



COMMUNITY PROFILE REPORT

©2010 Central Florida Affiliate of Susan G. Komen for the Cure®



2011

Disclaimer:

The information in this Community Profile Report is based on the work of the Central Florida 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.

Acknowledgements

The Central Florida Affiliate of Susan G. Komen extends our most sincere thanks to the Community Profile Team for taking the time to see this project through.

Author

Stefanie Steele, Central Florida Affiliate Mission Manager

The Community Profile Team

Jennifer Barge- Central Florida Affiliate Board of Directors
Diana Furey
Kelsey Howell
Dr. Jonathan Matusitz- University of Central Florida
Kelly McGillivray
Dr. Ann Miller- University of Central Florida
Ashley Pruitt
Yeselie Rivera
Stefanie Steele

In addition to the Community Profile Team, the Central Florida Affiliate thanks all the individuals and organizations who supported this process by taking surveys, attending focus groups and being interviewed.

Sources of Qualitative Data

Behavioral Risk Factor Surveillance System

www.cdc.gov/brfss

The Centers for Disease Control and Prevention

www.cdc.gov/cancer/nbccedp

Agency for Health Care Administration

www.fdhc.state.fl.us

Florida CHARTS

www.floridacharts.com

Florida Department of Health

www.doh.state.fl.us

United States Census Bureau

www.census.gov

National Cancer Institute. Surveillance Epidemiology and End Results (SEER) Data.

www.seer.cancer.gov

Thompson Reuters ©2009

Table of Contents

- Executive Summary 6**
 - Introduction..... 6
 - Statistics and Demographic Review..... 6
 - Methodology..... 6
 - Health Systems Analysis..... 7
 - Qualitative Data Overview 8
 - Affiliate Action Plan..... 9**
- Introduction 11**
 - Affiliate History..... 11**
 - Organizational Structure..... 12**
 - Description of Service Area 12
 - Purpose of the Report..... 14**
- Breast Cancer Impact in Affiliate Service Area..... 15**
 - Methodology..... 15**
 - Overview of the Affiliate Service Area..... 15**
 - Communities of Interest..... 17**
 - Conclusions..... 17**
- Health Systems Analysis of Target Communities..... 18**
 - Overview of Continuum of Care..... 18**
 - Methodology..... 19**
 - Overview of Community Assets 19**
 - Screening Availability 19*
 - Affiliate Grantees..... 21*
 - Key Informant Findings 22
 - Legislative Issues in Target Communities..... 23
 - A Woman’s Experience moving through the Continuum of Care..... 24
 - Insured Patient..... 24*
 - Uninsured Patient..... 24*
 - FBCCEDP Patient..... 24*
 - Undocumented Patient..... 24*
 - Conclusions..... 24**
- Breast Cancer Perspectives in the Target Communities 25**
 - Methodology..... 25
 - Review of Qualitative Findings..... 25
 - Conclusions..... 26**
- Conclusions: What We Learned, What We Will Do..... 27**
 - Review of the Findings..... 27
 - Conclusions..... 28**
 - Action Plan..... 28**

Executive Summary

Introduction

The Central Florida Affiliate of Susan G. Komen for the Cure was established in 1999 and serves nine counties in Florida: Brevard, Flagler, Lake, Marion, Orange, Osceola, Seminole, Sumter and Volusia. Before the Affiliate was established, a Race for the Cure took place in Daytona Beach, which was organized by a group of dedicated survivors in 1996, 1997, and 1998. Since being established, the Affiliate has grown in funds, grants, volunteers, Board members and employees.

In the 2008-2009 grants cycle, the Affiliate raised over one million dollars. This success was repeated in following years, allowing the Affiliate to grant funds to all nine counties during the 2010-2011 grants cycle. Funding has been awarded to programs that have included:

- Education
- Screening
- Diagnostics
- Treatment
- Genetic testing
- Financial support

The Central Florida Affiliate places an emphasis on educational events about breast cancer and has formed many community partnerships for fundraising and granting opportunities. The Race for the Cure is the largest event that the Affiliate produces annually, and each year, the event has grown in both participants and revenue.

The community profile acts as a detailed report on breast health information pertaining specifically to the Affiliate service area. The Affiliate heavily depends on the information in this report to fulfill the promise on which Susan G. Komen was founded: *to save lives and end breast cancer forever by empowering people, ensuring quality care for all, and energizing science to find cures*. The information enclosed will serve as guidelines for the Board of Directors to determine areas of need, granting opportunities, and next steps.

