



COMMUNITY PROFILE REPORT

©2011 Mid-Kansas Affiliate of Susan G. Komen for the Cure®



2011

Disclaimer:

The information in this Community Profile Report is based on the work of the Mid-Kansas 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. 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, materials, products or other information included or the companies or organizations referred to in the report.

Acknowledgments

The Mid-Kansas Affiliate of Susan G. Komen for the Cure would like to thank The Affiliate Board of Directors and the following individuals and organizations who participated in the creation of this report.

Community Profile Team

Elizabeth Ablah, PhD, MPH

Assistant Professor of Public Health
Department of Preventative Medicine and Public Health
University of Kansas School of Medicine School – Wichita

Kirsten Bruce, LMSW

Education and Grants Coordinator
Mid-Kansas Affiliate of Susan G. Komen for the Cure

Peggy Johnson

Executive Director, Wichita Medical Research and Education Foundation
Public Policy and Grants Chair, Komen Mid-Kansas Mission Advisory Council

Kurt Konda, MA

Senior Research Associate
Department of Preventive Medicine and Public Health
University of Kansas School of Medicine - Wichita

Christina Osbourn

Former Executive Director
Mid-Kansas Affiliate of Susan G. Komen for the Cure

Lindsay Smith

Executive Director
Mid-Kansas Affiliate of Susan G. Komen for the Cure

Tracy Wineinger

Intern, Mid-Kansas Affiliate
MPH Candidate – University of Kansas School of Medicine School – Wichita

Affiliate and Community Partners:

Shelly Nelson, Early Detection Works, KS Department of Health & Environment
Maria Elena Terrazas, Early Detection Works, KS Department of Health & Environment
Stephanie Thompson, Early Detection Works, KS Department of Health & Environment
Gertie Williams & It's About Me Breast Cancer Awareness Association
Kelly York, Early Detection Works, KS Department of Health & environment
All Key Informant Interviewees

Table of Contents

Executive Summary	1
Introduction.....	1
Statistics and Demographic Review.....	1
Health Systems Analysis.....	2
Qualitative Data Overview	3
Conclusions.....	3
Action Plan	4
Introduction	5
Affiliate History.....	5
The Mid-Kansas Affiliate	5
Organizational Structure	6
Description of Mid-Kansas Affiliate Service Area.....	6
Purpose of Report.....	7
Breast Cancer Impact in Affiliate Service Area.....	8
Methodology.....	8
Overview of The Affiliate Service Area	8
Communities of Interest	10
Conclusions.....	14
Health Systems Analysis of Target Communities.....	14
Overview of Continuum of Care.....	14
Methodology.....	15
Overview of Community Assets.....	17
Legislative Issues in Target Communities.....	20
Key Informant Findings	21
Conclusions.....	25
Breast Cancer Perspectives in the Target	27
Methodology.....	27
Review of Qualitative Findings.....	28
Conclusions.....	34
Conclusions: What We Learned, What We Will Do.....	35
Review of Findings.....	35
Conclusions.....	35
Selecting Affiliate Priorities	35
Action Plan	36
References	37

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

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

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.

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.

Introduction

Susan G. Komen for the Cure

Nancy G. Brinker promised her dying sister, Susan G. Komen, she would do everything in her power to end breast cancer forever. In 1982, that promise became Susan G. Komen for the Cure and launched the global breast cancer movement. Today, Komen for the Cure is the world's largest grassroots network of breast cancer survivors and activists fighting to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to find the cures. Thanks to events like the Komen Race for the Cure®, we have invested more than \$1.9 billion to fulfill our promise, becoming the largest source of nonprofit funds dedicated to the fight against breast cancer in the world. For more information about Komen for the Cure, breast health or breast cancer visit www.komen.org or call 1-877-GO KOMEN.

Affiliate History

The Mid-Kansas Affiliate

The Susan G. Komen for the Cure Wichita Race for the Cure ® was started in 1990 by the Junior League of Wichita. The Komen Wichita Race for the Cure was the first Komen co-ed Race for the Cure and the fourth Race for the Cure in Komen's history. The 1990 race was the largest first-year road race in Kansas' history, with over 1,400 participants taking part in the maiden race.

As a result of this initial success, the Komen Mid-Kansas Affiliate Free Mammography Program was started with the event's proceeds, and the program is still in operation today. The fund has provided over 33,000 free mammograms in the state of Kansas. The Affiliate's Free Mammography Program was the first such program for Komen nationally and served as a model program for many cities as they established their own Komen Race for the Cure Events. In 1993, the Komen Mid-Kansas Affiliate 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. Up to seventy five percent of all funds generated by the Affiliate stay in the 95 County service area. The remaining 25 percent of funds raised by the Affiliate goes towards the Komen Award and Research Grant Program supporting research awards and educational and scientific programs around the world.

In 2008, the Affiliate was the recipient of an extraordinary one-time fundraising opportunity. The Affiliate's media partner, KSN Channel 3 (NBC), developed and executed a project known as The KSN Dream House. The Dream House was designed and constructed with entirely donated time, supplies and money. The Dream House was then sold with all proceeds being provided to Komen. One hundred and fifty thousand of the \$600,000 sale price of the Dream House was provided to the Komen Headquarters for research. The remaining \$450,000 was provided as a donation to the Affiliate. The funds were utilized to open the Center for Breast Cancer Survivorship housed at the University of Kansas School of Medicine - Wichita. Post treatment services and options for survivors have been identified as community needs in the Affiliate's Community Profile for many years, and the development of the Breast Cancer Survivorship

Center addresses this important need. The Center offers a comprehensive, multi-disciplinary approach to assist those diagnosed with breast cancer and enhance their quality of life from the time they're diagnosed, through treatment, and even after. The Center opened its doors in August of 2010 and this collaborative effort has begun a new era for post cancer treatment options for women with breast cancer in Kansas.

Organizational Structure

Komen is headquartered in Dallas, TX and is governed by a Board of Directors. Komen Headquarters and the Komen Affiliates are separate, distinct legal entities, however a mutually interdependent unit, working together in pursuit of a common mission. Headquarters is charged with carrying out the mission on a national and international level and coordinating the efforts of all Affiliates. Headquarters is also responsible for managing the Award and Grant Research Program. The Affiliate is responsible for carrying out the mission on a local level.

The Affiliate is governed by a 12 member volunteer Board of Directors and employs three full time staff , one part time staff and 300 active volunteers who are helping make our mission a reality. Staff includes the following: Executive Director, Education and Grants Coordinator, Program Coordinator and Office Administrator. (Figure 1)

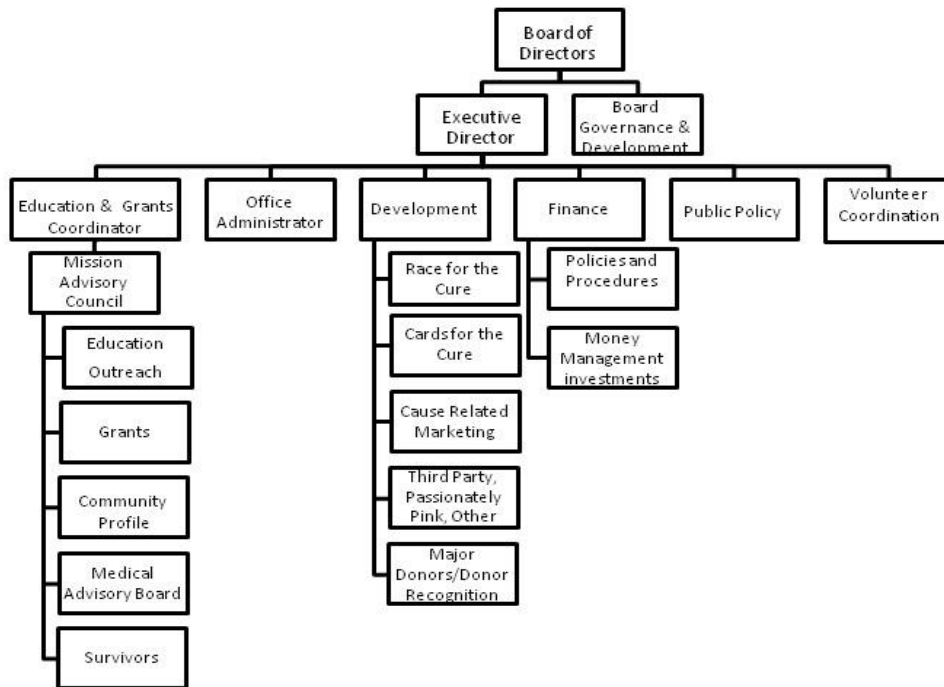


Figure 1: Mid-Kansas Affiliate Organizational Chart

Description of Mid-Kansas Affiliate Service Area

The Affiliate serves 95 of the 105 counties in the state of Kansas; the remaining ten counties are served by the Greater Kansas City Affiliate. The Affiliate serves the community through grant funding, education and outreach programs, advocacy and by providing assistance in finding

available services. The Affiliate acknowledges the many challenges such a large service area presents for the Affiliate in both funding and providing educational opportunities. 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 and which of these gaps should be addressed first by the Affiliate (Figure 2).

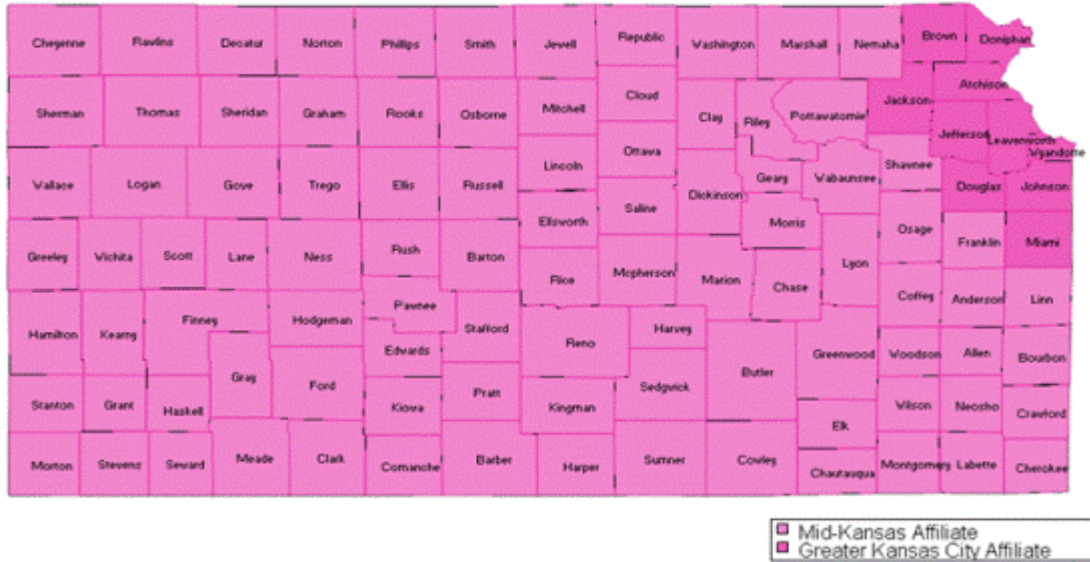


Figure 2: Map of Mid-Kansas Affiliate Area

Purpose of Report

The Community Profile is the result of an assessment process the Affiliate performs. Every two years the Community Profile document is 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 Community Profile assists Affiliates to establish focused granting priorities, establish focused education and outreach needs and activities, drive public policy efforts and strengthen partnerships. 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.

