COMMUNITY PROFILE REPORT

SUSAN G. KOMEN FOR THE CURE GREATER EVANSVILLE

2011

Disclaimer:

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

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Instructor of Health Services at the University of Southern Indiana
Dr. Eggleston provided oversight for the entire project and conducted the majority of the research and data collection. His service to Susan G. Komen for the Cure® has been invaluable and we appreciate him.

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Executive Summary

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 become 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.

The Greater Evansville Affiliate of Susan G. Komen for the Cure® was founded in 1998 and incorporated in 1999. We serve 28 counties in Southern Illinois, Southwestern Indiana and Western Kentucky with our education and grants.

To date, we have dedicated $5.2 million to tri-state agencies for breast health education, screening, treatment and support initiatives. In addition, we have directed $2 million to Komen Headquarters for National Research Grants.

Our top fundraising event is Race for the Cure®, drawing the most participation and dollars. However, we have a number of other fundraising events throughout the year, notably Hoops for the Cure and Bowl for the Cure events.

The purpose of our Community Profile is to ensure the efforts backed by Susan G. Komen for the Cure are targeted and non-duplicative and allows the organization to:

- Drive inclusion efforts in the breast cancer community
- Establish focused grant priorities
- Establish focused education priorities
- Establish direction for marketing and outreach
- Drive public policy efforts
- Strengthen sponsorship efforts
- Align strategic plans with operations and Affiliate goals

The Greater Evansville Affiliate's Community Profile is actively used as a framework for identifying the prevalence of breast cancer on a local level, recognizing service gaps in the communities we serve and developing priorities to address those needs through grant making and other strategic activities.

Map 1: Greater Evansville Affiliate Service Map
This map shows the counties served by the Affiliate as well as their geographic location in proximity to one another.

Breast Cancer Impact in Affiliate Service Area

Data used for this report was from the Vanderburgh County Health Department, Centers for Disease Control and Thomson-Reuters Healthcare report (2010). Demographic statistics are based on 2000 Census data and prevalence/incidence rates are based on the NCI's Surveillance Epidemiology and End Results (SEER) data estimates.

Based on figures gathered in 2009 from Thomson-Reuters, The Greater Evansville Affiliate population (823,646) is a homogenous population that is predominately white (94.4%), rural, less likely to have a college education and earns less then the national median salary ($55,000). Groups that are more likely to have greater rates of mortality and morbidity related to breast cancer include minorities (African-American and Latino), having less education than a college degree, living in a rural area and earning less than $25,000 a year. The service area's unemployment rate was documented at 9% in March of 2009.

Our highest poverty rates and uninsured population are the downtown Evansville, Indiana area and the Affiliate counties in Southern Illinois. Downtown Evansville has the highest mortality cases and highest rates of late stage diagnosis. Our Illinois counties also have high numbers of late diagnosis, lack of treatment facilities and a great need for education. Given that information, those are our target areas.

Health Systems Analysis

We utilized community asset mapping to determine where our service providers, partners and potential partners were in our communities. Key informant interviews of 38 medical professionals from throughout the service are were used to further strengthen the information that we gathered in mapping. These individuals ranged from hospital administration, patient navigators, grantees, nurses, health department educators, BCCP providers and regional directors for BCCP.

Facilities within the service area provide a full range of services from education and screening, through diagnosis and treatment, as well as, various support services. Age or ethnicity based disparities were not identified. The majority of facilities treat both breast cancer patients and breast cancer survivors. While residents of the entire service area have access to care, residents on the area's periphery have fewer providers to choose from relative to those closer to the Evansville area.

Medical service providers, including doctors, county health departments, clinics and hospitals are considered credible sources for breast health information. Health fairs are the preferred method for educating large number of women. The most often cited method to educate the public is physicians educating patients during regular office visits

based on responses from medical professionals. Our education outreach and grant programs seek to educate those people who not regularly see a physician.

It is indicated that peers and family member are the primary factors motivating women to obtain regular mammograms. Women who have access to either private of public insurance are most likely to get a mammogram. The populations most often identified as in need were those with low income or the underserved.

Although we have worked legislatively to strengthen our state Breast and Cervical Cancer programs, there is work yet to be done. Our education need can also be met by partnering with local health departments to provide more education to women in our Affiliate.

Qualitative Data Overview

We conducted two focus groups in the downtown area of Evansville, Indiana and conducted one-on-one interviews in the same area. Additionally to obtain the survivor perspective we interviewed survivors who were served by a treatment program for low income, uninsured and underinsured patients.

We found that lack of awareness of breast health issues was a concern. Women were aware of where to receive free or low cost health care, but breast health awareness and education are not top priority. Working with area providers and clinics, we can increase that awareness with providing teaching materials and opportunities.

Low income survivors said that although their treatment options were discussed with them, they had a lack of understanding of what was going on and didn't feel they were part of their healthcare team.

While there is a myriad of programs and services to promote breast health, women who are poor or underinsured continue to face significant barriers to obtaining care. The Affiliate's current grant strategy of funding screening and treatment, while promoting education efforts appears aligned with the communities perceived needs.

The following are the Affiliate's priorities:

1. Increase the screening rates within the Downtown Evansville area and the most rural areas of Illinois in order to discover breast cancer at an earlier stage and decrease the mortality rate
2. Increase education efforts to build awareness of breast health for those underserved women who are not aware of available programs and services. Maximize the partnerships and relationships with community education sources so that we can reach more people with breast health and early detection education.

Affiliate Action Plan

Priority 1: Increase the screening rates within the Downtown Evansville area and the most rural areas of Illinois in order to discover breast cancer at an earlier stage and decrease mortality.

