



COMMUNITY PROFILE REPORT

Tulsa Affiliate of Susan G. Komen for the Cure®



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, timelines, quality, efficacy or non-infringement of any of the programs, projects, materials, products or other information included or the companies or organizations referred to in this report.

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Executive Summary

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. In addition, \$25,551 was raised to fund scientific research. Over the past 14 years the Komen Tulsa Affiliate has grown considerably and in 2010, \$991,000 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 dedicated to scientific research. Since 1997 the Tulsa Affiliate has granted over \$4 million to local and national organizations in the fight to end breast cancer. Komen Tulsa also develops and implements breast health awareness programs for corporations and faith-based organizations which are meant to call women to action by promoting monthly breast self exams, and annual clinical breast exams and mammography.

Our Promise

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 2 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 focus was placed on three main areas in order to accomplish the 2011 report. First and foremost, an inclusive review of the demographics and breast cancer statistics was conducted in order to find correlations between diagnoses and death rate from breast cancer within Tulsa County. The statistical significance of the data led to the identification of key target groups based on age, race and ethnicity, which bridged the report into its second key element: a review of the breast health system within the Tulsa Affiliate's service area. In this section, conclusions were reached regarding the gaps, needs and barriers facing women in Tulsa County concerning breast health. The final component of the report focuses on data collected from women in 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. 19.6% of females in Tulsa County, age 18-64, did not have health insurance.

Ok2Share data indicated the most current breast cancer incidence/mortality rates. 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. Of the female population, 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.

One of the key factors in surviving breast cancer is early detection. According to Thomson Reuters, 64.4% of all 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.

Quantitative Findings

An analysis of the demographics of Tulsa County indicated that age distribution varied by racial/ethnic groups. For instance, Hispanic women are the youngest racial/ethnic group (60.4% are under 29 years of age) and White women are the oldest racial/ethnic group (38% were 50 years and older). For those females aged 18-64 in Tulsa County, approximately 19.6% (37,640) were estimated to be uninsured in 2009. According to the most recent data available through the Kaiser Family Foundation, 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.

Tulsa County was found to have a higher than average breast cancer incidence when compared with incidence rates for the state of Oklahoma and the United States. 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.

White and American Indian women had the highest, and similar, incidence of breast cancer. Breast cancer typically has a higher incidence as age increases. For White women this high incidence rate is largely a product of having an older age distribution, however, for American Indian women, their age distribution is generally younger, yet the burden of disease is similar.

Late stage - Stage III and IV diagnosis of breast cancer in African American women was approximately double that of all other races. 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.

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. 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.

Mammogram rates are difficult to qualify due to the fact that the percentage is based on self reporting. According to Thomson Reuters an 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 as a result 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 & Qualitative Findings

Two focus groups were held, one with key informants from medical organizations and the second with African American women and survivors. Health care providers (key informants) and women (focus groups) alike agree on the 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.

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”. Another cultural issue is that 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.

The need for education was echoed over and over. Women need more comprehensive education to raise their awareness about breast cancer and breast health, in lieu of facts. They require education about breast health and more specifically, information concerning mammograms such as it may be uncomfortable but it is not painful. Learning that education provided to the younger

generations may help them embrace a healthy concept of breast health was encouraging. Education can prevent them from having the same attitudes as their parents and grandparents.

Many uncertainties and misinformation regarding breast health exist, especially among older women. Many older women are advised by their physicians that mammograms are no longer needed after a certain age or are needed only every five years after age 65. Other misconceptions gleaned from the focus groups were “when” a woman should start breast self exams, clinical breast exams and mammograms. Many women were surprised to learn that family history is not the primary indicator of breast cancer risk, resulting in a lack of diligence in seeking screening.

The focus groups revealed that many women need to be enticed, convinced, and cajoled into seeking breast health services. Promotions and giveaways are often ample enticement for these women. However, incentives may not be financially feasible for health care providers. For those women not drawn in by incentives, the recommendation was made to encourage providers to make breast health messaging and services part of their annual exams. In this way, women needing to hear the message will. At that point, it is up to a woman to make breast health a priority, taking the tools given to them by their provider and becoming more proactive concerning breast health.

