

Executive Summary

Introduction

The Susan G. Komen for the Cure Wichita Race for the Cure ® was started in 1990 by the Junior League of Wichita and in 1993, the Mid-Kansas Affiliate of Susan G. Komen for the Cure® was officially formed. Through events like the Race, the Affiliate has raised nearly 5.1 million dollars to invest in research, education, outreach, and screening services. As a result of the initial success of the Wichita Race for the Cure, the Komen Mid-Kansas Affiliate Free Mammography Program was started with the event's proceeds, and the program is still in operation today. Additionally, in 2008, the Affiliate was the recipient of an extraordinary one-time fundraising opportunity. The Affiliate's media partner developed and executed a project known as The KSN Dream House. The Dream House was sold for \$600,000 with all proceeds being given to the Affiliate. One hundred and fifty thousand dollars of the sale was provided to the Komen Headquarters for research. The remaining \$450,000 was provided as a donation to the Affiliate to open a Center for Breast Cancer Survivorship in partnership with the University of Kansas Medical Center - Wichita.

The Mid-Kansas Affiliate serves 95 of the 105 counties in the state of Kansas, covering the entire state with the exception of a 10-county region in the Greater Kansas City metropolitan area located in the Northeast corner of the state. It is our mission and promise to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to find the cures. The Affiliate serves this vast region through grant funding, education and outreach programs, advocacy, and by providing assistance in finding available breast health services.

The biennial Community Profile provides an opportunity for Affiliates to conduct an assessment of selected communities within their region in order to determine which gaps in services and opportunities exist. The Community Profile contained herein will assist the Affiliate in establishing focused granting priorities, focused education and outreach needs and activities, drive public policy efforts and strengthen partnerships. As such, this report has been developed to understand and communicate the state of breast cancer, general breast health, and services available in the 95-county service area of the Affiliate. The purpose of the Community Profile is to gather information and set priorities to ensure that we serve the people who need our help the most.

Statistics and Demographic Review

As a whole, Kansas does not have exceptionally high or low incidences of breast cancer when compared to the rest of the country, but some troubling disparities do exist upon closer examination of the data.

Kansas is a largely Caucasian state of approximately 2 million adult residents, 1 million of whom are women. Among all Kansas women the breast cancer incidence was 129.6 per 100,000 women, but among Caucasian women, the breast cancer incidence was 139.8, placing it 12th among the states. For African-American women in Kansas, incidence rates were 86.3 per 2

100,000 women, which were lower than the rate among Caucasian women, but 14 percent of those cases were diagnosed in either stage III or stage IV, double the percentage of breast cancer cases in stage III or stage IV among Caucasian women. Among Hispanic women in Kansas, incidence rates are below both that of Caucasian or African-American women, but screening rates lag far behind the national average. Only 66 percent of Hispanic women in Kansas over the age of 50 reporting having had a mammogram in the past two years compared to over 80 percent of Hispanic women nationwide.

Based on these statistics and the demographics within the state, three regions, Cherokee County, Seward County and Geary/Riley County were chosen as the three focal point sites for the study. Cherokee County has the highest number of women who have not had a mammogram in 12 months, Seward County has the greatest Hispanic population in Kansas, and Geary and Riley County have the highest incidences of Stage III and Stage IV breast cancer in the state.

Health Systems Analysis

In order to examine the assets present in each of the three targeted communities, health care providers were asked to participate in a series of key informant interviews or complete an electronic survey and available resources were explored. Six key informant interviews were conducted with eight community managers or other key stakeholders in the three target communities. These key informants were selected based on their work in their respective communities in breast cancer specific agencies and organizations such as the Kansas Early Detection Works (EDW) program or the American Cancer Society. When reviewing the programs and services available in the three target communities there were a tapestry of support and services available to women. In fact the entire continuum of care is available to women, but when and how women access these resources varies by community, and often by the status of the women within the community. A strong health system exists, but challenges arise in making sure all women are able to avail themselves of these services.

The most substantial gap in the continuum of care exists at its point of entry. Among these women in the profiled communities, being on the margins makes it harder to even gain access to that continuum of care – if you never get screened; you never get into the system. Key informants feel that entire groups of people are ‘missing the boat’ when it comes to screening services. Lack of a centralized way to access screening and treatment services and lack of belief in the necessity of screening services among populations are problems that require systems level thinking. Communication in general and language specifically, stand as the largest barriers to care. Organizations and individuals working together, such as private practitioners, churches, and community health centers, can work together in coordinated campaigns that can help bridge those communication gaps, especially if the messages are targeted to communities properly.