Objective 1: By March 2012 target two grants that seek to increase screening rate by 5% in the Downtown Evansville population or rural Illinois.

Objective 2: By October 2013 reach 500 women while working with ECHO Clinic, Deaconess Family Medicine Residency Program, Downtown Evansville churches and the Evansville Housing Authority to promote breast health education and early detection screening.

Objective 3: By July 2012 work with the BCCP program in Southern Illinois to increase awareness of the program by 10% to women who qualify.

Priority 2: Increase education efforts to build awareness of breast health for those underserved women who are not aware of available programs and services. Maximize the partnerships and relationships with community education sources so that we can reach more people with breast health and early detection education:

Objective 1: By October 2012 complete education train the trainer training for all of our current grantees.

Objective 2: By December 2012 cultivate a working relationship with 20 of the 28 County Health Departments or County Health Offices in our service area in order to expand our outreach and referral base.

Objective 3: By October 2013 the grant committee will develop and over some type of education program or mini-grant to reach the underserved population in Southern Illinois.

Objective 4: By May 2012 educate 50 African American women on breast health and early detection with help from TRI-CAP and the Sister's Network.

Affiliate History

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.

The Greater Evansville Affiliate started in 1998 when the first Komen Greater Evansville Race for the Cure was held. The Greater Evansville Affiliate was officially established in 1999 to provide services throughout 28 counties in the Tri-State area. We continue to do so and are able to say that all of our counties are currently reached by at least one Komen funded grant.

Since the inception of the Greater Evansville Affiliate $5.2 million has been granted to local agencies. These grants are for breast health and breast cancer education, screening, treatment and support programs. In addition, $2 million has been distributed to Susan G. Komen for the Cure's National office to help fund its Award and Research Grant Program.

Our Komen Greater Evansville Affiliate conducts breast health programs for area businesses, groups and organizations. We have disseminated countless pieces of breast health educational literature; and, conducted community education conferences. We strive to be the go to source for breast health education and information within the communities we serve. With the help of our grantees, we continue to update a resource directory so we can help direct breast cancer patients and their families in the right direction for assistance.

We work closely with the organizations we fund through our grant program. We rely on these grantees to keep us up to date on what is occurring in their communities and to assist us in our educational outreach efforts.

Organizational Structure

The Greater Evansville Affiliate is a member of the Susan G. Komen for the Cure organization. The Affiliate is governed by a local Board of Directors comprised of community leaders. The current board structure is that of a working board and many of the members are also involved with committees. Employed staff includes an Executive Director, an Office Coordinator and a Community Outreach Coordinator for a total of 3 Full-Time Equivalents (FTE's). Volunteers serve on a number of committees including, Education, Grant, Race for the Cure, including subcommittees, Bowl for the Cure events in Evansville, Henderson and Owensboro and other ancillary committees to plan fundraising events.

Description of Service Area

The Greater Evansville Affiliate service area includes 28 counties in Southern Illinois, Southern Indiana and Western Kentucky. Specific counties included in the service area are presented in the table below.

Illinois Counties	Estimated Population	Indiana Counties	Estimated Population	Kentucky Counties	Estimated Population
Edwards	5,671	Daviess	29,416	Crittenden	8,531
Gallatin	6,103	Dubois	42,020	Daviess	95,978
Hamilton	8,690	Gibson	32,486	Hancock	9,731
Hardin	4,148	Knox	37,735	Henderson	44,882
Lawrence	14,927	Perry	18,369	Hopkins	46,834
Richland	15,372	Pike	11,842	McLean	10,170
Saline	26,556	Posey	23,042	Union	15,857
Wabash	11,828	Spencer	20,771	Webster	14,575
Wayne	16,431	Vanderburgh	177,538		
White	15,238	Warrick	58,905		
TOTAL	124,964	**TOTAL**	452,124	**TOTAL**	246,558

Table 1: Service Area Population

The total population in the service area is approximately 823,646. Total female population was estimated at 421,202. Service area population is concentrated in five counties, Vanderburgh and Warrick counties in Indiana; and Daviess, Henderson, and Hopkins counties in Kentucky. These five counties account for about half of the total service area population.

The Greater Evansville Affiliate provides services throughout the entire service area through the use of grants up to $100,000 fro breast health, education, treatment, screening and support. In addition the Affiliate offers Community Pink Ribbon (CPR) grants for 10, 25 or 40 screening mammograms, education programs and program marketing through a streamlined process.

Purpose of Report

Susan G. Komen for the Cure's® promise is to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to find the cures. To meet this promise, Greater Evansville relies on the information obtained through the Community Profile to guide the work needed to accomplish the promise in its communities.

A quality Community Profile guarantees that local efforts backed by Susan G. Komen for the Cure are targeted and non-duplicative and allows the organization to:

- Drive inclusion efforts in the breast cancer community
- Establish directions for marketing and outreach
- Fund, educate and build awareness in the areas of greatest need
- Bring the message closer to home, into the community, to strengthen relationships with sponsors
- Give focus to public policy initiatives
- Align strategic plans with operations and Affiliate goals

This Community Profile assesses the current state of affairs within the service area with respect to community breast health. Specifically, the Community Profile investigates the three following major topics. First, the service area's demographics are examined. Second the community resources available for education, screening, treatment and support are identified. Finally, barriers to care are addressed.

The Community Profile is intended to identify and focus the Greater Evansville Affiliate on specific areas of need within the service area. These areas of need will drive the affiliate's efforts in the areas of grants for programs and services, fundraising efforts and public policy advocacy initiatives. In addition, the Community Profile will serve as baseline data that can be used to evaluate the effectiveness of the affiliate's activities.