The Community Profile guarantees mission and non-mission work is targeted and non-duplicative. It is used to create strategic and operational plans and is one way that we communicate with community members, grantees, partners, sponsors and policy makers. The Affiliate recognizes the purpose and importance of the Community Profile. The Affiliate also knows its resources and limitations and the importance of these factors in setting realistic priorities and an action plan based on this report.

Breast Cancer Impact in Affiliate Service Area

Methodology

In order to assess which areas within the Affiliate warranted examination for this report, demographic data as well as health data from the National Cancer Institute (NCI), Kaiser Health Organization, and the Health Resources and Services Administration (HRSA) were obtained. These data allowed the Affiliate to determine which areas of the state had demographic profiles that might suggest a need for greater screening services or where gaps might exist within the continuum of care.

Three indicators were selected when determining which communities in the Affiliate service area might be suffering from gaps in access to services and care. These indicators were mammography rates, breast cancer incidence rates, and national breast cancer mortality data. In order to gain a well rounded profile for the state of Kansas, national cancer data from the NCI was used as benchmark or point of comparison to be compared to state-specific data obtained from HRSA, the Kaiser Health Organization, and county-level cancer data obtained from the Kansas Department of Health and Environment (KDHE). Data from these sources ranged from 2006 to 2008 data.

In addition to these sources, Thomson Reuters 2010 data was utilized to determine Kansas mammography rates, breast cancer incidence rates, breast cancer mortality rates, and demographics, such as race and socioeconomic status. Census Bureau data was also utilized in order to augment the demographic profile available from Thomson Reuters. These data were then collectively compared to the *Kansas Cancer Registry Multiple Year Report: Cancer Incidence and Mortality in Kansas* from the years 1997-2006.

These data allowed the Affiliate to paint a broad picture of the communities within the Affiliate, but did not allow for a closer examination of conditions within each community or a detailed analysis of the breast health services and barriers to these services present within each community. Therefore, the use of secondary data analysis served as the initial step in a detailed examination of the barriers and access available to women along the entire breast health continuum.

Overview of the Affiliate Service Area

Breast Cancer in the United States

The estimated new cases of breast cancer in the United States are 207,090 females a year (National Cancer Institute (NCI), 2010). The estimated number of female deaths in 2010 was 39,840 (NCI, 2010). The national average of breast cancer incidence is 120.4 per 100,000 women (Kaiser Family Foundation (KFF), 2011a). The national average of breast cancer deaths per 100,000 women is 22.8 (KFF, 2011b). According to the NCI's Surveillance, Epidemiology, and End Results (SEER) database, from 2005-2007, the average American's risk of developing

breast cancer was 12.2 percent (NCI, 2010). According to the same data source, a woman's risk of being diagnosed with breast cancer from ages 30-39 is 1:233; the chance of being diagnosed ages 40 through 49 is 1:69; the chance of being diagnosed ages 50 through 59 is 1:42; and the chance of being diagnosed ages 60 through 69 is 1:29 (NCI, 2010).

Breast Cancer in Kansas

Overall, the breast cancer incidence rate per 100,000 women in 2007 in Kansas was 123.9, which is above the national incidence rate of 120.4 (KFF, 2011a, KFF, 2011c). For Caucasian women, the breast cancer incidence rate was 139.8 in 2009 (Thomson Reuters, 2010), which placed Kansas as 12th highest in the United States and District of Columbia (Thomson Reuters, 2010). Among Caucasian women in Kansas, 66 percent of breast cancer incidences are Stage I, 27 percent are Stage II, three percent are Stage III, and four percent are Stage IV.

African American women had a lower incidence rate (86.3) in 2009 than Caucasian women, but just 55 percent of the incidences among African-American women were Stage I, 31 percent were Stage II, 6 percent were Stage III and 8 percent are Stage IV (Thomson Reuters, 2010). The lower incidence rate and the higher likelihood of being at a more developed stage of cancer indicates that African American women may not be getting screened as early, as regularly, or as often as recommended.

In 2007, the breast cancer mortality rate among Kansas women was 23.5 per 100,000 women (KFF, 2011d). By 2009, the breast cancer mortality rate had ticked slightly upwards to 23.6 placing Kansas as the 25th highest state for breast cancer mortality (Thomson Reuters, 2010). The mortality rate is much lower among females aged 18 to 44 (4.3) than it is among women aged 45 to 64 (31.6), or for females ages 65 years or older (92.1). Among Caucasian women in Kansas, the mortality rate in 2009 was 25.0, while the rate for African American women in Kansas was 26.4.

Nationally, Hispanics reported lower incidence rates (90.2) and mortality rates (15.5) than Caucasians or African Americans, but breast cancer remains the most common form of cancer among Hispanic women (American Cancer Society, 2010).

Seventy-eight percent (78 percent) of women in Kansas aged 50 years old and older reported having had a mammogram in 2008, which is slightly lower than the national average of 79.4 percent (KFF, 2011e). By race and ethnicity, just 78.2 percent of Caucasian women ages 50 years and older in Kansas reported having had a mammogram within the last two years, compared to 80.2 percent of Caucasian women nationally (KFF, 2011f). Among African American women in Kansas, 82.1 reported having had a mammogram in the past year, which was slightly higher than the national average of 81.3 percent (KFF, 2011f). However, by ethnicity a pronounced gap exists, as just under two-thirds of Hispanic women in Kansas over the age of 50 reported having had a mammogram within the last two years, while 80.6 percent of Hispanic women nationally reported having had a mammogram in the prior two year in 2006 (KFF, 2011f).

Demographics of Affiliate Area

Based on 2009 Census estimates, the total population for the Affiliate area was 1,827,837 (Census, 2011). The estimated total female population of the Affiliate areas was 915,780 with 349,684 of those between the ages of 15 and 44 and 480,075 between the ages of 35 and 54 (Thomson Reuters, 2010). There were an estimated 1,479,305 White non-Hispanics, 86,584 Black non-Hispanics, and 174,814 Hispanics in Kansas in 2009 (Thomson Reuters, 2010). Among Kansas residents, the most commonly reported income category was those with \$25,000-50,000 of annual income and the median average household income was \$49,773, nearly \$20,000 less than the median income of \$69,376 in the United States (Thomson Reuters, 2010). Less than half of the population (32 percent) has a high school degree, 32 percent have some college or an associate's degree, and 22 percent hold a Bachelor's degree or greater (Thomson Reuters, 2010).

Communities of Interest

Exploratory data provided the Affiliate the opportunity to statistically determine the most appropriate target communities for the Community Profile. Based on county demographic and statistical review, the Affiliate chose Cherokee County, Seward County, and Riley/Geary Counties as the three target areas for the Community Profile.

Cherokee County

Goal: The Affiliate is interested in understanding the reasons why women are not getting a mammogram in Cherokee County.

Cherokee County was chosen as a target community as they have the highest number of women in the Affiliate area who have not had a mammogram within the last 12 months. Cherokee County also has the highest uninsured rate for the female population at 25 percent. In Cherokee County, 43 percent of the women have not had a mammogram within the last 12 months. Eight percent (8 percent) of the women chose not to have a mammogram, 10 percent did not have time to have a mammogram, 4 percent did not need to get a mammogram, 4 percent have scheduled a mammogram, and 17 percent of the women did not have a mammogram for other reasons.

Cherokee County has a total population of 20,343. Sixty-one percent (61 percent) of the population is of working age (18 to 64 years old) (Policy Map, 2010). Forty-five percent (45 percent) of the population is in the age range of 30 to 64 years old. Fifty-one percent of the population is female (10,436). Ninety-one percent (91 percent) of the population is Caucasian. The median household income is \$38,597, which is less than the median income of the state of \$49,773 and as of November 2010, the unemployment rate for Cherokee County was 7.7, higher than the unemployment rate for the state of Kansas (6.7) (Policy Map, 2010). Twenty percent (20 percent) of the population works in the manufacturing industry, followed by 17 percent of the population works in the healthcare and social assistance industry, and 14 percent of the population works in the retail trade industry (Policy Map, 2010). An estimated 12 percent of families in Cherokee County live in poverty.

Table 1.