As discussions regarding incentives continued the topic of ‘there is nothing for free’ mentality came to the forefront. Women who are not familiar with services often feel as though “there is nothing for free”. It was felt that if an issue is found, they are going to be asked to pay for something to get fixed and the bottom line is they will not be able to afford it. In many single parent households women shoulder the burden of the home and family and make the unfortunate choice to put their own health care concerns and needs last or, not at all.

Conclusion

Findings from key informants and focus group participants were reviewed with the Community Profile team. It was agreed the focus of the Affiliate’s priorities for the coming year must be to downstage the disease through changes in awareness and behavior that result in decreased late-stage diagnoses and lower mortality rates, particularly for African American women. The following priorities will be incorporated into the Affiliate’s strategic plan and tasks and timelines will be developed to ensure the objectives are accomplished.

Priority 1: Downstage the disease by increasing screening rates among women in Tulsa County.

Objectives:

- 1) Champion a citywide breast health services coalition, made up of breast cancer professionals, organizations and facilities.
 - a. Determine how to address the loss of the mobile mammography van.
 - b. Determine new avenues to reach unobtainable at-risk women.

- 2) Establish a plan for implementing and measuring a citywide mammography campaign.
 - a. Partner with the Health Information Exchange to benchmark service area mammography rates.
 - b. Determine the components of the campaign and timeline.

Priority 2: Influence a woman's attitudes and behavior towards a proactive role in her breast health.

Objectives:

- 1) Convert awareness to action by encouraging the use of Breast Self Awareness (BSA).
 - a. Seek high-impact grants that maximize the Continuum of Care.
 - b. Establish an Ambassador program to include community organizations, business and medical sectors.

- 2) Strengthen the faith-based network as a distribution point for breast health information to African American women.
 - a. Determine the most effective way to address cultural differences.
 - b. Develop and implement a culturally sensitive awareness program, with measurements for effectiveness.

Introduction

Affiliate History

Susan G. Komen for the Cure[®] began as a promise built on the love of Nancy G. Brinker for her dying sister, Susan G. Komen. Nancy promised Susan that 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 the Komen organization 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. In addition, \$25,551 was raised to fund scientific research. Over the past 14 years the Komen Tulsa Affiliate has grown considerably and in 2010, \$991,000 was raised by the Komen Tulsa Race and other fundraising events. Of the funds raised, 75 percent stay here in Tulsa County to fund education, screening and treatment programs and 25 percent is dedicated to scientific research. Since 1997 the Tulsa Affiliate has granted over \$4 million to local and national organizations in the fight to end breast cancer.

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 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 is 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.

The focus was placed on three main areas in order to accomplish the 2011 report. First and foremost, an inclusive review of the demographics and breast cancer statistics was conducted in order to find correlations between diagnoses and death rates from breast cancer within Tulsa County. The statistical significance of the data led to the identification of key target groups based on age, race and ethnicity. This bridged the report into the second key element, a review of the breast health system within the Tulsa Affiliate's service area where conclusions were reached regarding the gaps, needs and barriers facing women in Tulsa County concerning breast health. The final component of the report focuses on data collected from women in 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

Data Source and Methodology Overview

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 © 2009.

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

Oklahoma State Department of Health – 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 – Vital statistics registry of births, deaths, and other vital statistic initiatives in Oklahoma.

National Cancer Institute – 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 – 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) – 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 – a non-profit, private operating foundation focusing on major health care issues facing the nation.

Overview of Tulsa County General Demographics

The Tulsa Affiliate service area consists of Tulsa County, where an estimated 315,765 women resided in 2009. 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 and older as compared to 23% in Hispanic women).