Map 1: Greater Evansville Affiliate Service Area Map

Breast Cancer Impact in Affiliate Service Area

Data Source and Methodology Overview

County level data was primarily collected for the City of Evansville from the Vanderburgh County Health Department. Demographic data came for the most recent State and National Reports for all three states served by the Greater Evansville Affiliate (Illinois, Indiana and Kentucky). State and National breast cancer incidence and mortality rates came from the Thomson-Reuters Healthcare report (2010). We also utilized information from the Centers for Disease Control

Affiliate Service Area Overview

The Greater Evansville Affiliate for Susan G. Komen for the Cure serves approximately 823,646 people in 28 counties in three states: Illinois, Indiana and Kentucky. The population is concentrated near the city of Evansville. More than one-third (33.6%) of the population is aged 40-64 and 15.4% are aged 65 or older. A majority (51.2%) of the population is female. In total there are about 206,000 women aged 40 or older in the Greater Evansville area.

The female population is predominantly white (94.4%), 3.5% are African-American, 0.9% are Latina and 1.2% are other races. In contrast, the national average is 74% white, 14.8% Latina and 13.4% African-American. Minorities are most heavily concentrated in the following three counties: Vanderburgh, IN, Henderson, KY and Union, KY.

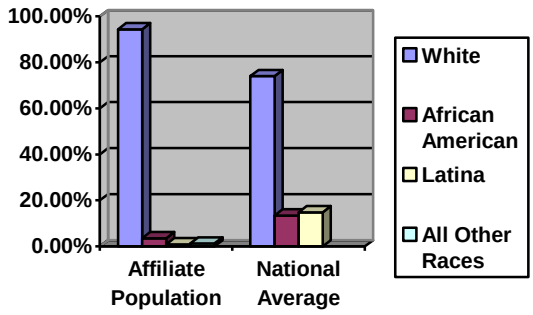


Table 2: Affiliate Race Population

The median household income is about $55,000 which is much less than the national average of $69,376. The percentage of families in poverty indicates that poverty is much more prevalent on the periphery of the service area. More than 17% (n=44,333) of women aged 18-64 do not have health insurance in the Greater Evansville area. In March of 2009 the unemployment rate for the area was documented as 9%.

Our average age of breast cancer diagnosis is 60.2 and in 2009 there were approximately 1829 prevalent cases of breast cancer with just over 300 of these being in Vanderburgh County (the largest county populations among the 28 in the Greater Evansville area). Nationwide the average age of breast cancer diagnosis is 59.1 and the total number of prevalent cases of breast cancer in 2009 was nearly 692,000. The incident rate per 100,000 women living in the Greater Evansville area was 115.49 in 2009 and 0.94 for males. The incidence rate per 100,000 for women aged 18-44 was 32.75, women aged 45-64 was 182.59 and women aged 65 or older was 311.53.[1]

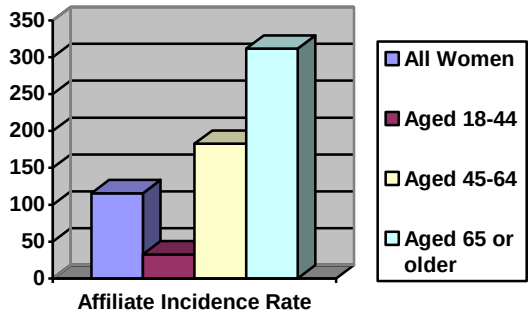


Table 3: Affiliate Incidence Rate

Most cases of breast cancers diagnosed in the Greater Evansville Affiliate area were in stage I (65.6%); with 26.8% in stage II, 3.3% in stage III and 4.3% in stage IV. [2]

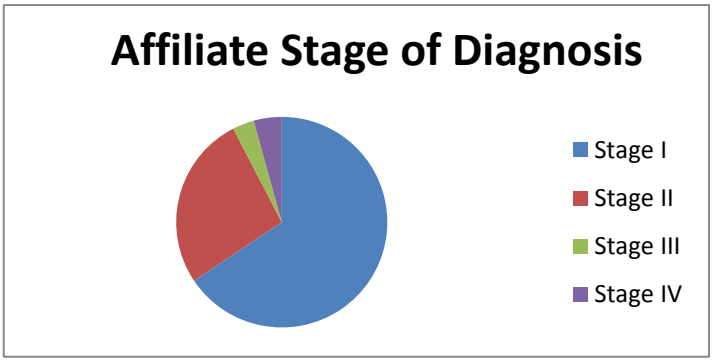


Chart 1-Affiliate Stage of Diagnosis

[1] 2009, Claritas Inc. 2010 Thompson Reuters
[2] Centers for Disease Control

Overall there is a general trend for a greater number of stage III and IV breast cancers to be diagnosed in the older, more rural counties of the Greater Evansville area. African American women are diagnosed in either stage III or stage IV in 13.9% of cases versus approximately 7.5% of other ethnic groups. It is estimated that just over 38% of women aged 40 or older did not have a mammogram in the past year. Overall in 2009 there were 117 deaths related to breast cancer in the Greater Evansville area.[3]

Communities of Interest

We chose to focus our attention on the African-American and under served population of Vanderburgh County, namely the downtown area of Evansville, Indiana. This location was chosen because of high mortality and high poverty rates. Facilities and services are readily available and are being underutilized. It also shows us that lack of facilities might not be a deciding factor for women throughout the Affiliate in whether or not to seek breast care.