Estimate of Parentage of Families Living in Poverty in 2010 in Cherokee County, KS

City	Zip Code	percent Living in Poverty
Baxter Springs	66713	10.44
Columbus	66725	12.46
Galena	66739	15.17
Riverton	66770	10.42
Scammon	66773	17.26
Treece	66778	9.09
Weir	66781	6.54

Seward County

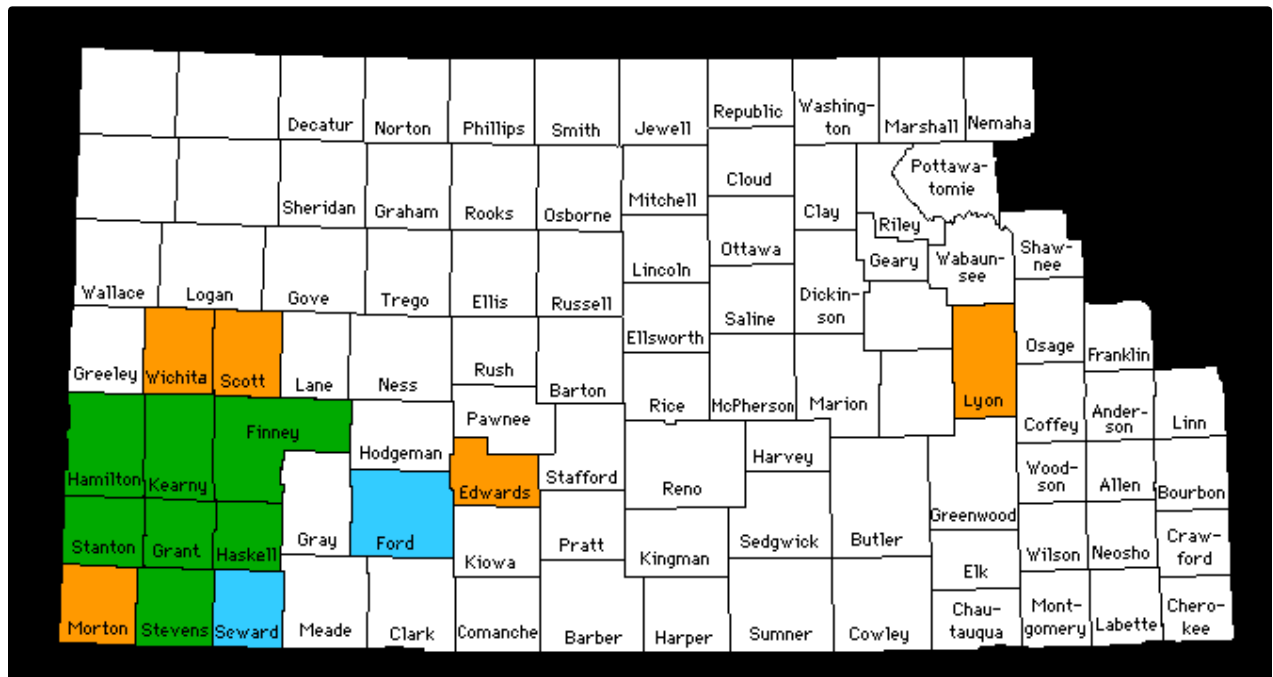
Goal: The Affiliate is interested in understanding the reasons why women are not getting a mammogram in Seward County and the unique role the demographic composition of Seward County plays in low mammography rates.

Seward County was chosen as a target community because Seward County has the highest percentage of Hispanic residents in Kansas (56.6 percent) and because of the high percentage of women in Seward County who reported not receiving a mammogram in the last 12 months (39.9 percent). Hispanics face barriers to obtaining mammograms such as language, lack of insurance, and cultural barriers. These barriers have resulted in Hispanic women having among the lowest screening rates of all racial and ethnic groups. This has led, in part, to breast cancer being the leading cause of mortality among Latina women and five-year survival rates for Latina women being among the lowest of any racial or ethnic group (Smigal et al, 2006; ACS 2009a, ACS 2009b, Engelman et al, 2011). Given these statistics, it is not surprising that over a third (35%) of Hispanic women report no regular access to health care, which is more than double the percentage (15%) of non-Hispanic who report now regular access to health care (NCHS, 2007).

According to 2010 Census Data, Seward County has a total population of 22,952, with 12,990 of those residents being of Hispanic origin, making Seward one of just two Kansas counties (Ford) with a majority Hispanic population (Census, 2011). Nine percent (9 percent) of the population in Kansas is Hispanic, with the largest concentrations of Hispanics being found in the Southwest corner of the state (Census, 2011). Sixty-two percent of the population of Seward County is of working age (18 to 64 years old) and 27 percent of the population makes less than \$25,000 per year. The unemployment rate in Seward County as of November 2010 was 4.5 percent, which was lower than the rest of the state (6.7 percent) (Policy Map, 2010). Nearly one in four women between the ages of 18 and 64 in Seward County (21 percent) are uninsured (Figure 3).

Given that just 66% of Hispanic women in Kansas over the age of 50 reported having a mammogram in the past two years (KFF, 2011f) coupled with the barriers to care faced by

Hispanic women, the need for culturally relevant programs tailored to the need of specific communities (Engelman et al, 2011), and the high percentage of Hispanic and uninsured women in the county, Seward County was selected as a target region that could serve as an emblematic county for the entire Southwest portion of the Affiliate area and its high concentrations of Hispanics (Figure 3).



Legend: Hispanic population by County in Mid-Kansas Affiliate

- Hispanic population 50% or greater
- Hispanic population 25-50%
- Hispanic population 15-24%
- Hispanic population less than 15%

Figure 3: Hispanic population in Mid-Kansas Affiliate by County

Riley & Geary Counties

Goal: The Affiliate is interested in understanding the reasons why women in Geary and Riley counties are experiencing such a high percentage of African American women diagnosed at Stage III and Stage IV.

Riley and Geary County are two contiguous counties in Northeast Kansas that center around the Kansas State University and Fort Riley communities located in the two counties. Additionally, Riley and Geary County have two of the highest concentrations of African-Americans in the Affiliate area. The median percentage of African-Americans in a given Kansas county is 0.61 percent, whereas the percentage in Geary County is 27.8 percent, which is the single largest concentration of African Americans in the Affiliate area and Riley County has 7.7 percent, the fourth highest concentration in the Affiliate area (Figure 4).

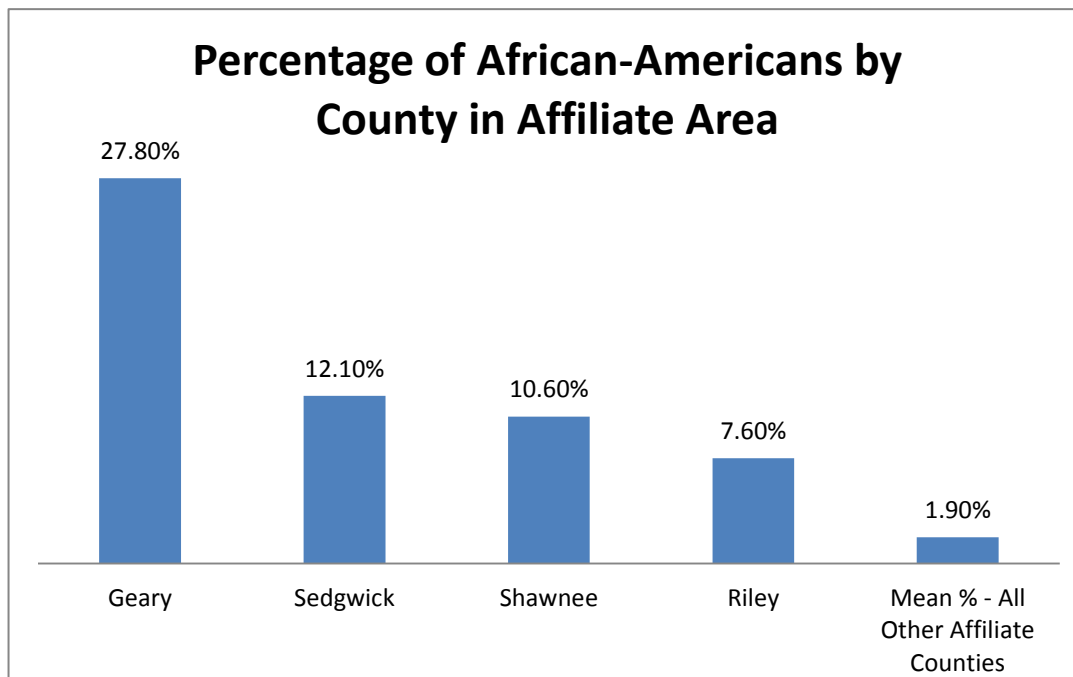


Figure 4: Percentage of African Americans by County in Affiliate Region

In addition to the high concentration of African-Americans within this target community, the Affiliate also chose the Riley and Geary County regions to be a target area due to the relatively high percentage of late diagnoses in the area. Geary County is the county with the highest percentage of cases diagnosed at Stage III (3.6 percent) and Stage IV (4.6 percent) in the state. The percentage of late stage diagnoses in Riley County is not significantly different than the other counties in the Affiliate region, but Riley County and Geary County do have two of the four highest concentrations of African-Americans in the state and African-Americans in Kansas have nearly twice the rate of Stage III (5.8 percent versus 3.3 percent) and Stage IV (8.0 percent versus 4.2 percent) when compared to White women in Kansas, making it especially important to examine potential barriers to screening among the largest African-American communities in the

Affiliate area (Thomson Reuters, 2010). Geary County also suffers from a lack of screening, as Geary County has the third highest percentage (42 percent) of women over the age of 40 in the state who did not receive a mammogram in the previous 12 months (Table 2).

Table 2:
Ten Counties in Kansas with the Highest Percentage of Females 40+ Without a Mammogram within the Last 12 Months

County Name	Number of women \geq 40 years of age	Percent w/ no mammography in previous 12 months
Cherokee	5,518	42.6%
Hamilton	659	42.0%
Geary	4,948	41.8%
Allen	3,623	41.8%
Labette	5,846	41.7%
Norton	1,347	41.7%
Kearny	965	41.6%
Crawford	8,852	41.5%
Cheyenne	889	41.5%
7 counties (Lyon, Stafford, Osborne, Woodson, Edwards, Greely)	N/A	41.4%
State of Kansas	441,330	38.4%

Conclusions

In conclusion, Cherokee County, Seward County and Geary and Riley Counties were chosen as the three focal point sites because of the unique demographic composition of each county and a desire to come to a greater understanding of the relationship between those demographic characteristics and the relatively low utilization of mammography services or the high percentage of late breast cancer diagnoses in each community. 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 3 and Stage 4 breast cancer in the state.

Health Systems Analysis of Target Communities

Overview of Continuum of Care

The breast cancer continuum of care recognizes that breast cancer prevention and treatment is not a static, one-time event, but rather, it is part of an ongoing larger process of screening, diagnosis, treatment, and follow-up care. This continuum means there is no one-stop shopping when it comes to fighting breast cancer. Screening alone is no more the entire picture than treatment alone. Because of this circular process, it often requires a community approach and multiple organizations or agencies to provide an effective continuum of care for all women in an

entire community. A given community may have excellent capacity to treat and provide follow-up care for breast cancer patients, but have gaps in their abilities to provide screening services. Therefore, when analyzing a community, it is important to look at the gaps and barriers that may exist in each part of the continuum (Figure 5).