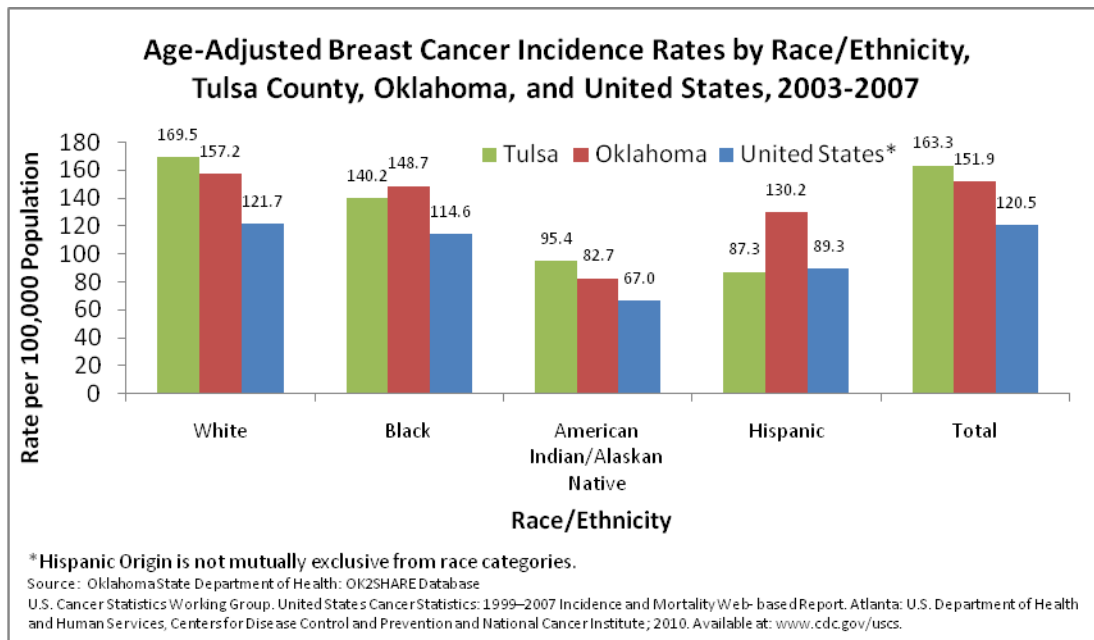
An estimated 601,961 people lived in Tulsa County during 2009 according to the US Census Bureau. The estimated median income for the county was \$46,857 and 13.6% of the people lived below the poverty line.

Ok2Share reported that from 2003-2007, 2,553 women in Tulsa County were diagnosed with breast cancer. The average age of these cases was 58.9 years.

Breast Cancer Incidence

Breast cancer 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.

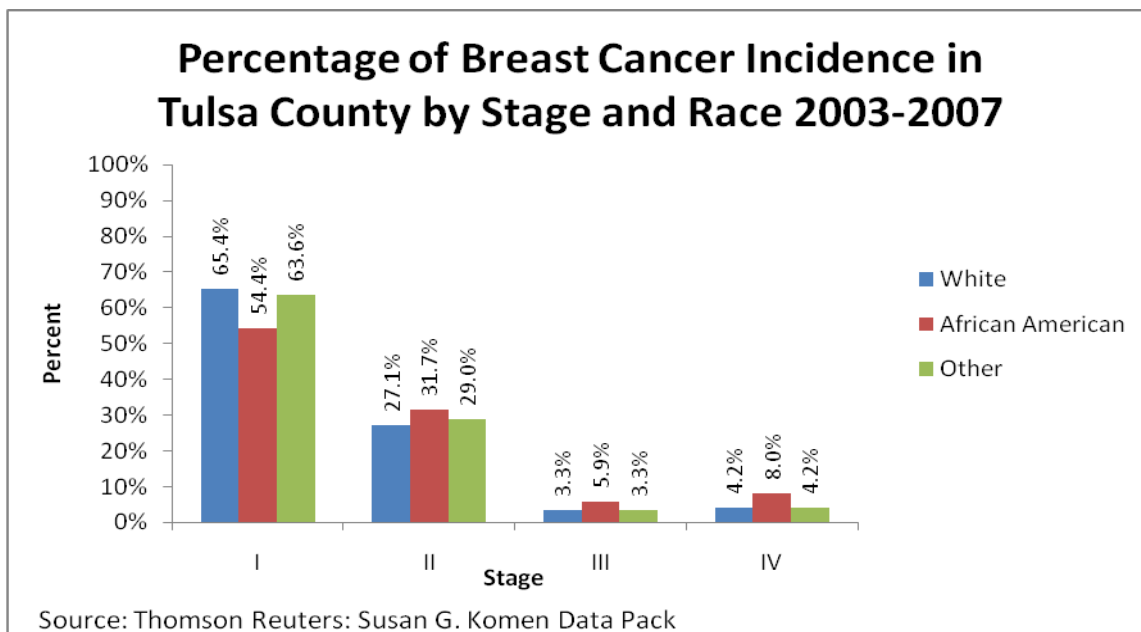
According to the CDC the age-adjusted incidence rate for all Tulsa County between 2003 and 2007 (163.3 per 100,000) was higher than the state of Oklahoma, (151.9 per 100,000) and the nation (120.5 per 100,000). The graph below compares Tulsa County's incidence rates by race and ethnicity with the state and U.S. rates.