Statistics and Demographic Review

Methodology

Statistics were compared from multiple sources, but the ones most heavily relied upon come from Florida CHARTS, Thompson Reuters © 2009, the United States Census Bureau, The Department of Health and the United States Department of Labor Bureau of Labor Statistics.

According to Florida CHARTS, the areas in the Affiliate service area with the lowest screening rates were: Orange (61.1%), Osceola (54.5%) and Volusia (59.9%). Late stage diagnosis was more prominent in Orange (38.2%) and Osceola (37.9%). Mortality was also highest in Orange (22.9%) and Osceola (21.6%). Orange County has the largest female population and African

American population in the entire service area, as well as lower health insurance rates. Osceola has the largest Hispanic population in the nine counties as well as low insurance rates. These factors are the reason these areas were chosen as the target Counties for the 2011 Community Profile.

Health Systems Analysis

In order to gain a better understanding of the current health systems in Central Florida, the Community Profile Team looked at access to screening services by creating GIS maps for Orange, Osceola and Volusia County. The maps displayed where screenings were available. The team also interviewed Key Informants in the breast health community from the three Counties of concern. Key Informants were selected due to their knowledge and expertise. There were a total of 12 Key Informants from local hospitals and breast health organizations, including doctors, nurses, and breast cancer advocates. The purpose of the GIS maps and Key Informant interviews was to determine if enough screening services were offered in the area, if patients were able to access them, and what gaps existed beyond screenings.

The observation was made that both Osceola and Volusia County did not have many screening services. Osceola, in particular, is lacking screening services in much of its county. Key Informants from Volusia County felt that the importance of regular breast health is being overlooked based on the lack of breast health education and low screening rates. Key Informants from both Orange and Osceola seemed to also focus on the need for screening but instead on the higher need for gaps that fall under diagnostics.

All Key Informants were in agreement from each County that better partnerships and programs with a better continuum of care need to be developed. It was often noted that patients fall out of the continuum of care due to programs only providing assistance or service in one area of care, difficulty navigating programs, and patients not understanding their health insurance benefits. Currently, referral programs are in progress to keep patients in the continuum of care. It was evident that more complete programs need to be developed to ensure patients do not get moved between different programs to complete their care. More education about health insurance and current government funded programs is also necessary to ensure patients are taking advantage of their benefits.

The FBCCEDP program is noted to be Option One under the Medicaid Treatment Act, meaning a patient must begin her care with the program. If a screening is done outside of the program, the patient cannot use the benefits that the program has to offer to patients who do their screening there. Knowledge and education about the program are not common in the Affiliate area, causing many women to be disqualified. When used properly, the program saves lives and offers a full continuum of care. The program is strictly for uninsured women who are at or below poverty levels and who are between the ages of 50-64, leaving women ages 40-50 to find other assistance.

Qualitative Data Overview

To fully understand the breast health community, it is important to talk to the patients who both use and do not use, the available services. General breast health surveys were sent out via e-mail blasts and posted on social media sites, including Komen Central Florida's website. Grantees were also encouraged to help distribute the surveys within their community service areas. Over 500 responses were collected from Orange, Osceola and Volusia County. A survivor survey was also designed in the same method as the general breast health survey but only sent to survivors. There were 92 responses from the three Counties of concern. Finally, one focus group was held in Volusia County with fifteen survivors: one male and fourteen females.

The key findings varied slightly in each County. Volusia County demonstrated a lack of breast health education, causing them to have low screening rates. Many of the surveys in Volusia agreed with statistics that showed clinical exams and screenings were not very high in the area. Both Orange and Osceola County survey respondents stated that the most common reason they would see a physician for breast health was if a lump was found or there was a major change in the breast. Residents of Orange County seemed to be more aware of screening programs, but survivors mentioned the lack of help for steps after screening, such as biopsies. Osceola County residents were less likely to name organizations or programs that could help with screenings. In all three Counties, survivors echoed the need for financial assistance during treatment. Financial hardship was the most common response when asked how the disease changes lives.

Komen Central Florida plans to utilize the information obtained through these surveys to implement more education on the continuum of care and the importance of regular clinical exams and screenings. It is thought that if more women know what is available to them, they are less likely to fall through the gaps of the current health care system. Financial assistance to those going through treatment will also be necessary to those who fall at or below poverty levels.