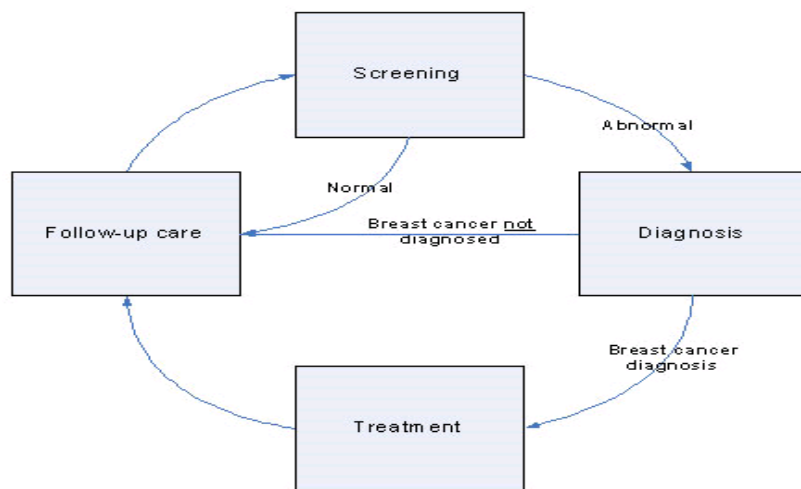


Figure 5: Continuum of Care

For the target communities included in the study, the entire continuum of care was important, but available screening and diagnosis services were selected for emphasis in the target areas. For Seward County, the barriers faced by Hispanic women in getting access to care and the overall low screening rates among Hispanic women made screening the point of emphasis of Seward County. Cherokee County did not have a unique racial or ethnic demographic composition that warranted its inclusion in the study, but the high number of those living in poverty or unemployed made access to screening services the focal points of the continuum of care in that community. Finally, In Geary and Riley Counties the relatively large proportion of Stage III and Stage IV cancers made diagnosis the point of emphasis along the continuum of care.

Methodology

In order to assess the assets present in each of the three targeted communities, health care providers were asked to provide data utilizing one of two approaches. Health care providers who were deemed key informants for their communities were asked to participate in a key informant interview which provided in-depth qualitative data for each target area from multiple individuals. Health care providers from the general community not deemed key informants were asked to complete an electronic survey that was designed to provide a quantitative component to the data collected for each target area as well.

This approach allowed for both an in-depth examination of an individual community's assets in relation to the continuum of care from a couple of more focused perspectives as well as a broader perspective based on the qualitative survey data of a larger number of key informants. These qualitative data were analyzed utilizing content analysis after each key informant interview was transcribed. Common themes were identified from these transcripts and compared with

frequency counts from the quantitative surveys to determine the degree to which the assets identified qualitatively matched the collective asset description provided quantitatively.

Key Informant Interviews

Participants

Six key informant interviews were conducted with eight community managers or other key stakeholders in three different Kansas counties or communities (Cherokee, Geary/Riley, and Seward). 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. These key informants largely had at least five years of institutional experience and were qualified to speak to the gaps and barriers in the continuum of care. Each key informant was asked to take part in a 13-question semi-structured interview.

Instrument

The key informant interview script focused on the characteristics of women who are not currently being screened for breast cancer, what type of barriers to screening they encountered, and ways to increase breast screening among the most vulnerable communities.

Procedure

Interviews were done using in-person or telephone interviews, with each informant's responses being recorded in writing by the interviewer. Once all interviews had been completed, responses were collected, and transcripts were analyzed for common themes.

Provider Surveys

Participants

The provider survey was designed and sent to all EDW providers in Kansas. EDW is the breast cancer and cervical cancer screening program that provides free pap tests and mammograms under the auspices of the Kansas Department of Health and Environment. As such, the population of EDW workers within the 95-county affiliate region who were sent the provider survey included physicians, CEOs, nurses, and other clinical and support staff at EDW providers.

Instrument

The provider survey consisted of 33 items designed to assess basic information about the clinic providers themselves, the source and type of breast health education information provided at the clinic, including the availability of materials in multiple languages, the demographic characteristics of the clientele who utilize services at the clinic (including breast cancer knowledge and ability to pay), the availability of screening services at the clinic, outreach efforts to encourage utilization of these services, and the existence of and willingness of providers to partner with community organizations such as Komen.

Questions were almost entirely close-ended, with respondents asked to select either a binary yes/no type response, complete a rating scale, or select an answer from a categorical list, such as the type of language in which educational materials were available. Open-ended responses were

available to allow respondents to add an ‘other’ response to some questions and to list specific community partners or specific attributes of the clinic.

Procedure

In order to distribute the survey to EDW providers, a survey link was provided to the KDHE who then distributed the link to one of five regional nurses located throughout the state of Kansas and the 95-county affiliate service area. These regional nurses are charged with oversight of the 104 EDW providers located throughout the state, and, as such, maintain a listserv of contacts for each provider clinic. Each regional nurse then provided a link to the survey to contacts on his or her listserv with a request for each clinic to designate one person to complete the survey.

Limitations

By using both interview and survey methods to gather qualitative data, this analysis should be able to paint a more broad picture of the experiences of women in each of the targeted communities from the provider perspective, but this approach may also yield inconsistent results that may be difficult to paint a true picture of women’s experience interacting in the continuum of care. Additionally, qualitative data often yields rich and detailed data about women’s experiences in the continuum of care, but these data are often anecdotal and may not reflect the true opinions or experiences of the entire community. However, by selecting multiple key informants from each region to be interviewed and including a survey as well, it is hoped that many of these limitations may be somewhat lessened.

Overview of Community Assets

The Mid-Kansas Affiliate has strong and long-term grantees in each of the target communities.

- In Cherokee County the Affiliate has a grant with the Southeast Kansas Early Detection Works Regional office to provide breast self awareness educational outreach, breast cancer support groups, and screening funds to pay for mammograms or partial mammogram fees for women who do not qualify for Early Detection Works due to income, age or insurance status.
- In Cherokee County, and 13 other Southeast Kansas counties, the Affiliate funds the Via Christi – Pittsburg hospital’s mobile mammography unit which provides mammograms, clinical breast exams and breast education.
- In Geary County the local health department is funded by the Affiliate to provide outreach to the African American community through community breast self awareness presentations, to increase the number of women who receive clinical breast exams at the health department, and to increase the number of referrals to the state EDW program.
- In Geary County the Affiliate provides a small grant to a local association entitled “It’s About Me” which provides education and outreach to African American women in Geary County through a one day event each October.
- In Riley County the Affiliate provides a small grant to the local university to provide an educational event for African American women in Riley County through a one day event each October.

- In Seward County, Komen funds are used to pay for screening mammograms and ultrasounds for undocumented women. These funds are provided in a grant to United Methodist Mexican American Ministries, Inc. (UMMAM). UMMAM also provides breast health education outreach and survivor support programs to Hispanic women in Seward County.

For a number of years the Affiliate has provided a grant to the Kansas Department of Health and Environment's Early Detection Works program to fund screening for women under the age of 50 who do not qualify by age for the CDC funded services.

The Affiliate's partnership with the Kansas Department of Health and Environment's Early Detection Works (EDW) program began when the program began funding breast and cervical cancer screenings in 1995. EDW provides breast and cervical cancer screenings and diagnostic services to women between the ages of 50-64 who meet income and insurance guidelines. Women diagnosed with cancer through EDW have access to treatment through the Kansas Medicaid Program (to be eligible for Medicaid, women must have no insurance, be legal residents of Kansas and diagnosed through EDW). EDW is primarily funded by the Centers for Disease Control and Prevention (CDC). CDC funds breast screenings for women age 50-64. These guidelines create a gap in breast services available to women under age 50. Grant funding from Komen ensures that breast services are offered to women under the age of 50. This year it is anticipated that Komen funding will provide services to 1635 women across the state.

Asset Map

An asset map of the 95 county service area was created. The data to determine the location of mammography centers was collected from the state department of health who compiled lists of Early Detection Works providers, Safety Net Centers and certified mammography facilities as determined by the U.S. Food and Drug Administration.

The asset map shows that mammography facilities are available in the priority areas identified in this profile. However, as mammography or diagnostic rates are lower than the state average in the target communities it is apparent that other factors such as language, education or insurance status play a part in women not understanding the value of screening (Figure 6).

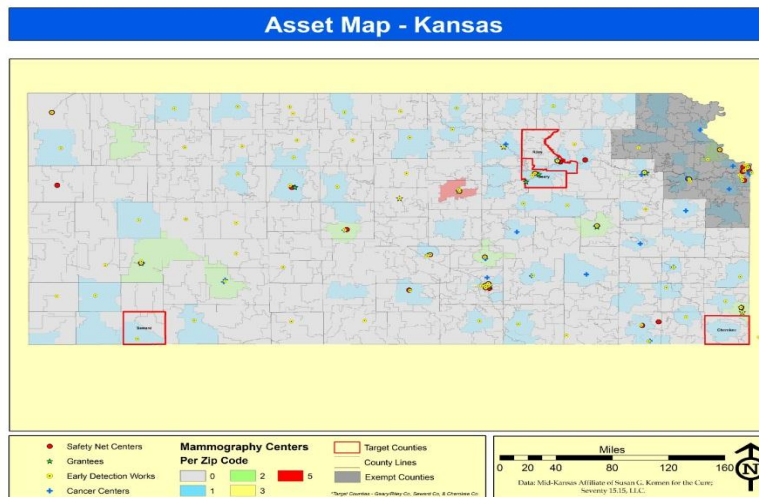


Figure 6: Community Asset Map Depicting Mammography facilities

In addition to the larger assets available to the Affiliate across its entire 95-county region, each of the three targeted communities also brings assets to bear. Some of these assets are unique to the region, while others draw upon the larger resources available to communities across the 95-county region. These assets include individual assets, such as individual survivors within each community, public health nurses and educators, and community volunteers. Communities within the targeted regions also have access to statewide institutions such as EDW and local chapters of the ACS. But they also have assets unique to the communities that play a role in supporting breast health such as the VFW in the military communities of Riley and Geary counties. Local communities also enjoy organizational assets such as community churches and large area employers that can serve as a point of contact and who can encourage breast health through their employee policies and programs. Finally, each community enjoys physical assets, such as oncology clinics and screening clinics, as well as strong community visibility through posters and brochures at local health departments, to local media awareness campaigns, to ‘pink’ games at local high schools (Figure 7).