Breast Cancer Stage of Diagnosis

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 all women were diagnosed in Stage I, 27.6% in Stage II, 3.5% in Stage III, and 4.5% in Stage IV.

As the graph below indicates, 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. As previously mentioned, high incidence rates could potentially indicate an increased underlying risk factor for this population. 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.

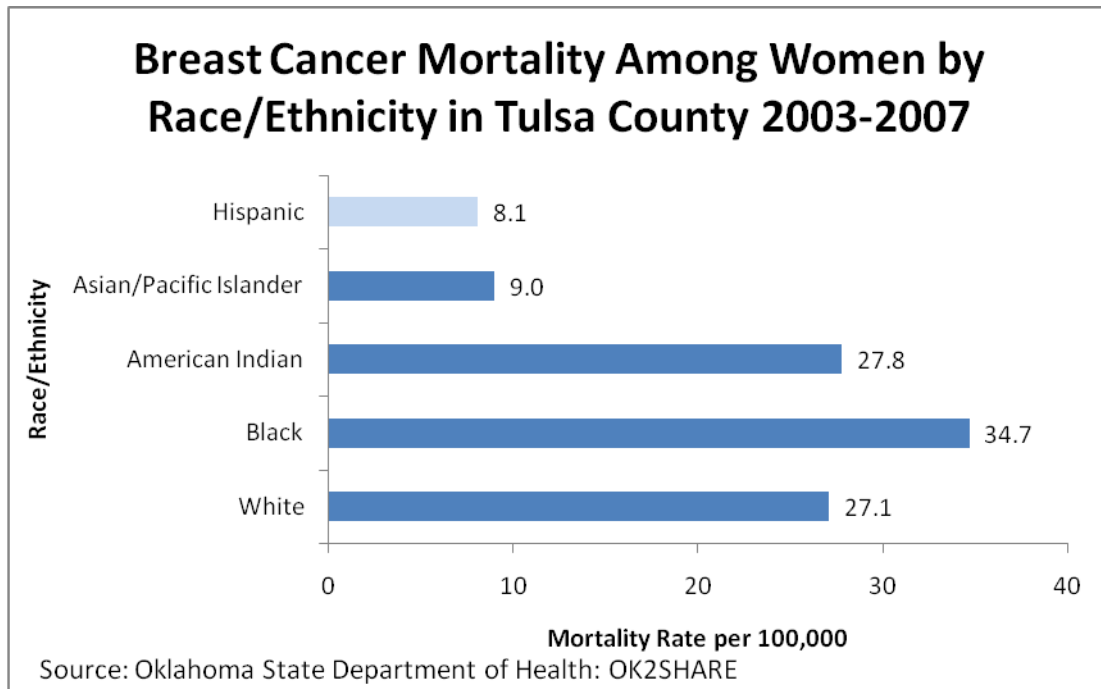


Breast Cancer Mortality

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.



Mammography

The goal of screening for breast cancer by mammography is to improve survival through early identification of disease. Mammogram rates are difficult to qualify due to the fact the percentage is based on self reporting. That said, 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” according to Thomson Reuter.