Within the city of Evansville we find the highest mortality cases (25) and the highest rates of late stage diagnosis in the Affiliate (7.8%). This is of concern because the number of screening and treatment locations is highest in Vanderburgh County.[4]

There is a high level of uninsured women in Evansville (18.8%). The three zip codes we focused on primarily were 47708 which has a median household income of $17,833 for a 13% poverty rate; 47722 whose median income is $31,250 with a 6.9% rate of poverty and 47713 with the highest poverty rate in the Affiliate of 22.2% and a median income of $26,840.[5]

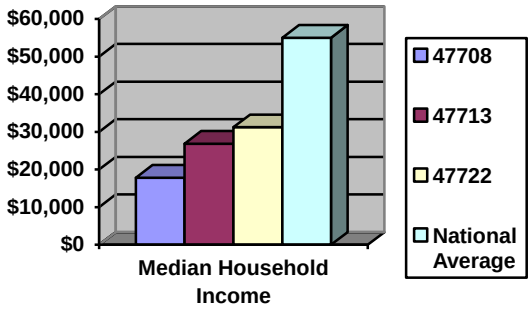


Table 4: Median Household Income Downtown Evansville

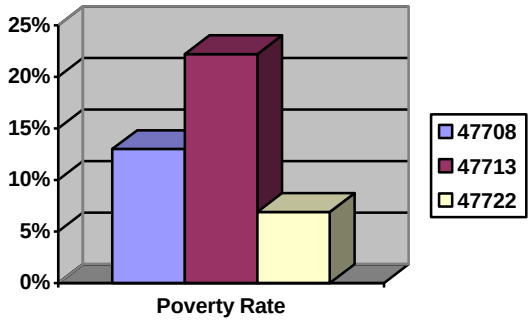
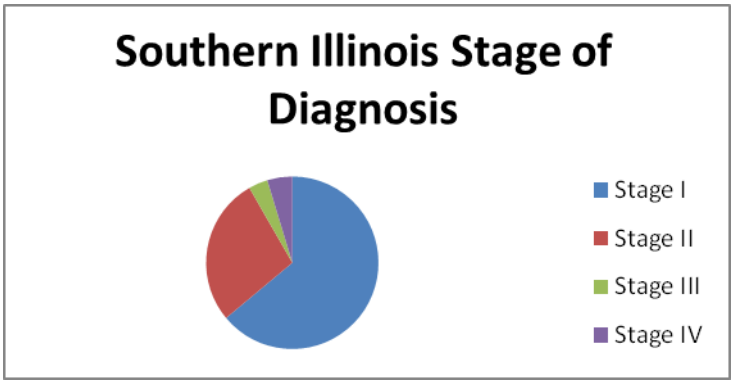


Table 5: Poverty Rate Downtown Evansville

[3] 2009, Claritas Inc. 2010 Thompson Reuters
[4] Vanderburgh County Health Department
[5] 2009, Claritas Inc. 2010 Thompson Reuters

Our secondary target was our counties in Illinois based on their rural location and lack of insurance. Southern Illinois also has high numbers of late diagnosis, lack of treatment facilities and a great need for education.

In our Illinois counties the rate for stage III diagnosis is 3.6% and stage IV diagnosis is 4.7%. They also have the highest rate of noncompliance with yearly mammogram recommendation from Susan G. Komen for the Cure. [6]



The rate of uninsured women in Southern Illinois is very high. All of the counties in our service area have uninsured rates higher than 23% except for Edwards County which is 16.4%. It should be noted that the county population for Edwards is less than 3,000 people. Gallatin County has the highest uninsured rate of 35% and 15.9% of families living below the poverty line. Gallatin County has a population of about 5,500 and has seen a population decline of nearly 14% in the past ten years. There is not a hospital located in the county.[7] [8]

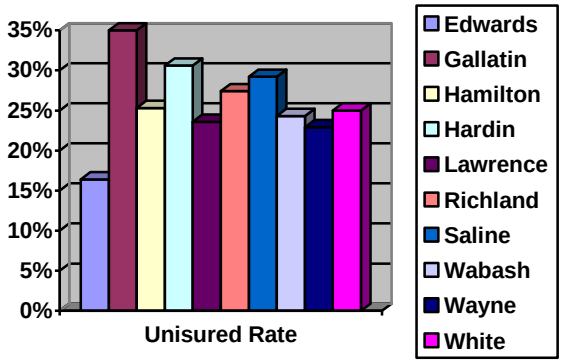


Table 6: Southern Illinois Uninsured Rate

[6] 2009 Claritas Inc. 2010 Thompson Reuters
[7] 2009 Claritas Inc. 2010 Thompson Reuters
[8] Illinois State Health Department

Education is also an issue in Southern Illinois because of the strong BCCP program in the state and the number of women who are still not utilizing it for yearly screening mammograms. In Illinois, any woman over the age of 40 without insurance, regardless of income, qualifies for free screening services. However, without knowing this service is available, it is difficult to utilize. By using our outreach, we can educate women over the age of 40 to take action toward lessening their risk of breast cancer and practice early detection methods.

Conclusions

Rather than focus on the entire Affiliate service area, we chose to take a narrower approach by focusing on Downtown Evansville, Indiana and our Southern Illinois Counties. This will allow us to create targeted programs that have the potential to impact the entire Affiliate.

We have found that women residing in the Downtown Evansville area are poor and uninsured. They have several free options for screening, but are not accessing them which is of concern because this area is also home to the largest late stage diagnosis figures in the Affiliate.