Individual Assets	Survivors	Reach to Recovery Volunteers	Public Health Nurses	Friends and Family members	Social and Community Outreach Workers
Institutional Assets	Early Detection Works	American Cancer Society	VFW	Hope For You	Komen Mid-Kansas Affiliate
Organizational Assets	KDHE	Community Churches	Local Breast Cancer Support Group	Local Health Departments	Major Local Employers
Physical Assets	Women's Health Clinic	Local Hospitals	Oncology Clinic	Screening Clinic	Community Health Clinics
Community Visibility	Race for the Cure	Mobile Mammography	Relay for Life	Health Fairs	Posters and Brochures
	"Pink" Games at local high schools	Local Community Service	Local Television Media Campaigns	Community Calendars	October Pink Ribbon Campaign

Figure 7: Community Asset Map

Legislative Issues in Target Communities

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 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. Komen provides additional funding, through grants, for screening and education in Cherokee, Geary/Riley and Seward counties.

During the 2004 legislative year the Affiliate testified before the House Health Services committee to convince members of the Kansas legislature to provide \$230,000 in state general funds for EDW to screen symptomatic younger women. This marked the first time the state had contributed funds to the program. The Affiliate continues support of the EDW program through grants directly to the program and to the regional EDW nurses. During the 2010-2011 grant cycle \$206,000 were granted to the EDW Program for screening and an additional \$91,250 was granted to the program for outreach and education programs. The funds granted to the program from the Affiliate have allowed eligible women to continue to have access to screening when the EDW federal and state funds have been depleted before the fiscal year ended for the last three years.

The Affiliate continues to build strong relationships in the legislative community. The Affiliate has been a member of the state Comprehensive Cancer Control Program (CCCP) since its inception in the late 1990s. Members of the Affiliate Public Policy Committee have served on the Steering Committee of the CCCP and the Affiliate Public Policy Chair serves as Public Policy Chair for the Plan. Members of the Affiliate continue to be called on to provide testimony for the Plan on such subjects as expanded cancer screenings, clean indoor air programs and to support an increase in the tobacco tax to provide funds for health care reform in Kansas, including increasing the state general fund support of EDW.

Through these partnerships and with the leadership of the EDW the Affiliate continues to provide access to breast health screenings to the women in the Affiliate's 95-county service area. During the current fiscal year the \$230,000 from state general funds appeared to be in jeopardy of limitation. The leadership of the Department of Health and Environment and the Affiliate restored the funds and signaled its continued support of the women of Kansas and the mission of Komen.

Public Policy Goals for 2011-2012:

- Maintain current funding for the state Early Detection Works program for breast and cervical cancer screening.
- Strengthen the Kansas Clean Indoor Air law to protect all Kansans from known carcinogens.
- Support advocacy efforts in the state to pass a bill to increase the tobacco tax and secure the funding for health reform, including expanded cancer screenings.

- Implement the national health care reform laws in Kansas
- Continue to work with members of Congress in support of Komen national initiatives.
- Continue to work with the Greater Kansas City Affiliate to build strong relationships in the state.

Key Informant Findings

1. There is no single type of woman least likely to get screened

“The biggest diversity is [being] poor.”

Based on key informant interviews and survey responses, there are barriers and gaps in the continuum of care in two primary areas, the first is even getting women into the continuum of care with an initial screening for breast cancer.

Descriptions of ‘who’ is not being screened varied widely from community to community and reflected the underlying racial and ethnic differences within each community. The ascriptive statuses of those least likely to receive screening services included Hispanics, Native Americans, and Caucasians. However, when looking beyond the physical characteristics of those least likely to be screened, social class became readily apparent as the one unifying factor among all women. The names of the specific employers changed from community to community, but those women least likely to be screened primarily worked in low-skill blue collar occupations such as the garment industry or meat packing plants. One informant reported that women in her areas least likely to be screened were even cut off largely from television, newspapers, and telephones, making them even harder to reach.

So, while a single, over-arching profile cannot be constructed of those women most in need of breast cancer screening but least likely to receive services, they are easy to find, existing on society’s margins working in menial occupations, often living paycheck to paycheck or on disability – they are, in short, the working poor. Language, education, and insurance all serve as barriers for those women to screening services, making it a necessity to bring the services to these women least likely to be receiving screenings. According to providers, the uninsured, the working poor, those with less formal education, and low income women were the groups of women least likely to be screened for breast cancer (Figure 8).

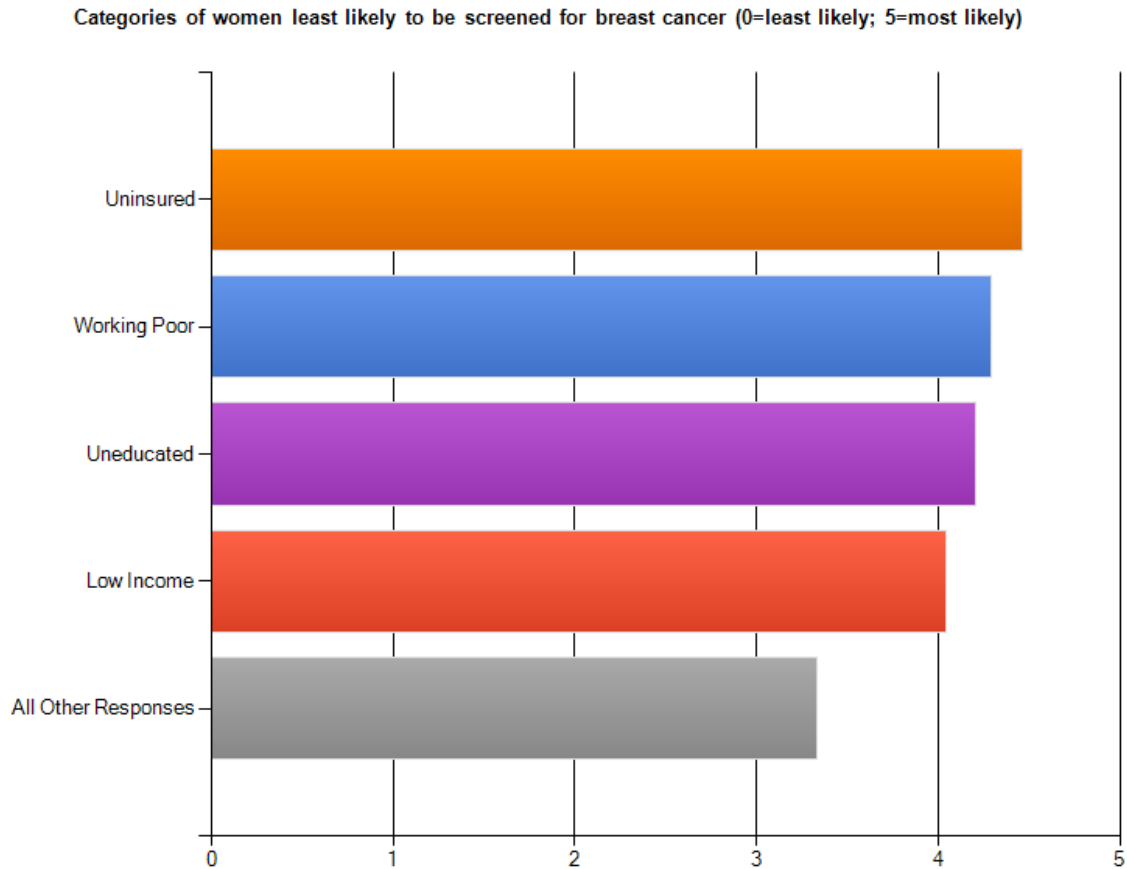


Figure 8: Categories of women least likely to be screened for breast cancer

2. Lingual and Cultural Differences are a Barrier

It was the opinion of the key informants *interviewed* that the most basic knowledge about breast cancer and mammography is not a major problem, but among key informants *surveyed* knowledge was cited as a factor in women not being screened for breast cancer.

Reasons for this gap likely rest on lingual barriers as well as the difference between general knowledge and actionable knowledge. Among the English-speaking population, one level of breast health knowledge may exist, but among the Spanish-speaking population, another may exist. The majority of key informants surveyed (79 percent) indicated their clientele included non-English speakers who would benefit from breast health services, and while many of these same providers (72 percent) also provided such Spanish language breast health information, more than half (54 percent) still indicated there was a need for interpreters to provide breast health information in their communities.

Beyond lingual barriers, cultural barriers also exist in getting women to move from general knowledge about breast health to taking action to get screened. The need to bridge the gap between the general knowledge that women in general should get screened for breast cancer and that actionable knowledge that *I* will get screened serves as another gap in the continuum of care.

Perhaps underlying this gap are misconceptions about what mammography entails. The women who are most in need of screening, have never been screened and have heard the procedure hurts. There are also cultural barriers to moving women to action. When a general lack of a history of preventive measures and screenings exists within a family or cultural group it is difficult for individuals to move beyond that pattern and start getting screened. Key informants surveyed

“[The] biggest barrier [is] breaking through the tradition of family preconceptions...no one in my family has ever been tested and they are fine.”

indicated that after knowledge and lack of transportation, negative stereotypes surrounding breast health was the biggest barrier preventing women from getting screened (Figure 9).

Even when individuals do finally get screened or go in for treatment, getting patients to follow through with a care plan following a diagnosis can be a challenge, so, in many instances keeping individuals engaged can be as steep a hurdle as getting individuals to take action in the first place.

Too often, the key informants reported, individuals are staying away from screenings because they do not understand the value of screening and will only see a doctor once a lump has been felt or discoloration has been noticed – a point when the more positive outcomes associated with early detection may no longer apply. While economic issues and concern over paying for medical visits are very real issues, the lack of a supportive wellness culture for screening and services and the lack of structural incentives to partake in screening services stand alone as a unique and considerable barrier to individuals getting screening services.

Biggest barriers preventing women from seeking or obtaining breast health services. (1 = LEAST SIGNIFICANT BARRIER; 5 = MOST SIGNIFICANT).