What the Data Shows for Tulsa County

Through data analysis we have seen that incidence rates are highest among White women who comprise 70% of the population. 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.

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.

Conclusions

Development of the research approach and methodology followed the data analysis and target selection process. Data collection was divided in two separate phases - qualitative and quantitative research.

The Komen Tulsa Affiliate service area contains only one county however, data analysis conveyed distinct differences among certain demographic and geographic groups for breast cancer incidence, late stage diagnoses and cancer mortality. It became immediately evident that the greatest opportunity to address service gaps is among those with similar demographic and geographic profiles to those breast cancer patients with the highest mortality and late stage diagnoses. The key target is African American women.

Overall Potential Targets for Enhanced Screening and Education

African American, American Indian, White, Hispanic, and Asian women

More Refined Targets

- African American women
Late stage diagnosis and high mortality
- American Indian women
Incidence numbers that meet or exceed White women
- White women
High incidence numbers

Hispanic and Asian women were found to be statistically insignificant for the purposes of this study based on population, breast cancer incidence and mortality.

Health Systems Analysis of Tulsa County

Overview of Community Assets

The Continuum of Care is how 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, our three targeted focuses are African American women due to late stage diagnosis and high mortality rates, American Indian and White women due to high incidence rates. The geographic locations for these groups have been identified and we know that physicians are not practicing in the areas where health care is needed most, mainly north and west Tulsa. There exists a lack of full-service medical facilities and mammography services in these areas as well.

Since the last Community Profile conducted by the Komen Tulsa Affiliate, mammography services have become available in the underserved parts of Tulsa County. In October, 2010, Morton Comprehensive Health Center began providing screening mammograms to uninsured low income women from the targeted communities in Tulsa County. One of the most devastating setbacks was the loss of the mobile mammography van that was serving Tulsa County. This loss was not only a misfortune for Tulsa as a whole, but more specifically for those communities in the County that were underserved and used the mobile van the most. Mammography services require a woman to make and keep an additional appointment following her well-woman exam plus travel outside her geographic area in order to get a mammogram. This extra appointment poses to be a huge barrier for many at-risk women who do not have transportation or the time to make or keep a separate appointment. This also becomes an issue when a woman is diagnosed with breast cancer and all of her treatment requires her to travel continually to a facility that is inconvenient to her lifestyle and mode of transportation.

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 Tulsa 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 for the underserved 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
- A woman's ability to make one appointment for her well-woman exam and mammogram
- Transportation to the mammography centers

Partnerships and Grant Opportunities

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.

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 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.

New Grant Opportunities

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.

Evidence-Based Programs

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 Perspectives

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.

National Breast and Cervical Cancer Early Detection Program (NBCCEDP)

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.

Conclusions

Gaps and barriers in education and the Continuum of Care will remain a focus for the Komen Tulsa Affiliate. Education efforts need to be more culturally sensitive not only in the written information provided but also in the way the material is presented. There needs to be continued emphasis on education and awareness while encouraging women to put themselves and their health care as a priority. The loss of women in the Continuum of Care will remain a spotlight, not only in what efforts need to be addressed to get women into the continuum, but how to get her to stay once she is in.

Breast Cancer Perspectives in Tulsa County

Methodology

In an effort to fully understand key attitudes regarding breast health and begin to identify service gaps, qualitative focus groups were conducted first to fully explore and understand core issues.

Likewise, the initial focus group was conducted among area clinic and health care providers to understand their perceptions, experiences and expectations regarding the state of breast health services and Tulsa area service/program gaps. Service providers also discussed current programs that have proven successful in addressing service/program gaps and brainstormed regarding new solutions to further address deficiencies.

Due to the HIPAA laws, which are in place for good reason and Komen Tulsa supports, it was difficult to find individuals that would provide valuable insight into the gaps and services they have found in the system regarding breast health. With that said, we switched gears and found members of our community to come together in a 'community' focus group to share their thought and concerns as to where they see breast health heading in Tulsa County and how all breast health organizations can work together to close gaps in service.