Our Southern Illinois counties are not densely populated, but overall have a high poverty and uninsured rate for women. The Illinois Breast and Cervical Cancer program is one of the least restrictive in the country, but isn't being used by all of the women who qualify. This is leading to late stage diagnosis for women who should not have to wait because free screening is available to them.

By educating women in our target areas about the importance of early detection we hope to increase our screening rate and in turn will increase our early detection rate. By helping women in our service area locate and utilize the free and low cost screening sites that are available, we can help them to enter and remain in the continuum of care.

Health Systems Analysis of Target Communities

Continuum of Care

The continuum of care refers to the range of services available within the health care sector, and to some extent, outside it, available address a patient's health and wellness. The term suggests a concept of an increasing intensity of care rather than a specific and unvarying list of services. The arrangement of preventative public health services, primary care clinics, local hospitals, and regional hospitals with intensive and specialty care units, is another array of the continuum of care. Theoretically, patients enter care at the lowest level capable of addressing their problem, and advance to higher levels only as their problems become more complex and demanding. Because of the constraints of financial access to care, lack of information to assist patients make best choices, geographic and cultural barriers, and other factors, the continuum of care is a theoretical model rather than an actual system of care delivery.

Our goal is that once a woman has entered the breast cancer continuum of care, she remains there for her lifetime. Our cycle begins with screening mammogram and takes a woman through diagnostics, treatment and follow up care. However, if a woman needs no further testing the continuum would be that she continues to receive yearly screening mammograms even if no problems exists.

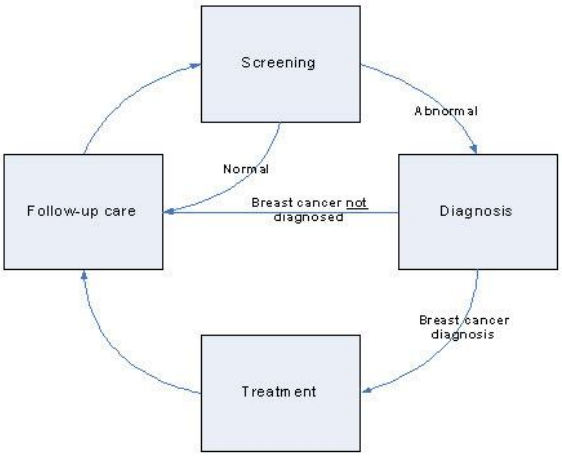


Table 7: Continuum of Care Model

By looking at the Continuum of Care and the assets we have in our service area we are able to identify gaps and barriers in our health care system. By focusing on the Continuum of Care, we hope to identify possible gaps before they become serious problems.

Methodology

In order to determine our strengths and potential weaknesses, we had to first study the service area to determine where our assets lie. We used a mapping process to determine where screening facilities, treatment locations, referral sources, current grantees, sources for educational information, community health departments and sources for financial assistance were located. This process included looking at our current resource guide, talking with our grantees about their specific areas and making phone calls to facilities in all of our counties to determine what services were offered. We then took a map of our service area and marked screening facilities, health departments offering breast health services or education, treatment facilities, support services providers and denoted which of those facilities were recipients of a Greater Evansville Affiliate Susan G. Komen for the Cure grant.

We also used a survey of key informants, all medical professionals from our Affiliate Service Area. These people we hospital administrators, patient navigators, grantees, nurses, health department educators and/or nurses, BCCP providers and regional directors for BCCP. Key informants answered 14 open ended questions regarding services provided in the area, local leaders in the breast health community, barriers to access, how to increase awareness of breast cancer and what drives someone to have a mammogram. The survey was conducted by phone and 38 people participated.

Some limitations we found in gathering data were we did not receive answers from a key informant in every county because some individuals chose not to participate or in some cases no one was available. The participants were not randomly selected, but instead a convenience sample was collected. Additionally, all participants in this section represent individuals who have an above average knowledge regarding prevention and treatment of breast cancer and might not be representative of the communities they serve.

Community Assets

Our service area has many assets in terms of screening and diagnostic mammography services. We have at least one screening facility in 20 of our 28 counties. Additionally, four of the counties without a facility are currently being reached by a mobile mammography program provided by two different Komen funded grantees. So, one gap that we discovered is that one county in Kentucky and three counties in Illinois do not have screening facilities and are not being served by a mobile program. However, all of our screening facilities serve surrounding counties, and those that do not have screening services have them available within a 30 minute drive.

Women and men residing in all of our counties have access to a treatment assistance program funded by a local Komen grant. The intent is to care for women and men who are under or uninsured who do not qualify for state or federally funded programs either because of insurance status or income. Patients must live in one of our 28 counties and

must meet financial guidelines of 250% of poverty and have either little or no insurance coverage. Each patient is capped at $6,000 and the patient navigator works diligently to obtain provider write-offs to maximize the dollars. Even those who do not qualify for treatment assistance receive education and other resources from the patient navigator. However, one gap is that we do not have many treatment providers in our service area. We have ten treatment providers, six of which are within 30 minutes of one another. The majority of patients in our outlying counties travel anywhere from 1-3 hours for care or they choose treatment outside of the service area. Without additional infrastructure, we are not sure how to correct this problem.

Residents living outside of the Evansville metropolitan area do not have services as readily available as those within. However, we did not identify lack of transportation as a significant barrier. Many of our grantees offer transportation assistance, predominately gas cards, however, some are able to offer bus tokens or cab fare for patients in need.

Currently we have working relationships with the majority of our screening and treatment facilities. Many of those providers are also grantees. However, two of our treatment facilities and four screening facilities are for profit and we do not have as strong as a relationship as we probably could. We need to reach out to these facilities as a partner rather than just a sponsor opportunity. Additionally, we should strive to have a better partnership with the local health departments. Because they are located in most of our Affiliate counties we can serve as resources for one another.