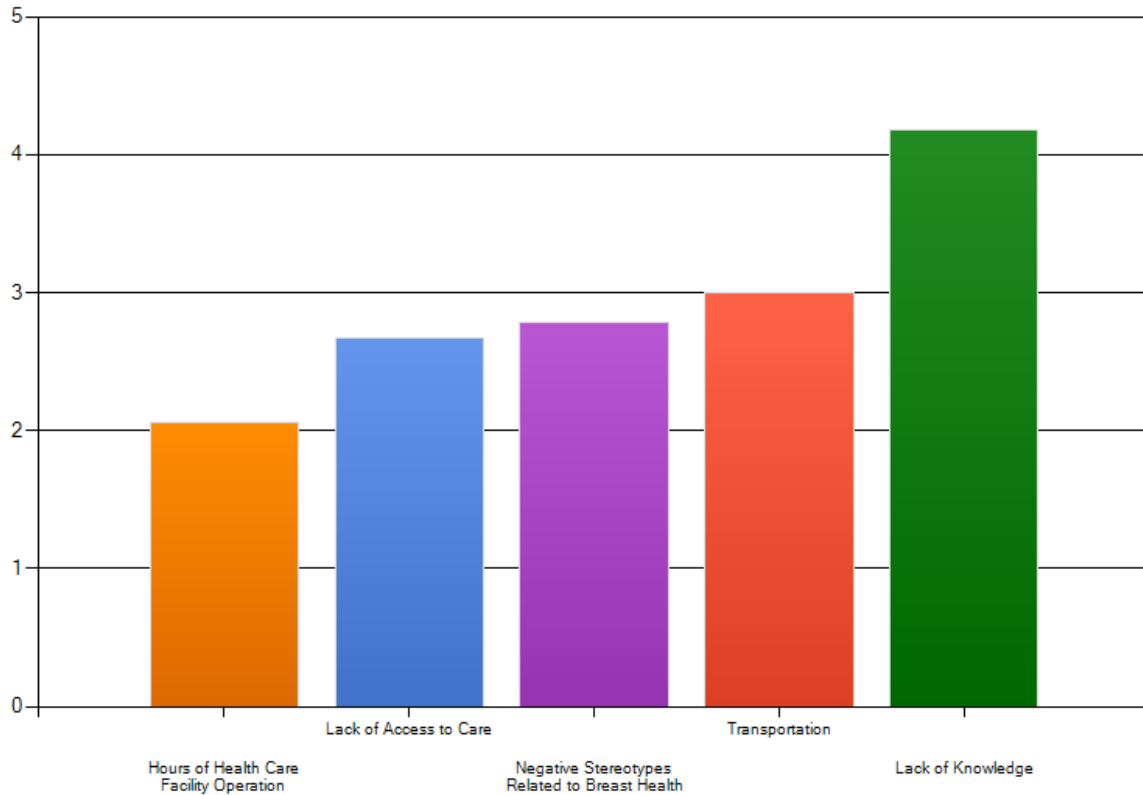


Figure 9: Barriers preventing women from seeking or obtaining breast health services

3. Navigating a patchwork of services and organizations can be detrimental to your health

According to the providers surveyed and interviewed, the biggest gap in the continuum of care occurs in initially getting women into the continuum to be screened, but additional gaps exist within the continuum of care once women do get screened. Among providers surveyed, 96 percent provided screening services, but just eight percent provided diagnostic services, and less than half provided any kind of outreach services.

The lack of a single, comprehensive medical system to encourage breast cancer screening was a central issue to many of the key informants. Navigating a murky maze of hospitals, doctors, mobile clinics and non-profits can be a difficult proposition under the best of circumstances. Adding in language barriers, a lack of insurance, or even the psychological distress of a recent cancer diagnosis can turn this maze into a veritable labyrinth of caregivers, information, and medical providers.

None of the individual informants in each community reported an overall lack of resources being available to those most in need of screening. Free screenings, mobile mammography, community health clinics, and non-profit hospitals were all cited as resources that do a good job of meeting community needs. However, a sense of connectedness between these organizations or a general

coordination of care for individuals was not reported by key informants and exactly which services were available in which community varied widely. Furthermore, a lack of insurance, a general inability to pay, and language barriers all serve to stymie access to the health system, which, once again, places the working poor and recent immigrant women at the greatest disadvantage to navigating the health care services available to them. Therefore, it is not surprising that among the key informants surveyed, a patient navigation program, as well as survivorship programs were cited as among the most potentially helpful programs to help women in their communities (Figure 10).

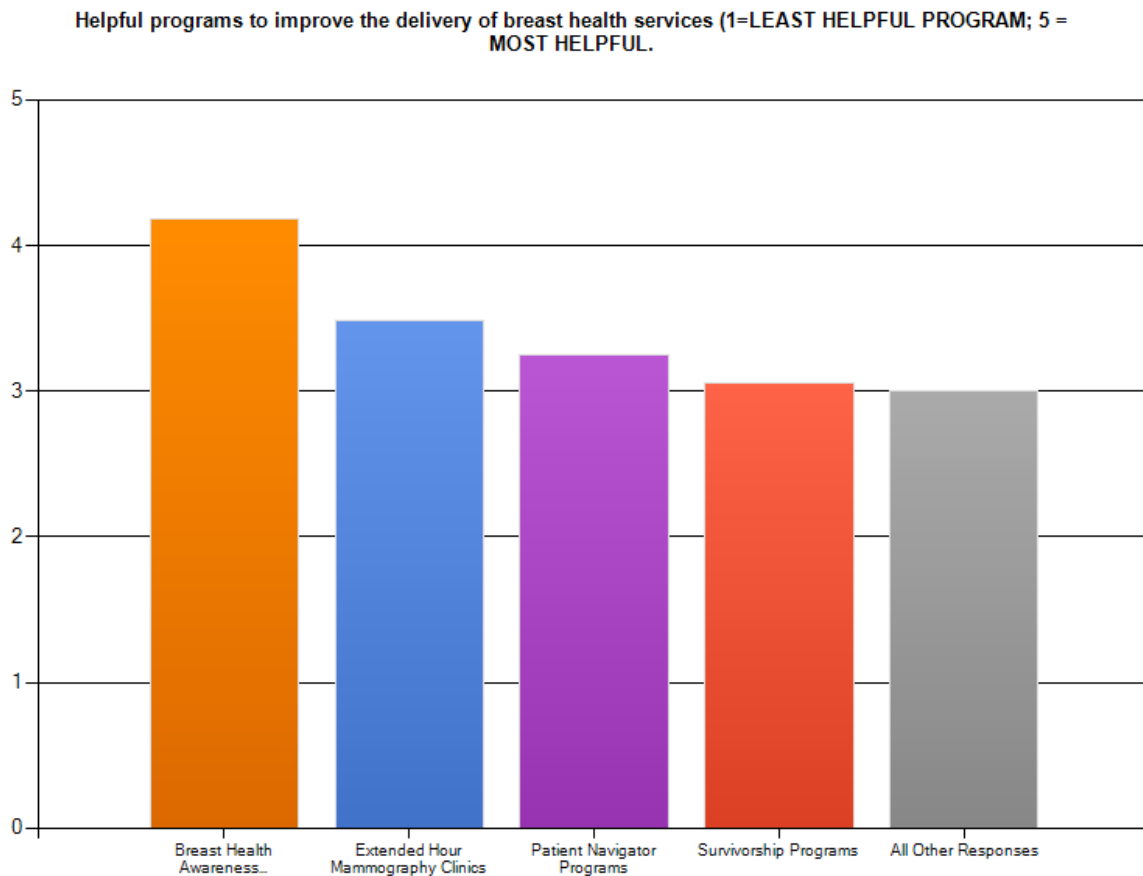


Figure 10: Potentially helpful programs for breast health

Conclusions

Continuing to meet the needs of women from all racial, ethnic, and socio-economic backgrounds will be an ongoing challenge, but certainly not an insurmountable challenge. There is no stereotypical breast cancer survivor – the ‘typical’ woman impacted by breast cancer in general and those at highest risk to fall through the gaps in screening and diagnosis varies from community to community. This lack of a common profile means that in order to meet the needs

of its constituency in the 95-county affiliate service area, grassroots solutions and community partnerships will likely be necessary to bridge the gaps that exist in the continuum of care.

The most substantial gap in the continuum of care exists at its point of entry. Among women in the profiled communities, being on the margins makes it more difficult to gain access to that continuum of care – if you never get screened; you never get into the system.

Informants did not report a lack of services in any one key area or report horror stories about one individual trying to navigate the system or deal with insurance companies or anything else. Rather, they reported 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 other major structural impediment is no doubt 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 or the challenge of navigating bureaucratic regulations to receive some of these services serve to 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, limited vacation time or sick leave, as well as multiple obligations at home. 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. Mobile mammography and on-site screening services at large industrial employers could prove a beneficial outreach option and patient navigation services could prove a valuable solution to helping bridge the gaps that exist within the continuum of care.

Breast Cancer Perspectives in the Target

Methodology

Survivor Surveys

Participants

Participants for the survivor survey were those breast cancer survivors from Komen events, such as the Race for the Cure®, from whom the Affiliate had e-mail addresses. Beyond e-mail addresses and residency within the 95-county affiliate region, no other exclusion criteria for participation were utilized.

Instrument

The survivor survey consisted of 43 items designed to assess: 1) attitudes about screening, 2) individual's breast cancer diagnosis and treatment, 3) any experience with clinical trials, 4) health insurance status, 5) current cancer status, 6) experiences and support services utilized while they were actively battling cancer, 7) experiences with the Komen organization, 8) and basic demographics.

Most questions were close-ended, with respondents asked to select either a binary-type response, complete a rating scale, or select an answer from a categorical list, such as household income. Open-ended responses were available to allow respondents to add an 'other' response to most of the items with categorical response structures. A more limited number of open-ended response items were provided to allow respondents to detail their experiences with clinical trials and to expand upon their perceptions.

Procedure

In order to distribute the survivor survey to the selected participants, a personalized e-mail invitation explaining both the purpose of the survey and its voluntary nature was sent to all breast cancer survivors in the Affiliate region whose e-mails were available to the Affiliate. Each personalized e-mail also contained a link to the survivor with instructions how to access and complete the survey.

Focus Groups

Participants

Focus groups were conducted in three different communities in the 95-county region and participants were recruited from organizations and agencies in those regions. The three communities selected were: 1) Cherokee County, which is in the Southeast corner of the state; 2) Seward County, which is in the Southwest corner of the state, and 3) Riley and Geary Counties, which are adjoining counties located in Northeast Kansas.