Conclusions

After examining statistical data, speaking to local breast health experts, community residents and breast cancer survivors, assumptions can be drawn as to what areas need to be addressed in the continuum of care for the Central Florida region. The Community Profile Team discussed which areas of concern in the region should be a top priority for the Affiliate. The following areas were agreed to be the most prominent and problematic in the service area. They were selected based on the statistical evidence and the frequency of the responses that were presented in focus groups, surveys and interviews.

- Particularly low screening rates in the Affiliate service area, specifically in Orange, Osceola and Volusia County among women ages 40-49 due to a lack of programs.
- Patients being diagnosed in later stages and having higher mortality rates in Orange and Osceola County, and Key Informants in these areas stating a need for programs that continue treatment after screening, implement a continuum of care for the patient.

- Financial hardships with which survivors struggle during treatment.
- Lack of breast health education for minorities, who have a greater chance of not surviving the disease.

Affiliate Action Plan

The goal for the next two years will be to focus on the areas of concern brought up in this Community Profile. This will be done by setting the following priorities:

- 1. Problem:** Low screening rates among women in Central Florida, specifically in Orange, Osceola and Volusia County, and a lack of screening programs for women ages 40-49.

Priority: Provide screening services for patients between the ages 40-49 in Central Florida with a heavy focus on Orange, Osceola and Volusia County.

Objective 1: Look into funding breast health services on a mobile mammography bus by the grant cycle of 2012-2013 that can cover all of Central Florida.

Objective 2: Work with current grantees to expand their services to patients outside of their county by the next grant cycle.

Objective 3: Increase educational information on the importance of regular screenings in the form of community presentations (two per year) and monthly social media videos and articles highlighting available programs.
- 2. Problem:** Women in Osceola and Orange County are being diagnosed at later stages and having a higher mortality rate from breast cancer, specifically black women.

Priority: Increase access to diagnostic testing for patients in Orange and Osceola Counties with a large focus on black women while educating them on the importance of early detection.

Objective 1: Work with current screening programs and develop a continuum of care by implementing assistance for diagnostic testing by January 2012 and then implementing next steps.

Objective 2: Increase education on the importance of early detection for women in these counties by being involved in two educational events during the next year. The goal will be to get these patients to the doctor before a lump is found.

Objective 3: Fund more diagnostic testing in Orange and Osceola Counties by the 2012-2013 grants cycle.
- 3. Problem:** Survivors going through breast cancer treatment are experiencing financial hardship due to the cost of treatment.

Priority: Aid survivors that are at 200% of the federal poverty level with expenses such as, but not limited to, medical co-pays and living expenses.

Objective 1: Fund grants to assist with financial hardships for patients going through treatment.
- 4. Problem:** Minorities and the younger population are less likely to be educated on breast health and also less likely to seek screenings.

Priority: Increase breast health education in places that are heavily populated by minorities and a younger population.

Objective 1: Develop specific marketing strategies by August 2012 that will target minorities and youth and inform them of breast health.

Objective 2: Implement strategies and develop programs on breast health specific to minorities and youth by October 2012.

Objective 3: Fund educational programs on breast health for minorities and youth by the 2012-2013 grants cycle.

Introduction

Affiliate History

Susan G. Komen for the Cure (Komen) is a national non-profit organization established in 1982 by Nancy Brinker. Her sister, Susan Komen died in 1980 at age 36 of breast cancer. Susan requested that her sister do whatever she could to end the disease.

The organization reflects the promise made between two sisters:

“To save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to fund the cures.”

The national organization has established Affiliates in more than 120 cities and communities. The Susan G. Komen Central Florida Affiliate had its first race for the Cure in 1997 spearheaded by a dedicated group of survivors. By 1999, the Affiliate was established to carry out the Foundation’s mission. The Central Florida Affiliate serves the nine counties of Brevard, Flagler, Lake, Marion, Orange, Osceola, Seminole, Sumter, and Volusia. The Affiliate is involved in National fundraising activities, such as:

- Race for the Cure
- Yoplait Save Lids to Save Lives
- Rally for the Cure
- Wacoal Fit for a Cure
- Coldwater Creek Fit Events

Local fundraising initiatives include but are not limited to:

- The Promise Chair Affair
- High School Pink Out
- Third Party Events

Over the years, the Affiliate has grown and established strong community partnerships that have resulted in significant milestones:

- The historical development of the Race for the Cure in the Central Florida region continues to grow the number of participants and annual funds raised. The event’s first three years were at the LPGA golf course, then the next four years around the Daytona International Speedway, followed by five years at the Walt Disney World Resort, with the last two years being at the University of Central Florida.
- The Affiliate raised its first million dollars in 2008-2009 and repeated the success the following year despite economic hardship in the community.
- The growth of the Promise Chair Affair had a financial increase of 32% from 2009 to 2010.
- The Affiliate funded its first genetic testing grant in 2007-2008 through Halifax Medical Center.