Map 2-Asset Mapping

BCCP Program and Legislative Issues

Beginning in 1991 our three states adopted a federal program to provide Breast and Cervical Cancer screening and treatment. In this program, federal funding as well as state funding is combined to care for women who are diagnosed with breast cancer. At its inception, states were given the option of three levels for treatment and care. Our three states chose different options.

In Illinois women have the least restrictive program in our service area. Any woman without insurance, regardless of income, who is over the age of 35 can enter the program and remain there until she has completed her treatment. The state of Illinois began their capacity building program in 1992 and their comprehensive program in 1995. Money is received from the Centers for Disease control in the amount of $6.5 million and the state provides $5 million. In 2009 the program added an incentive to women to be screened for breast cancer by offering them a $25 gift card from

Walgreen's. The only gap discovered with this program is our service area does not have a primary care facility for Illinois BCCP so women have to travel outside of the service area for treatment. However, women can be screened at any facility and still enter into the program if diagnosed with cancer. We also have a treatment center in Indiana that is a provider for Illinois BCCP so that takes the burden of travel off of some patients.

On July 1, 2009 Indiana's program became less restrictive. Women are able to enter the program regardless of where they received their original screening and/or diagnosis. Our Affiliate has made a commitment to continue, or increase where possible, our screening to take the burden off of the state. Women are able to stay in the program for the duration of their treatment. We still have a goal to lower the BCCP age from 50 to 40 so that more women are served, however, at this point preserving the state dollars budgeted for BCCP is more pressing. We are working closely with state officials, our Advocacy Alliance team and other Indiana Affiliates to keep funding levels current before we push for lower age or more dollars. The gaps in Indiana are too little funding and age requirements are too strict.

Kentucky's 120 County Health Departments serve as the home for screenings and referrals for diagnostic tests and treatment for the Kentucky Women's Cancer Program (KWCP). Women must be screened through the health department in order to gain access to the program. Eligibility is from age 21-65 without health coverage. Most of the counties do not have onsite mammography services and women are referred to a screening facility, occasionally outside of their county of residence. Medicaid services last for the duration of treatment and can be extended if a physician deems it necessary and reapplication is approved. Gaps in the Kentucky program are limited screening options and not being able to enter the program after diagnosis.

We have had much success in the past few years working with local legislators in Illinois and Indiana. In 2009 we were able to reduce the restrictions on screening for the state of Indiana. In Illinois we have spoken with local legislators about the possibility of a Regional Cancer Center. We are hopeful for the reopening of a hospital in 2012 in Southern Illinois giving us an additional provider. Kentucky has not been a focus of the Affiliate based primarily on manpower and lack of pressing need. In the 2012 and 2013 legislative cycles, we plan to partner with other Kentucky Affiliates to make moves toward making the BCCP treatment program less restrictive.

Key Informant Perspective

Our key informant surveys gave us valuable information that we can use moving forward. We found that most services are readily available in our Affiliate for those who know how and where to access them. We also learned that once a woman enters the continuum of care, regardless of insurance status, she typically remains there.

Most women in our area obtain reliable information related to breast healthcare from their primary care physician. This is the most effective way to reach women who have an existing relationship with a physician. Local health departments, local hospital and cancers centers were also mentioned. Heath departments are access point for the uninsured or underinsured.

Our key informants believe that health fairs and meeting personally with physicians were the two best ways to disseminate breast health information and to have women enter the continuum of care. Newspapers and brochures were identified by key informants who were from rural counties. Health fairs are methods to educate large numbers of people with limited resources. Physician patient interaction is the second most frequently mentioned which is consistent with previous responses listing physicians as the most credible source for breast health information.

Clinics and health departments were the most common places for regular breast healthcare. Health departments were more commonly reported in Kentucky where they direct the BCCP, making it clear that through health departments is the most effective way to reach the underserved population in Kentucky. ECHO Clinic in Evansville was listed as a source of regular breast care in Indiana; they are also a BCCP site.

Key informants identified low income or underserved women as those in the most need regarding breast health. These women were often characterized as likely having health insurance, but with high deductibles that made regular beast healthcare and treatment not a financial reality. Additionally, other women in these groups may not have health insurance and may not be aware that they qualify for a no-cost or low-cost program such as the BCCP or other programs sponsored by organizations such as Komen. We should continue current efforts of providing funding for screening and working to educate at-risk populations of other options available to pay for care.

Cost was identified as the top barrier for women receiving routine breast healthcare. This may be correlated with other question which identified women who do not have health insurance or who have high cost deductibles with their health insurance as underserved. Interestingly, while key informants rated cost as the top barrier to receiving services by a wide margin, they still cited education ahead of cost as the best way to reduce of eliminate these barriers to care. This may reflect the belief that it is unrealistic to expect free services for everyone. It may also indicate that the key informants believe that the most effective solution, given the current economic climate, is more education to increase awareness of the need for screenings and to overcome fear.

The top motivators for women to remain in the continuum of care are peers, family and education. A number of informants indicated that having a family member diagnosed was a strong motivator. Komen may be able to leverage this to reach underserved minority populations. However, one of the top barriers that still exist is education. Most key informants recommended that increasing education and awareness efforts, while

decreasing costs related to care would be the most effective improvements to breast healthcare continuum of care in their communities.

It was indicated that women with some form of private or public insurance are most likely to seek breast health services and remain in the continuum of care. Susan G. Komen for the Cure® funding is a component of the safety net attempting to assist those women without access to some form of health insurance.