Focus group participants for the Cherokee County region were women over the age of 30 who were residents of Cherokee County. No additional exclusion criteria were established for Cherokee County participants. For the Seward County and Riley/Geary County regions, the same residency and age requirements for participation were established, but additional racial and ethnic components were included. In

Seward County, focus group participation was restricted to those who self-identified as Hispanic and in Riley/Geary Counties; participation was restricted to African-American women.

Instrument

Each focus group was conducted utilizing a structured nine-item interview script. Each item was a single question, with no questions containing multiple parts or embedded follow-up questions. The nine items included in the script included items assessing what Komen means to the participants, where the participants believe people in their community turn for information on breast cancer, perceived barriers and incentives to breast health screening and services, and experiences with breast cancer providers within their communities.

Procedure

Six focus groups were conducted during the month of February with community members in three Kansas counties (Cherokee, Geary/Riley, and Seward). In order to recruit participants, a combination of snowball or convenience sampling was utilized. Given the targeted nature of the focus groups and the qualitative nature of the research this sampling method was appropriate for a study of this design.

Women were initially recruited via phone calls from EDW nurses or community members to local business and organizations. In addition to these efforts, flyers were produced and distributed at locations such as churches, African-American sororities, major area employers, and with those who used mobile mammography services. These flyers promulgated the locations, time, inclusion criteria, and purpose of the focus groups to be conducted in the region. The flyers also promised meals, gift bags, and prizes as incentives for each participant.

Once participants had been recruited and agreed to participate in the focus groups, they arrived at the focus group site and were then read a script in which the purpose of the group, the voluntary nature of participation, and group confidentiality were explained. The focus groups in Geary and Cherokee County were facilitated by the same individual. In Seward County the groups were facilitated by a local individual whose first language was Spanish. The entire group was facilitated in Spanish, with a translation of the proceedings provided to Komen for analysis. The same script was used at each location and notes, but not transcription, were taken at each focus group.

Review of Qualitative Findings

With six different focus groups conducted with over 93 different participants in three different Kansas counties, there was a diversity of individual responses to each question included in the focus group; however, despite these individual variations, several key themes regarding breast cancer screening and health information emerged from the focus groups.

Results from the survivor survey were less conclusive than the results derived from focus group respondents, in part, because the populations were very different. Whereas the focus groups targeted low income and minorities, the survey respondents were 94 percent Caucasian, 91 percent had at least some college education, 82 percent lived in households making over \$50,000 a year and 60 percent lived in households making over \$75,000 a year. Yet, despite these differences from the women who provided input in the focus groups, the status of these women as survivors and volunteers with Komen help paint a more well-rounded picture of the gaps and barriers that exist within the continuum of care in our entire service area.

1. **Komen really matters to women**

While such a simple statement appears on the surface to be obvious, it belies the depth and uniformity of sentiment attached to the organization by breast cancer survivors. When asked what Komen means to women, the words ‘hope’ and ‘help’ appeared 41 separate times from among the 54 individual responses collected during the focus groups.

Participants expressed variations in the form that help or hope took in their own lives, but the image of the Komen organization serving as a beacon to women during what is often the darkest of hours was unmistakable. Providing information, supporting research, and advocating for a cure are all critical functions of Komen, but to these respondents, simply existing – the knowledge that there is somewhere to turn – is perhaps the greatest service it provides to breast cancer patients.

Komen’s ability to stand as the proverbial shining city on the hill for all women and organizations dedicated to the fight against cancer served as a real strength within each community. Komen serves as a beacon of hope and source of light and information for women within the target communities. Despite whatever socio-cultural-economic barriers the women within each community faced, knowing that an organization like Komen exists is critical to women.

“Hope for the health of women.”

Responses about what Komen means to women are included below:

- *“An organization that helps and promotes information to women over breast cancer and their health”*
- *“[You] Don’t have to be cut up and scared and don’t have to die because of Susan G. Komen”*
- *“Help for women that has[sic] no insurance”*
- *“Means that there is hope for women, that Susan G. Komen is trying to find a cure”*
- *“They inform people and get you information that you need.”*

2. **Clinics are a critical source of information**

As a primary point of contact into the medical establishment, rural health clinics, community clinics, and mobile health screening services also serve as important conduits of information to the community. When asked about where people should turn for information on breast cancer, doctors were specifically singled out as a source of information, followed by clinics and women who have survived breast cancer. However, when asked about where people do turn for information about breast cancer, the term ‘clinic’ was largely substituted for ‘doctor.’

So, in respondents’ minds the more specific source of doctor stands out as the ideal type when it comes to sources of information, but clinics were the predominant response when the question centered on actual behavior. Additionally, while breast cancer survivors were identified as a good source of information to which individuals could turn for information, it was much less likely for respondents to identify breast cancer survivors as an actual source of information to which individuals turn.

Survivors can be an excellent source of information, especially in their ability to relate information on a personal level, so reasons for this gap warrant further exploration, but perhaps if a breast cancer survivor is not in an individual’s immediate social network or among an individual’s family and friends, it may seem awkward or uncomfortable to discuss.

Clinics served as both a strength and a weakness within the target communities. For those able to access their local version of a clinic, they were able to provide information to women in the community, but there was differential access to clinics reported within each community and the fact that a clinic is an institution and in most cases a static one that individuals must go to, their ability to provide information, as well as support and guidance is limited. Therefore, in order to serve as an unmitigated strength, it is important that clinics exist as part of a larger network or support and information available to women within each community, so that their holistic health surrounding breast cancer is addressed across the entire continuum of care.

“The ones that have someone going through this or have experienced this [are ideal sources of information].”

Responses about where one *should* get treatment are included below:

- “Doctors and people that have had breast cancer or family members.”
- “Health centers, people that have had cancer.”
- “I think those persons that have been there something like cancer of family members.”
- “Survivors of breast cancer.”
- “Women that work in the clinic and in charge of programs about breast health.”

Responses about where one actually does go to get treatment are included below:

- “Clinic or Doctor.”
- “Community Clinics.”
- “Methodist Clinic and Health Department.”
- “To our center of health closest to us.”

3. Money matters

Financial issues loom as the primary barrier to care for many women. Misinformation, fear about the procedure, and a lack of awareness about the need for preventive services all contribute to individuals not being screened as often as recommended, but oftentimes the bottom line in terms of screening *is* the bottom line.

Financial barriers to care included not just an inability to directly pay a bill for services, but extend to an inability to afford insurance, working in a job that does not offer benefits, and working in an occupation with inflexible schedules that makes the ‘cost’ of getting screened prohibitive for many women. When you add fear, stigma, and confusion to the cost equation, the mental and emotional toll of being screened or treated can become substantial.

Finances served as a real weakness within the targeted communities. Finances and financial difficulties are far-reaching in that they can range from a simple inability to pay to more complicated financial issues such as lack of access to insurance or lack of flexibility within a job to leave work for screening. In those instances, even if direct ability to pay is not at issue, the larger economic uncertainties, undiversified local economies, and high unemployment make women unwilling to risk wages or jobs to obtain screening services. Providing direct financial assistance can help to a degree, but many of the financial barriers are driven by larger structural factors that are beyond the control of a single organization such as Komen. Therefore, until local economies improve, more employment options, or more employment with flexible scheduling or on-site screening, the larger financial barriers will stand as a weakness within each community and will stand as a weakness that is perhaps most beyond the purview of Komen’s ability to affect change within a given community.

Responses about financial barriers to screening and treatment are included below:

- *“Embarrassed, short on money, for them to build trust, establish good patient relation, better customer service from the clinic.”*
- *“Economy, there is not enough information, embarrassed, language, training for the staff/personnel to be nicer.”*
- *“Hard to get away from work.”*
- *“Lack of Insurance.”*
- *“Provide support assistance if they don’t have support.”*

“Being turned away for lack of insurance, looked down on or made to feel like a charity patient [can be a barrier to care].”

4. Creativity is Essential

Reaching the intended audience with the appropriate message is critical to any marketing campaign and addressing the gaps that exist in screening for at-risk populations will be no different.

According to respondents this creativity in approaches to meeting the screening needs begins with the need to establish a women's only clinic. Responses across questions struck upon stigma, embarrassment, lack of support from medical staff and a general need for a safe haven to receive medical screening and care related to breast cancer.

In addition to thinking beyond the existing provider structure, respondents offered multiple suggestions to take the need for screening to the people in an effort to make screening services more accessible. Some of these solutions include coupling a desire for cheaper services with existing health campaigns, such as free and reduced screenings during October, national breast cancer awareness month. Another suggested strategy included going beyond the existing health care system and bringing screening information and service to places such as Wal-Mart so that time no longer stands as a deterrent to getting screened. Finally, awareness campaigns targeted specifically to certain cultural groups, such as the Hispanic population were also identified by multiple individuals within focus groups.

“Need to focus on diverse women. Do not put info just for one race because isolates other women.”

With no one face of breast cancer and breast cancer screening gaps, it logically follows that solutions will also not be macro-level changes, but rather a series of community level structural changes that can help meet the needs of individuals within each community. By taking this approach it is possible to reach *all* women who need breast cancer screening.

The creativity and ability of each community to attempt programs and outreach efforts serve as strengths within the targeted communities. As each community has its own structural, cultural, and economic realities, it is vital that each community exhibit the ability to tailor services to the unique needs of their community. Each of the target areas had exhibited the ability to adapt to the needs of their community be it working within the network of churches highly utilized within the community, providing Spanish-language materials, or providing mobile screening, the ability to meet the needs of the population is a real strength within the target areas.

Responses about ways to breach the barriers to screening and treatment are included below:

- *“Advertisement in newspapers, flyers, mailings.”*
- *“To have a clinic from women here in _____ like in _____ to understand that cancer doesn't hurt, sometimes it can happen so fast. It is good to have reminders and announcements.”*
- *“Mobile mammography for screening for harder to get to areas. Make it more accessible.”*
- *“Give women more information, classes, teach them about health so we can lose the fear and shyness, best of all give confidence.”*
- *“Give more information and services at lower cost. Programs, radio, TV, mail, etc.”*
- *“A special clinic for women in this community, educate us.”*

- *“More visitations from other organizations (like today’s), something more direct/related to this.”*
- *“Provide transportation.”*
- *“Providers need to do public service announcements of who are doctors in Community so that people know who to contact.”*
- *“For younger women can connect through facebook, twitter, blogging, conversations.”*
- *“Go out to schools and talk about breast health like they do for dental care.....when start talking about sex talk about breast health.”*
- *“Go to churches to talk about breast cancer.”*
- *“Have companies pass the message.”*
- *“More apt to pay attention to literature actually handed to them, rather than on a rack.”*

5. Social Status Matters

Both the focus group respondents and survivor survey respondents reported a sense of confusion surrounding breast cancer screening. The majority of survey respondents (56 percent) reported that women in their community were confused on when to begin breast cancer screenings. Additionally, the experiences of these respondents again indicates how important simply getting screened and getting into the continuum of care is for women. A plurality (47 percent) of survivors indicated their breast cancer had been detected by a mammogram and 58 percent indicated it had been definitively diagnosed via mammogram. Among these women, either a routine annual exam (36 percent) or finding a lump upon breast self-exam (31 percent) were the most common reason for getting screened for breast cancer, whereas family history, educational programs, or hearing public service announcements about the need for screening did little to motivate women to get screened, indicating again that the one of the biggest non-structural barriers to screening lies taking personal action.