- There has been a substantial increase in the number of local businesses wanting to become more involved with fundraising and education.

Up to seventy-five percent of the net proceeds raised by this Affiliate stay within the local area to fund breast health programs and initiatives that address the specific unmet needs within the service area. These projects are selected based on a needs assessment performed by the Affiliate. During the 2009-2010 grants cycle, the Affiliate funded over \$800,000.00 to local breast health programs.

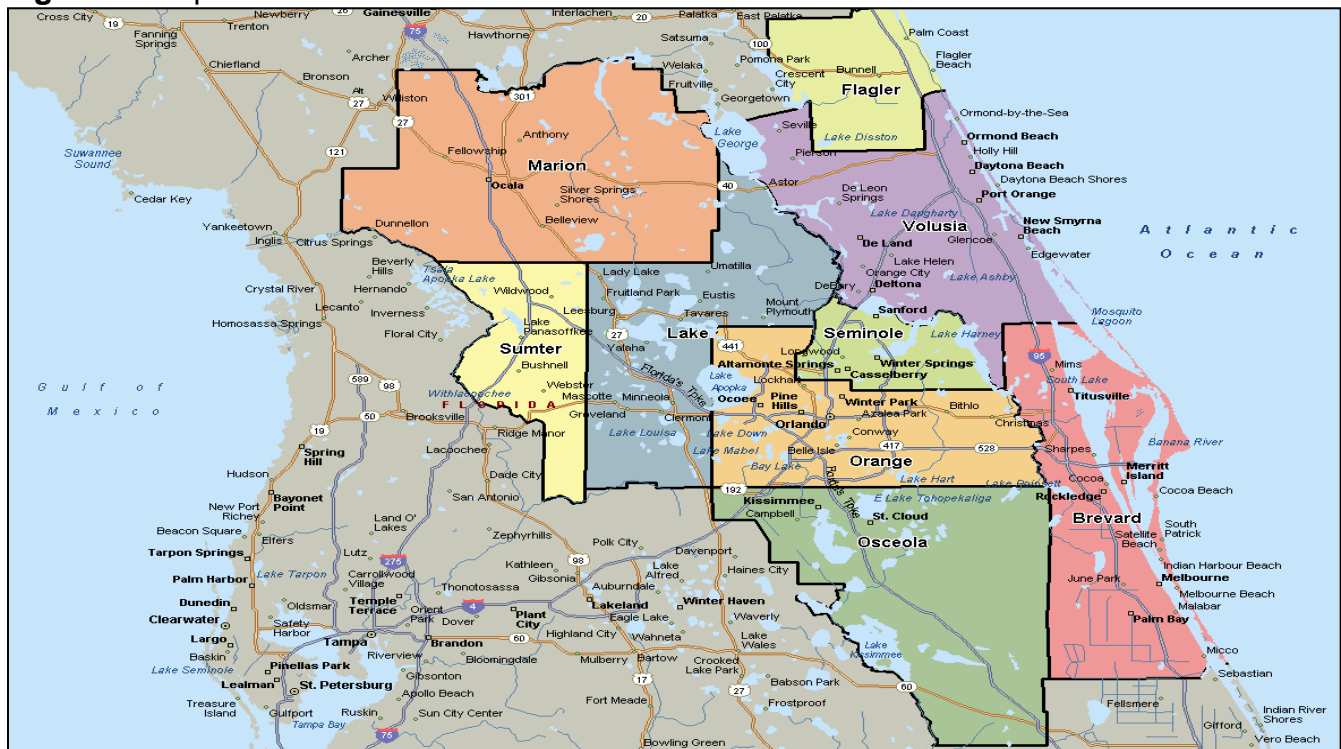
Organizational Structure

The Affiliate is a non-profit organization, and all business is conducted under the guidance of the Board of Directors. At the end of 2010, the Affiliate consisted of a Board of Directors with 8 members, 1 full time staff person, and 1 part time staff person. Committees and panels also play a large role in the Central Florida Affiliate. They are comprised of volunteers who are the lifeblood of this organization. To date, 1,177 volunteers are registered in the Affiliate’s database.

