take a proactive role in their breast health.

Priority 1

Partner with grantees, community leaders and safety-net health care organizations in Tulsa County to fill the gaps in the continuum of care.

Objective 1

In 2011, Komen Tulsa will begin transitioning grantees to Breast Self Awareness messaging in all awareness and education programs. Beginning in April 2012, 100% of grantees will use BSA messaging.

Objective 2

Of the grantees chosen for 2012 funding, at least 50% will have a priority and/or goal of addressing the breast health needs of African American women.

Goals

- a) 100% participation by Komen Tulsa Grantees in annual grant writing workshops.
- b) In 2011 monthly phone conversations conducted with each Komen Tulsa Grantee encouraging the use of Komen material containing BSA messaging in their awareness and education programs.
- c) Identify 2 new potential grant applicants who provide programs designed to address the breast health needs of African American women.

Priority 2

Develop partnerships that encourage and activate African American women in Tulsa County to take a proactive role in their breast health.

Objective 1

By March 2012, identify and establish two new partnerships with African American organizations that will educate young women on Breast Self Awareness messaging.

Objective 2

Develop a faith-based network that includes 10 African American churches who will serve as a distribution point for breast health information by October 2011.

Goals

- a) Work with Links through their Knowledge is Power program to identify appropriate avenues to reach young African American women.
- b) Networking through our current Ambassadors to develop relationships with the First Ladies of 10 African American churches in order to grow their commitment to breast health.