However, there were important differences in this group that diverged from the common themes observed elsewhere in this research. Most survey respondents, survivor and provider respondents, (75 percent, 81 percent) rated both the quality and availability of breast cancer treatment services to be ‘good’ or ‘excellent.’ Most (51 percent) women did not feel a need to take part in breast cancer support group services and more women found their insurance provider (32 percent) more helpful than support groups (28 percent) during treatment. However, in addition to the demographic differences between this group and the focus group participants, another key difference emerged, as 98 percent reported having insurance. Thus, whether or not a woman finds gaps within the continuum of care of barriers to the continuum of care depends in large part on her social standing and financial wherewithal.

Despite having very different experiences navigating the continuum of care, more survivors selected financial assistance for screening from a list of 12 potential programs or services that could help improve screening rates, followed by mobile mammography, which again reinforces the common theme that while the entire continuum of care is important, simply getting women screened and actively into that continuum remains the most substantial barrier to screening and overall breast health among women in the 95-county region (Figure 11)

Types of programs that could help increase mammography screening rates

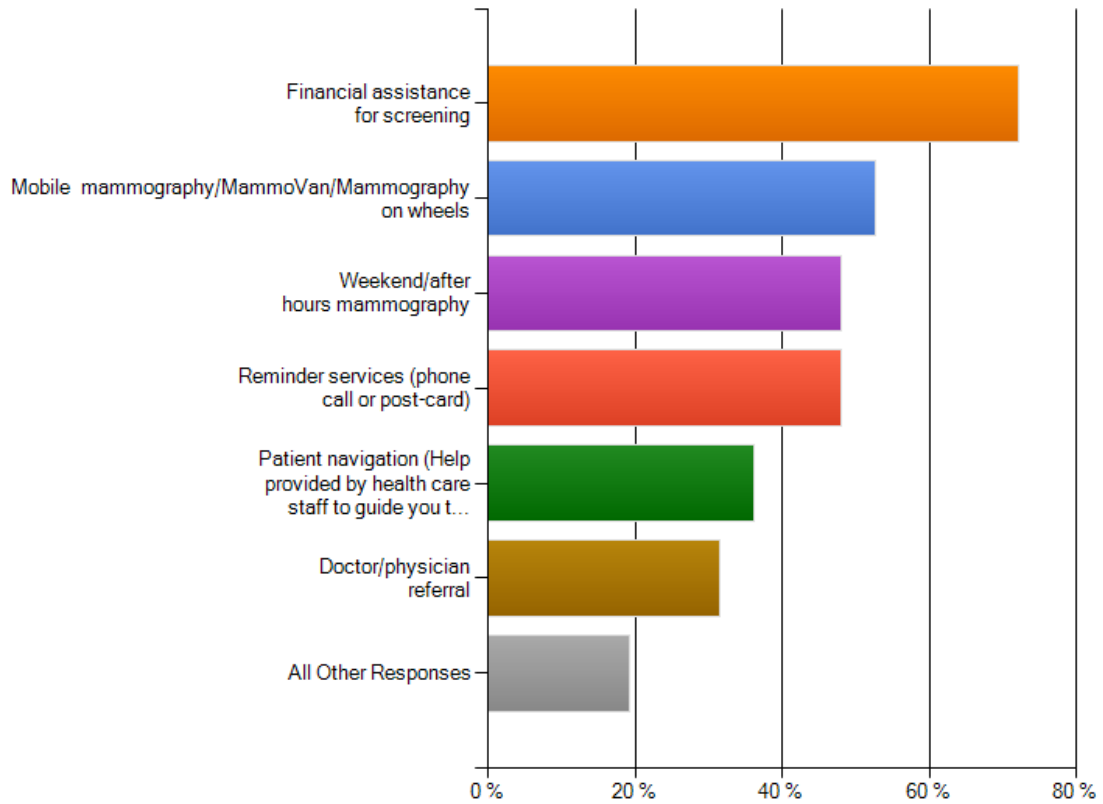


Figure 11: Programs to increase mammography screening rates

Conclusions

Several smaller themes merged throughout the analysis of selected communities in the 95-county region, but when combined with the previous analysis of key informants and the analysis of the communities in question, it becomes clear that screening itself is the largest barrier to getting women in the continuum. Differences between women exist from community to community, but even within communities, social class and social standing matter. From the analysis, though the degree to which this is true might vary from community to community, it appears a fairly substantial structure exists to allow women to take part in all portions of the breast health continuum. However, barriers do exist in even getting into the continuum via an initial screening and then once in the continuum finding out how to move through the continuum following a diagnosis can be difficult for women.

Conclusions: What We Learned, What We Will Do

Review of Findings

Komen overall has a relatively strong presence in the Affiliate area and enjoys a strong degree of public support and a favorable public impression. However, demographic differences across the state of Kansas mean that accessing the continuum of care is a different experience for different women in Kansas.

Those who have less access to health care do not speak English, who have low incomes, or have minority racial or ethnic statuses can often have difficulty getting into the continuum of care. Important barriers within these groups, such as education, an inability to speak the language, popular misconceptions about mammography and breast cancer, an inability to afford services or a lack of sufficient autonomy to structure their day so as to access breast health services and screenings all erect barriers between these women and better breast health.

Programs that reach out to these women and are able to facilitate their ability to avail themselves of screening services or are able to combat misconceptions about breast cancer have the most potential to reach women.

Conclusions

In order to address the gaps and barriers that exist in the continuum of care in the Affiliate, it will require outside-of-the-box thinking. While social class and social status stand out as the predominant themes in women'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 that drive these experiences for these women. 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.

A strong grassroots approach within each community, ensuring local resources are brought to bear and partnerships being created or enhanced, could serve as the ideal conduit of the Affiliate to effect change in these communities. Working within the communities to make mammography more accessible to women in the community will ensure that the largest gaps in the continuum of care in the Affiliate region will be addressed.

Selecting Affiliate Priorities

The Community Profile team reviewed the findings from both the quantitative and qualitative data to determine the common themes that we needed to address through our action plan. After reviewing the data it was determined that priorities fell into two categories: actionable education and addressing barriers to accessing care.

Action Plan

Overall Objective: Increase 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, 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 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.

References

- American Cancer Society. (2011). *Breast Cancer Facts and Figures: 2009-2010*. Available from: <http://www.cancer.org/acs/groups/content/@nho/documents/document/f861009final90809pdf.pdf>
- Census Bureau. (2011). *Kansas Counties Resident Total Population Estimate* (July 1, 2009). Available from: <http://censtats.census.gov/cgi-bin/usac/usatable.pl?State=20000KansasCounties=20000&TableID=AAA&x=12&y=9>
- National Cancer Institute: . (2010). *Surveillance Epidemiology and End Results* [data file]. Retrieved from: <http://seer.cancer.gov/>
- PolicyMap Geographic Information Systems. (2010). PolicyMap [computer software]. Available from: <http://www.policymap.com/>
- Kaiser Family Foundation. (2011a). *United States: Breast Cancer Incidence Rate per 100,000 Women, 2007* [data set]. Available from: <http://www.statehealthfacts.org/profileind.jsp?ind=469&cat=10&rgn=1>
- Kaiser Family Foundation. (2011b). *United States: Breast Cancer Deaths per 100,000 Women, 2007* [data set]. Available from: <http://www.statehealthfacts.org/profileind.jsp?ind=471&cat=10&rgn=1>
- Kaiser Family Foundation. (2011c). *Kansas: Breast Cancer Incidence Rate per 100,000 Women by Race/Ethnicity, 2007* [data set]. Available from: <http://www.statehealthfacts.org/profileind.jsp?ind=470&cat=10&rgn=18&cmprgn=1>
- Kaiser Family Foundation. (2011d). *Kansas: Breast Cancer Deaths per 100,000 Women, 2007, 2007* [data set]. Available from: <http://www.statehealthfacts.org/profileind.jsp?ind=471&cat=10&rgn=18>
- Kaiser Family Foundation. (2011e). *Percent of Women Age 50 and Older Who Report Having Had a Mammogram, 2008* [data set]. Available from: <http://www.statehealthfacts.org/profileind.jsp?ind=480&cat=10&rgn=18>
- Kaiser Family Foundation. (2011f). *Kansas: Percent of Women Age 50 and Older Who Report Having Had a Mammogram Within the Last Two Years, by Race/Ethnicity, 2006*[data set]. Available from: <http://www.statehealthfacts.org/profileind.jsp?ind=481&cat=10&rgn=18>
- Thomson Reuters. (2010). *SGK Community Profile Analysis Data Pack* [data set]. Unpublished raw data from Susan G. Komen.
- Smigal C, Jemal A, Ward E, Cokkinides V, Smith R, Howe HL, ThunM. Trends in breast cancer by race and ethnicity: update 2006. *CA Cancer J Clin*. 2006 May-Jun;56(3):168-83.

Engelman KK, Cupertino AP, Daley CM, Long T, Cully A, Mayo MS, Ellerbeck EF, Geana MV, Greiner A. Engaging diverse underserved communities to bridge the mammography divide. *BMC Public Health*. 2011 Jan 21;11:47.

American Cancer Society. *Cancer Facts & Figures for Hispanics/Latinos 2009-2011*. Atlanta, GA: American Cancer Society; 2009.

American Cancer Society. *Breast Cancer Facts & Figures 2009-2010*. Atlanta, GA: American Cancer Society; 2009.

National Center for Health Statistics. *Health, United States, 2007 With Chartbook on Trends in the Health of Americans*. Hyattsville, MD; 2007.