Description of Service Area

The Central Florida Affiliate's region is very large geographically and includes both rural and large urban areas. The Affiliate currently serves nine counties: Brevard, Flagler, Lake, Marion, Orange, Osceola, Seminole, Sumter, and Volusia.

Figure 1: Map of Central Florida



- Brevard County (pink) is 1,018.19 square miles with 467.8 residents per square mile. The county is known for the space industry and borders the Atlantic Ocean.
- Flagler County (light green) is 485 square miles with 102.7 residents per square mile.
- Lake County (blue) is 953.15 square miles with 220.9 residents per square mile.
- Marion County (red) is the largest geographic area at 1578.86 square miles with 164 residents per square mile.
- Osceola County (dark green) is 1321.9 square miles with 130.5 residents per square mile. The county is home to the second largest Hispanic population in Central Florida.
- Orange County (orange) is 907.45 square miles with 988.3 residents per square mile. It is the most urban part of the Affiliate area. It is home to the largest population in Central Florida for total population, Hispanic population, Black population and female population. The county is well known for tourist attractions, particularly Disney World.
- Seminole County (medium green) is 308.20 square miles with 1371.6 residents per square mile.
- Sumter County (yellow) is 545.73 square miles with 97.7 residents per square mile.
- Volusia County (purple) is 1103.25 square miles with 401.9 residents per square mile. The county is known for its famous beaches and other tourism activities.

Florida is diverse in age and ethnic groups. The majority of its residents are between the ages 35-54 (Thompson Reuters © 2009). The female population at the state level is very close to the national rate at 50.8% (2009 US Census Bureau), and an estimated 25% of females in Florida between the ages 18-64 have no form of health insurance (Thompson Reuters © 2009). The state is also heavily populated by Hispanics. In 2009, 21.5% of the state's population was Hispanic, compared to the national rate of 15.8%.

In the past few years, Florida has been hit very hard by the recession.

- The unemployment rate at the end of 2010 was 12%, making it higher than the national average of 9.8% (United States Department of Labor Bureau of Labor Statistics).
- Hispanics have the highest poverty rates of all ethnicities in Florida, being 1.6 times higher than non-Hispanic ethnicities (2000 Census of Population and Housing).
- The average family income in the Affiliate Service area is \$48,476.00 (Thompson Reuters © 2009).

Insurance rates in the service area are relatively close to the state average, in some cases being higher, according to data from 2007. The number of uninsured residents was still significant to the Community Profile Team. It also should be noted that 2007 was the most mature data available, and since then, more residents of the area have become unemployed and uninsured. Rates are as follows in Table 1.

Table 1

Adults With Any Type of Health Care Insurance Coverage Grouped By: Sex Year: 2007			
County	Male	Female	Total (Male & Female)
State Total	80.3	82.4	81.4
Brevard	90.9	88.7	89.8
Flagler	85.5	88.6	87.1
Lake	80.2	86.3	83.4
Marion	73.2	79.2	76.3
Orange	77.0	82.2	79.7
Osceola	76.9	78.6	77.8
Seminole	85.1	86.6	85.9
Sumter	79.4	84.7	81.7
Volusia	83.5	80.3	81.8

Source: Florida CHARTS

Purpose of the Report

Susan G Komen for the Cure was founded on a promise between two sisters to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to find the cures. A community profile is a snapshot of the community, specifically looking at breast health. The Komen Central Florida Affiliate uses the information obtained in the Community Profile to guide the work needed at the local level to meet this promise. Local experts were consulted to assure accurate information and stay involved every step of the way.

The information in this Community Profile will serve as an assessment of the local breast health community and will guide the following Affiliate Activities:

- Drive inclusion efforts in the Central Florida breast health community
- Set granting priorities
- Advise on educational needs
- Strengthen our message to the community and sponsors
- Establish methods of outreach in target communities
- Drive public policy efforts
- Serve as a tool for the Board of Directors

In short, the Community Profile provides an up-close look at the unique characteristics of the Central Florida Community. By observing the local needs, gaps and requests, the community can be better served.

Breast Cancer Impact in Affiliate Service Area

Methodology

Demographic data was obtained from both Thompson Reuters ©2009 and the United States Census. Unemployment rates were obtained from the United States Department of Labor, Bureau of Labor Statistics, released December 2010. Poverty information came from the Census, and insurance, screening and diagnosis data was available at Florida CHARTS and Thompson Reuters ©2009.

Overview of the Affiliate Service Area

In 2007, the average number of woman 40 years and older to receive a mammogram in the past year in the entire state of Florida is just 64.9% (Florida CHARTS). The Affiliate service area had four rates lower than the state average as shown in Table 2.