Conclusions

The resounding message from the key informants was education and awareness being the keys to women entering and remaining in the continuum of care. While cost is an important factor, there are programs in existence to help women pay for screening, diagnosis and treatment who are uninsured or underinsured. However, they can only be accessed by those who know about them. One way that we can continue to educate our communities is to build stronger relationships with our county health departments.

Additionally, each state has an acceptable BCCP program, but there is more work that we can do to strengthen them. In Illinois we need to advocate for a regional cancer center or for one of the existing facilities to become a primary care center for BCCP. In Indiana we need to lower the application age from 50 to 40 to allow more women to receive yearly mammography screening. In Kentucky we need to work toward having women allowed to enroll in the program regardless of where she was diagnosed. Access to quality care is a high priority for our Affiliate and will be in the coming legislative sessions. We will also work toward preserving program dollars so that the state programs can remain.

We have strong relationships and partnerships with our providers and grantees. Many of the perceived gaps are due to lack of facilities. Although we cannot change that, we can leverage our assets and make sure that patients are cared for by neighboring facilities. Outreach efforts of ours and of our grantees can improve education.

Breast Cancer Perspectives in the Target Communities

Methodology

For this section we chose to conduct three focus groups with women from the downtown Evansville area. However, we actually conducted two focus groups and one-on-one interviews took the place of a planned focus group due to bad weather. We also conducted one-on-one interviews with six survivors from Evansville who received treatment assistance from a Komen funded grant based on lack of insurance and low income. We chose interviews over surveys because when you are talking to someone you can ask follow-up questions and get clarification where a written survey does not allow that.

One focus group was held at the Potter's Wheel, located in Evansville, Indiana in the 47713 zip code, in conjunction with a parenting class that takes place at the facility. Participants were asked ahead of time to be part of the focus group and in turn received breast health information and goodie bags from us and points toward supplies such as diapers from Potter's Wheel. We had 12 participants. One limitation was that four of the group members were men. This was unintentional, but may have hindered some of the women from answering questions openly. This location was chosen because they offer a day time soup kitchen in conjunction with their classes and we hoped to attract a largely diverse group of participants without using financial resources.

Our second focus group was to be held at Patchwork Central, but was cancelled twice because of snow. Instead, we conducted interviews with people as they came to the food bank and other assistance programs. We provided participants with breast health information and resources as well as a $10 Wal-Mart gift card. Participants did not know they were receiving anything for their participation. Patchwork Central is located in the 47708 zip code in downtown Evansville, Indiana and was chosen because it is a community meeting place for many families who live in this target area. We wanted to have a sample of everyday women who utilize the services of the facility.

Our third focus group was at Patchwork Central with women whose children attend an after school tutoring program. This group was small and probably the most effective, possibly because of the size of the group and perhaps because of the diverse participants. Participants received breast health information and resources as well as a $10 gift card to Wal-Mart, which they did not know about beforehand.

Limitations included not being able to target Evansville, Indiana zip code 47722 because it is primarily post office boxes and determining where those individuals live proved to be difficult. Also, because of the spread out nature of Southern Illinois we did not conduct focus groups or interviews during this Community Profile cycle. We did, however, rely on information obtained by grantees and medical providers in those counties.

Survivor interviews

Six individuals were interviewed that ranged in age from 33 to 56. The survivors were all women and lived in the target zip codes of 47708 and 47713 in Evansville, Indiana. Participants were chosen by the patient navigator of our Affiliate's grant funded treatment program. All of the women were post-surgery and several were post treatment. Most had insurance, but some did not. Those who had insurance had a mammogram as a part of routine care with the exception being those under 40.

Most were able to get information from pamphlets, the Internet and discuss treatment plans with their physician. Individuals reported a strong desire for more information regarding how to pay for treatment of breast cancer; where to go to meet with other women who were getting treatment or were breast cancer survivors; and also assistance in getting transportation to and from appointments.

Most people get information about breast cancer from their physicians, nurses and the Internet. However, one person reported being given false information from nurses and another individual reported getting poor and inconsistent information regarding triple negative breast cancer.

Barriers that were identified through the interviews were not being given consistent information and needing transportation assistance to and from appointments. It was also mentioned by almost all of the survivors that they would have liked someone to talk to about their experience.

In order to address the issues discovered, we have reintroduced our area support groups to local physicians and treatment providers. We support several support groups in the area, with the two largest being Woman to Woman and Ribbon Chicks located in Evansville and that meet monthly. The Ribbon Chicks is open to women diagnosed before the age of 45 and the Woman to Woman is open to any woman who has breast cancer.

Additionally, we are working with providers and a local gas station chain to assist with providing gas cards to women and men needing assistance.

Focus Groups

The individuals that participated in these interviews were coming to get free groceries through the Central Food Bank or obtain vouchers for baby supplies from the Potter's Wheel. We also rewarded them with a $10 gift card for Wal-Mart for their participation. Following asking the questions, we gave them information and resources such as where to get a mammogram and what services were available. At Patchwork Central Food Bank four women were interviewed and two in their later thirties, one in her early forties and one in her early fifties. One was African American, one was Latina and two were white. There were 12 people present at the Potter's Wheel Focus Group, four of which

were men. One man was African American and three of the women were African American. The remaining participants were white. Ages ranged from 19-45 but most were in their 20s.

Knowledge of breast health varied among participants in the focus groups. Many individuals did not have a primary care physician and were not getting regular breast exams and mammograms. When it comes to local sources for healthcare ECHO and TRI-CAP were to organizations that were commonly mentioned. When it comes to where to get financial assistance for mammograms, Deaconess (Family Practice Residency Program) and ECHO were two sources, but most did not know of any source besides paying for it themselves. One participant said, “I have a mammogram every year, maybe not the same time, but when I can pay for it. I didn’t know you all did that.” As she was learning there are resources available to assist in paying for screening mammograms.