A total of 13 respondents participated in the two focus group sessions as follows:

- Group 1: 6 Tulsa area health care providers
- Group 2: 7 Tulsa area women

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 groups were facilitated by a Tulsa Komen employee and transcribed by a second Komen Tulsa personnel. The information obtained through these groups was utilized for report writing purposes.

Review of Qualitative Findings

Our focus group participants shared their perceptions and experiences regarding the state of breast health services and gaps in Tulsa area services and programs. There are many obstacles that prevent women from seeking breast health services including the mindset that “going to the doctor means you are sick” there is a lack of knowledge regarding preventive health care; and a “survival mentality” among lower-income women where breast health is not a priority due to focusing on meeting their day-to-day needs (e.g. family, job, etc.).

Fear is often an obstacle, the fear of knowing something might be wrong. Many women echoed another barrier of fear for women is having watched friends or family go through breast cancer and they are not interested in going through it themselves. With this mindset it becomes very difficult for these women to seek medical attention due to fear of not wanting to know.

Another cultural issue that kept reappearing in discussions was that of women not making themselves a priority. Women, by nature tend to place everyone else ahead of themselves, finding themselves too busy taking care of everyone else around them that they do not stop long enough to realize they may have a problem until it is too late. One focus group member mentioned, ‘it boils down to, how important are you’.

Next to making themselves a priority the next most common obstacle for women was that of education, or lack thereof. Women can’t take a proactive approach with their health unless they are aware that they need to. An effort on educating Tulsa County on what to expect when it comes to breast health and more importantly what a mammogram consists of and that it may be uncomfortable but it will not hurt a person needs to become a main concern for the Tulsa Affiliate. Through information gained in our focus groups education efforts need to begin with the young generation for they are more likely to embrace different ways of viewing breast health.

Staying in line with education it was surprising to learn that many uncertainties and misinformation still remain regarding breast health – especially among the old women. 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.

Well-woman exams and screening mammograms require at least two different appointment dates and times. Low-income, uninsured women are often unable to participate in these preventative

measures due to lack of transportation, time off from work or family obligations and/or financial resources.

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.

There is a very strong faith element among African American women and they are strong and vocal supporters of each other and their trials. We found many women lacked knowledge of recommended breast health and early detection guidelines. Many indicated they had no need for a mammogram due to a hysterectomy or that mammograms were only needed once every five years after age 60. All were surprised to learn that family history is not the only indicator of a woman's breast cancer risk.

In addition, health care providers and women agreed that breast health messaging of facts and statistics could be presented more positively.

Conclusions

Many uninsured, low-income women's fears can be addressed by providing information on breast health services available to them through free clinics and other programs. Utilizing Komen's BSA program 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. Utilizing key women influencers in the community and determining effective media is vital to reaching women and facilitating positive change in their breast health practices.

Komen Tulsa is working diligently to implement an Ambassador program that spans the scope of the Tulsa community in order to prompt women to action. By definition an ambassador is an authorized messenger or representative, which is exactly what Komen Tulsa is hoping to accomplish through the Ambassador program, to have messengers of the Komen promise and mission representing Komen within different facets of the community. Faith-based Ambassadors 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 an 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

This project is a continuation of the 2009 report. It was the intent of the Tulsa Affiliate to let the data guide the report. No significant changes were found, a serious concern still remains regarding late stage diagnosis and a very high mortality rate in African American women within Tulsa County. There also appears to be no change for the White population the women still had a higher incidence rate than the state and U.S. average.

It became clear that the questions needed to be asked why are African American women in Tulsa County getting diagnosed late? What role does socioeconomic status play in the late stage diagnosis? And most importantly, why does the mortality rate of African American women in Tulsa County exceed all other races/ethnicity?

Another question that came to mind after reviewing the data was why is there a higher incidence of breast cancer in Native American women, as well as White women in midtown Tulsa?

As a closer look was taken at culture and races the question was raised why do women seem to embrace education about mammograms but the hiccup remains in converting them to action? Are there systemic changes that could be addressed?