Table 2

County	Total
State Total	64.9
Brevard	71.8
Flagler	72.9
Lake	67.1
Marion	70.3
Orange	61.1
Osceola	54.5
Seminole	63.2
Sumter	74.8
Volusia	59.9

Source: Florida CHARTS

The Community Profile Team found it disturbing to see that roughly 20%-30% of women in all counties were not getting an annual mammogram and decided to look back one more step to determine if clinical breast exams were being completed regularly. The results for this were just as troublesome, if not more so. Volusia County stood out to the Community Profile Team from the information portrayed in Table 3.

Table 3

Percentage of Women 18 Years and Older Who Had a Clinical Breast Exam in the Past Year Year: 2007	
County	Percentage (%)
State Total	66.1
Brevard	65.2
Flagler	69.7
Lake	68.9
Marion	65.9
Orange	69.4
Osceola	60.3
Seminole	68.5
Sumter	70.8
Volusia	58.5

Source: Florida CHARTS

Looking further into the available data at mortality and late stage diagnosis, there were more areas to stand out from the rest.

Table 4 shows that Orange and Osceola Counties had the highest rates for cancer diagnosed in late stages. Five counties in the service area had higher rates than the State total.

Table 4

Advanced Stage Breast Cancer at Diagnosis	
County	Rate Percent 2004-06
State Total	33.1
Brevard	32.1
Flagler	31.6
Lake	30.4
Marion	23.9
Orange	38.2
Osceola	37.9
Seminole	35.3
Sumter	36.1
Volusia	33.4

Source: Florida CHARTS

According to Thompson Reuters ©2009, late stage diagnosis was almost twice as high for black women than any other race in the service area.

Table 5 shows that the same two counties (Orange and Osceola) also ranked highest for mortality due to breast cancer for all females. The table also demonstrates that Black women had a higher death rate in almost all counties.

Table 5

Age-Adjusted Breast Cancer/ Age Adjusted Death Rate				
By: Race				
Years: 2006-08				
County	Black	Hispanic	White	Total Female Population
State Total	31.2	17.0	21.8	22.9
Brevard	24.3	6.6	20.9	21.1
Flagler	15.9	0.0	13.5	13.5
Lake	18.8	12.4	17.6	17.5
Marion	32.6	2.5	17.1	19.1
Orange	24.0	13.0	23.0	22.9
Osceola	29.6	12.3	20.6	21.6
Seminole	20.1	12.5	20.9	21.0
Sumter	29.3	0.0	19.0	19.4
Volusia	26.0	12.9	18.7	19.4

Source: Florida CHARTS

This information led the Community Profile Team to determine three areas of concern for the service area: The lack of clinical exams and perhaps education on the importance of routine check-ups that may cause a low use of screening mammography, the high rate of late stage diagnosis, and mortality from breast cancer in particular areas, specifically for black women.

Communities of Interest

The communities of interest were selected based on the low usage of mammography, highest rate of late stage diagnosis and highest rate of mortality due to breast cancer, as well as low insurance rates. Areas of low participation in health insurance were included in this process because the Community Profile Team felt that by directly cross analyzing these numbers with the three breast health variables, results would more accurately describe the population in need. Areas of concern were chosen based on the frequency they appeared in the statistics analyzed, as well as the frequency with which they coordinated with lower insurance rates. Based on this breakdown, the counties that stood out as areas of concern were Orange, Osceola and Volusia Counties.

After these areas were selected, other variables were examined for frequency to determine what may be causing these problems. Population by gender, poverty levels, race and clinical exams correlated in some of the selected areas. Orange County has the highest percentage of blacks and the most families living below poverty. Osecola County has the highest female Hispanic population, and Volusia County has the lowest clinical exam rates (Florida CHARTS), which was an area of concern for the Community Profile Team.

Conclusions

- Orange County was chosen due to having a high population of blacks, low insurance, low screenings, high late stage diagnosis and high mortality.

- Osceola County was chosen for having low insurance rates, the highest black mortality rate from breast cancer, high mortality from breast cancer in general, low screening, highest female Hispanic population and high late stage diagnosis.
- Volusia County was chosen due to the lack of clinical breast exams and low screening rates suggesting women were not entering the continuum of care and breast education was needed. Insurance rates in this county were also fairly low.

The low screening rates and high late stage diagnosis and mortality rates suggest that there may not be enough breast health services and funding available to the public in these regions. It is crucial to determine why screenings are not being accessed.