The most important legislative issue affecting the target communities identified in the Community Profile is ensuring that funding is not decreased or eliminated for the Early Detection Works (EDW) program, the state’s Breast and Cervical Cancer Program (BCCP). The Affiliate has a strong working relationship with EDW and Komen leverages federal and state funds by contributing additional resources for EDW in local communities. Additionally, the 3

Affiliate continues to work with EDW, Medicaid and members of the legislature to ensure that all women diagnosed with breast cancer through either a Komen mammogram or an EDW mammogram have access to treatment through Medicaid.

Qualitative Data Overview

Analysis of the qualitative data from both the key informant interviews and focus group participants revealed that continuing to meet the needs of women from all racial, ethnic, and socio-economic backgrounds will be an ongoing challenge for the Affiliate. Among key informants, four central themes emerged; 1) there is no single type of woman least likely to get screened, 2) lingual and cultural differences are a barrier, 3) navigating a patchwork of services and organizations is difficult within the continuum of care, and 4) socio-economic class matters.

The most common barrier to women accessing the continuum of care is in simply getting screened, but the identity and characteristics of this ‘typical’ woman who is not getting screened adequately varied from community to community. However, what these women do share is experience encountering a barrier at the point of entry. Among these women in the profiled communities, being on the margins makes it harder to even gain access to that continuum of care. Therefore, if women do not get screened, they never even encounter any other areas in the continuum of care.

The major structural impediment to increased utilization of screening services is larger than the auspices of a single organization, but financial impediments to receiving screening services make it a challenge to access these services for entire populations. Not only does the cost of services hinder screening for all at-risk women, the opportunity cost of getting screened can simply be too great for women working in hourly occupations with little freedom to the structure of their days. Even if the money is readily available to pay for services, simply making screening worth their time is a major area in which screening services could be improved for the medically underserved. After financial considerations, communication in general, and language specifically, also stand as a substantial barrier to care.

Conclusions

Addressing the gaps and barriers that exist in the continuum of care will require outside-of-the-box thinking. While social class and social status stand out as the predominant themes in a woman’s ability, or lack thereof, to access the continuum of care via an initial screening, just who occupies this social class and why varies from community to community. There were different racial and ethnic compositions within each of the three communities of interest in this report, and different economic realities drive the experiences for each woman. Therefore, a one-size-fits-all approach is not likely to be able to do much to bridge the gap between women needing to be screened and women actually being screened. Working within individual communities to make mammography more accessible to women and addressing misconceptions about breast cancer and mammograms will likely ensure the biggest barrier in the continuum of care in the Affiliate will be addressed. 4

Action Plan

The Community Profile team reviewed the findings from the data to determine the overarching priority of increasing screening rates for women in the state of Kansas, with a focus on Hispanic, African American, and women in rural Southeast, Kansas.

Priority One- Actionable Education

Effectively educate women on breast health and services available to them in language and culturally appropriate methods leading to increased screening.

Objective 1: By the end of April 2012, host a minimum of a day-long workshop focusing on health literacy and cultural awareness. Ensure part of this includes “Train the Trainer” methodology so attendees can train providers and other constituents in target communities.

Will also discuss developing a piece (or pieces) of educational material for lower literacy levels and ethnically diverse populations.

Objective 2: By the end of May 2012, collaborate with community based outreach organizations and providers in Seward County to offer a breast health education event in the Spanish language and aligned with cultural traditions of the Hispanic population. Invite entire families to attend.

Objective 3: By December 2012, partner with community based outreach/health organizations to identify community leaders in target communities who are willing to be champions for breast health and educate them on Komen messaging and resources available.

Objective 4: By March 2012, develop and implement a marketing campaign that includes a wide variety of media outlets that educates the public, in a way that is language and culturally appropriate on: (1) where services are available (2) what assistance is available (3) the importance of preventative health and (4) upcoming events.

Priority Two- Addressing Barriers to Accessing Care

Decrease the difficulty of getting screened by addressing barriers identified in the Community Profile, such as finances, transportation, clinic hours, and cultural norms, to therefore increase screening.

Objective 1: By the end of March 2013 provide funding for after-work screening events in Cherokee, Seward, Riley, or Geary County.

Objective 2: Through March 2013 continue to provide funding (and ensure state funding is secured) for breast cancer screenings for the uninsured, transportation assistance, patient navigation and mobile mammography programs. Achieve this through public policy efforts and continued granting through Early Detection Works and community organizations in Cherokee, Seward, Geary and Riley Counties.

Objective 3: By May 2011 become a member of the Kansas Rural Health Association to enhance the health and well-being of rural Kansans through united advocacy, leadership, education, collaboration and resource development.