In addition a variety of negative trends existed, such as the time involved in making and keeping one appointment, let alone two – one for well-woman, the second for a mammogram. This issue coupled with the distance and inconvenience of mammography facilities in south Tulsa is a deterrent to good breast health practices. And these two factors do not encompass the fact that mammograms don't help low-income women meet their immediate day-to-day needs.

The quantitative findings continued to be substantiated by what was heard from the women in focus groups.

Marketing

The Affiliate is developing an awareness campaign in recognition of the 15th Anniversary of the Komen Tulsa Race called “The 15 Faces of Breast Cancer”. Fifteen categories of people have been identified who have been strongly impacted by breast cancer – high-risk populations, families, caregivers, doctors, researchers, survivors, Race participants, volunteers and more. Each individual has a story to tell which will allow us to educate on what steps should be taken to allow for a clear understanding of the continuum of care – from self-exams to mammograms to follow-up care and after treatment. With “15 Faces” the hope is to bring about action on the part of the high-risk population, potential donors, possible volunteers and probable Race participants in Tulsa County. The campaign includes print, outdoor, TV and radio advertising as well as editorial placement and content on KomenTulsa.org which will allow us to tell the 15 stories as to why each person fights for a cure for breast cancer in a compelling way.

While the “15 Faces” campaign is being developed in conjunction with the Race anniversary, the intent is for it to be the first step in a multi-year campaign. It is important to raise awareness among all women regarding the importance of good breast health and its role in early detection and survival rates. However, it is equally important that women take action on their awareness by practicing BSA which includes monthly self-exams, and yearly clinical exams and mammograms.

Affiliate Action Plan

After analyzing the qualitative and quantitative data, the research findings were presented to the Community Profile team. It was agreed that addressing the statistically significant mortality rate among African American women in Tulsa County was a priority. There must also be increased proactive participation by women in their own breast health if we are going to “move the needle” on late-stage diagnosis in Tulsa County.

The Community Profile team identified the top 2 priorities that will best address the findings. In order to ensure the priorities are accomplished the Affiliate’s strategic plan will include these priorities and tasks and timelines and timelines will be developed for each objective.

The Tulsa Affiliate priorities for 2011-2012 are to:

- 1) Downstage the disease by increasing screening rates among women in Tulsa County.
- 2) Influence a woman’s attitudes and behavior towards a proactive role in her breast health.

Priority 1: Downstage the disease by increasing screening rates among women in Tulsa County.

Objectives:

- 1) Champion a citywide breast health services coalition, made up of breast cancer professionals, organizations and facilities.
 - a. Determine how to address the loss of the mobile mammography van.
 - b. Determine new avenues to reach unobtainable at-risk women.
- 2) Establish a plan for implementing and measuring a citywide mammography campaign.
 - a. Partner with the Health Information Exchange to benchmark service area mammography rates.
 - b. Determine the components of the campaign and timeline.

Priority 2: Influence a woman’s attitudes and behavior towards a proactive role in her breast health.

Objectives:

- 1) Convert awareness to action by encouraging the use of Breast Self Awareness (BSA)
 - a. Seek high-impact grants that maximize the Continuum of Care.

- b. Establish an Ambassador program to include community organizations, business and medical sectors.
- 2) Strengthen the faith-based network as a distribution point for breast health information to African American women.
 - a. Determine the most effective way to address cultural differences.
 - b. Develop and implement a culturally sensitive awareness program, with measurements for effectiveness.

Conclusions

As with a profile of any magnitude the discoveries that are uncovered are varied, however the thread that continued to stream through this profile is that of education and avoiding barriers that caused women to fall out of the Continuum of Care. Through the qualitative and quantitative elements of the 2011 Community Profile it became immediately evident that the greatest opportunity to address service gaps is among African American women. With the highest incidence of late stage diagnosis and higher mortality rates than any other race or ethnicity in Tulsa County extreme attention through education and outreach programs need to be geared towards the African American community. 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 continue to implement the Ambassador program through churches, schools, neighborhood associations, local business and Tulsa-based corporations.

Komen Tulsa will continue to march forward in this fight against breast cancer so one day the community can stand up together in a victory over an illness that has taken too many.