The common sources for trusted health information were doctors, family, and the Internet. “When I have a health question, I call my mom to know what to do,” said a participant whose mother was also present.

Results show that the individuals from at risk communities (lower socioeconomic status and minority groups) still have difficulty in connecting Susan G. Komen for the Cure® as a place to information and assistance when it comes to their breast health. Many participants reported not knowing how to pay for mammograms and treatment regarding breast health/cancer. It is recommended for Susan G. Komen of Greater Evansville to do more outreach in areas where there are individuals without health insurance and at increased risk. Komen is a popular organization, but perhaps some individuals are not properly associated with the broad range of services and information that are available to the public. Komen goes far beyond raising money to find a cure for breast cancer and its efforts include increasing awareness, screening, and some assistance in treatment. It also carries over to the grantees that should be responsible for letting patients know that the education and services they are receiving is provided by a Susan G. Komen for the Cure® grant.

Conclusions

There are many health care providers in our Affiliate, but they are not equally distributed. The lack of medical facilities in the rural areas may prevent equal access to care. Underserved individuals experience disparities across the board from screening and early detection, to treatment and quality of care all affecting survival. The Greater Evansville Affiliate has strong programs that offer education, screening and treatment. We are able to provide services over a large geographic area. However, not all counties have all of the services available.

All 28 counties are still in need of additional efforts and resources for breast health outreach and education. The barrier of a lack of knowledge of resources related to screening, treatment and support need to be addressed throughout the service area.

Key informants identified health fairs, health departments and newspapers as methods for increasing education and awareness related to breast healthcare.

The only group in the entire process to mention transportation as a barrier to care was survivors who were assisted by the Affiliate's treatment grant. It was mentioned that going for treatment on a daily basis became a burden. This will be addressed within the treatment grant itself.

Conclusions: What We Learned, What We will Do

We are doing a good job in most areas of our Affiliate. Our grant portfolio is geographically diverse and we are reaching all of our 28 counties with at least one grant.

We work well with our community partners (healthcare providers, facilities, health departments, community members) however will strive to have stronger working relationships with our health departments in order to have a wider outreach.

The areas in greatest need of education, screening and outreach are Downtown Evansville, Indiana and the counties in Southern Illinois. By targeting on these areas, we hope to impact the entire Affiliate by increasing the early detection rate and decreasing late stage diagnosis. We have found the resounding theme of increasing education throughout this report so we plan to partner with organizations already conducting education in communities such as the county health departments in order to maximize our impact.

Affiliate Action Plan

Priority 1: Increase the screening rates within the Downtown Evansville area and the most rural areas of Illinois in order to discover breast cancer at an earlier stage and decrease mortality.

> Objective 1: By March 2012 target two grants that seek to increase screening rate by 5% in the Downtown Evansville population or rural Illinois.
>
> Objective 2: By October 2013 reach 500 women while working with ECHO Clinic, Deaconess Family Medicine Residency Program, Downtown Evansville churches and the Evansville Housing Authority to promote breast health education and early detection screening.
>
> Objective 3: By July 2012 work with the BCCP program in Southern Illinois to increase awareness of the program by 10% to women who qualify.

Priority 2: Increase education efforts to build awareness of breast health for those underserved women who are not aware of available programs and services. Maximize the partnerships and relationships with community education sources so that we can reach more people with breast health and early detection education:

Objective 1: By October 2012 complete education train the trainer training for all of our current grantees.

Objective 2: By December 2012 cultivate a working relationship with 20 of the 28 County Health Departments or County Health Offices in our service area in order to expand our outreach and referral base..

Objective 3: By October 2013 the grant committee will develop and over some type of education program or mini-grant to reach the underserved population in Southern Illinois.

Objective 4: By May 2012 educate 50 African American women on breast health and early detection with help from TRI-CAP and the Sister's Network.

Community Partnerships

Susan G. Komen for the Cure® will partner with area health care providers, grantees, local health departments and physician offices to maintain a consistent message from Komen. We will insure that our messages are consistent and aligned with National Center.

Existing Grant Solutions

Upon approval of this Community Profile our Request for Funding Application (RFA) for our Grant program will need to be rewritten to fit the current needs of the Affiliate. We will continue with our Grant Workshop outlying the needs of our communities. We will seek new and innovative grant programs for possible funding.

Marketing /Fund Raising

We, as Greater Evansville Affiliate Susan G. Komen for the Cure®, need to continue to market ourselves as being more than just a Race. It is important that our communities view us as an expert in breast health information. We need to further educate and market to our communities on the education and grant activities that take place in their city and town. With increased education more awareness is created and we can leverage that awareness into sponsor and funding opportunities.

Public Policy Efforts

We will continue to work with state BCCP programs, health departments and legislators to make sure that our BCCP programs are providing the best possible care for our women in need. We will advocate for either level or increased funding for breast cancer research and care at both the state and National level.

Education and Outreach

We will continue our community education and will focus energy toward educating those people who have direct contact with women in our area. This will include meeting one-on-one with health departments, clinics and physician offices. We will explore the idea of again hosting a Breast Cancer Symposium within the Affiliate to provide updated continuing education for breast health professional.

We will attend screening events, health fairs and community events to provide education materials and screening location resources. We will provide materials to be used with local support programs so that women will have many of the resources they need upon diagnosis of breast cancer.