Health Systems Analysis of Target Communities

Overview of Continuum of Care

The continuum of care is a model that describes each step in the healthcare process through which a patient transitions, beginning with screenings and continuing through treatment, if required. There are four steps in the continuum of care: Screening, Diagnosis, Treatment, and Follow-up Care. Figure 2 demonstrates the full continuum of care.

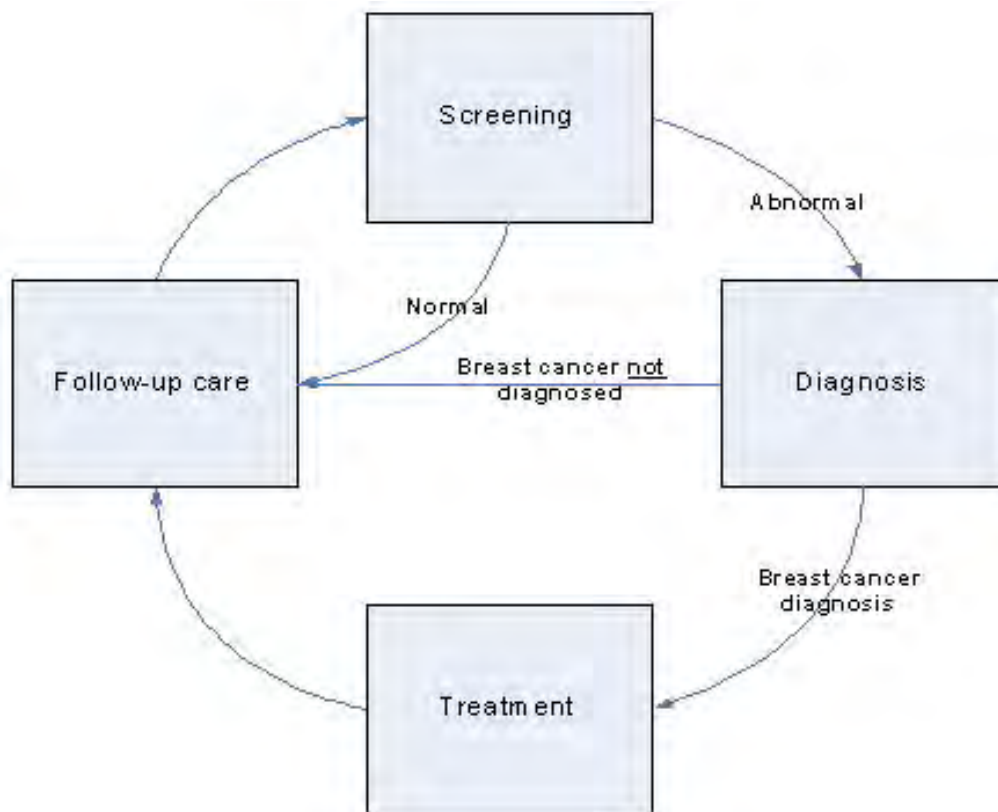


Figure 2: Continuum of Care Model
Source: Susan G Komen for the Cure

Some women stay in the screening stage if results are normal and will do annual follow-up care. Others may go to diagnosis, have normal results and go back to the follow-up and screening stage, while some may go through the entire model from screening, diagnosis, treatment, and follow-up care. The model is very important and ideal because it sees that all gaps and barriers can be overcome through the process.

Low screening rates point toward the conclusion that many women are not entering the continuum of care at all, particularly in Volusia County. Also, those who do enter the continuum may not be completing it due to the high rate of late stage diagnosis and mortality in Orange and Osceola Counties. There are many factors that may keep a patient from proceeding through the continuum of care such as, but not limited to; lack of education, lack of insurance, lack of screening and treatment services, as well as program limitations.

Methodology

To determine if entering the continuum of care was problematic due to lack of available services, screening facilities were located in the three counties of concern: Orange, Osceola and Volusia. Locations of available services were obtained through multiple means, including the Bureau of Chronic Disease Prevention, Florida Breast and Cervical Cancer early Detection program (FBCCEDP), Florida's State Primary Care Office, and other similar links online.

To further understand why patients were not entering or following through the continuum of care, Key Informants were interviewed in each of the three counties of concern. They were interviewed by phone or face to face. These Key Informants were selected based on their positions in the breast health community. Partners from the FBCCEDP, Komen Grantees, doctors and nurses at local hospitals and clinics, other breast cancer organizations, and breast cancer advocates were included in the interview process. Each Key Informant was asked the same questions about the characteristics of breast cancer in their community.

Certain limitations to the information collected need to be kept in mind. Though Key Informants were chosen based on their knowledge of the local breast health community, it is impossible to completely remove all bias due to their familiarity with the programs about which they were asked. An attempt to remove biased opinions was made by changing the wording in some of the questions.

Overview of Community Assets

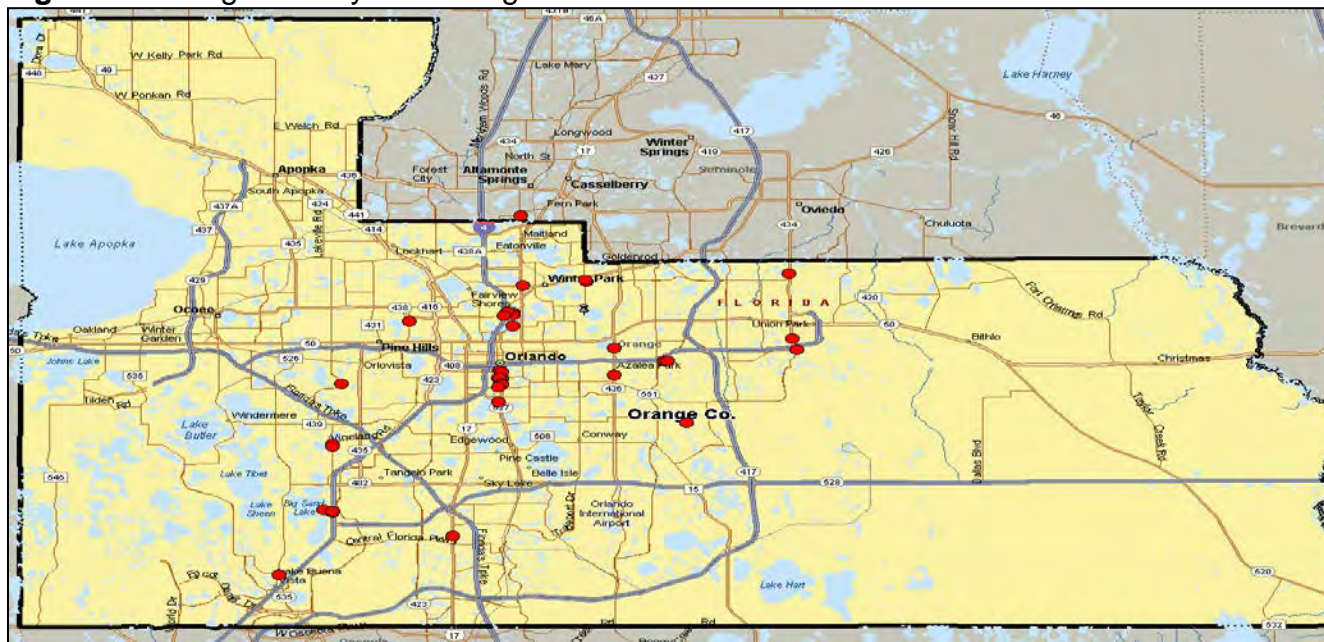
Screening Availability

Asset maps for each county of concern (Orange, Osceola and Volusia) were created to review the availability of screening. Red dots on the maps indicate where mammography service is available.

Orange County has just over 20 facilities that can perform screening mammograms. Being the most populated county in the Affiliate service area, it also had the most screening facilities. By

looking at Figure 3, the majority of them are located in the central part of the county. Out of the facilities contacted, only a limited number had assistance for uninsured patients.

Figure 3: Orange County Screening Services



Osceola County had even fewer facilities that perform screening; less than ten facilities fell into this category. Figure 4 shows that all of these facilities are located in the north-east part of the county, making it very difficult for patients without transportation to travel to these places. Public transportation is limited in this area as well. Much like Orange County, assistance for the uninsured was limited and heavily concentrated in one area.

Figure 4: Osceola County Screening Services



Volusia County also had fewer than ten facilities that offered screening mammograms. These centers were more spread out in the county as shown in Figure 5, but many of them did not have programs for uninsured patients.

Figure 5: Volusia County Screening Services



Affiliate Grantees

During the 2010-2011 grants cycle, the Komen Central Florida Affiliate was able to grant over \$800,000 to local services in the nine-county service area. In Orange, Osceola and Volusia Counties, just under \$500,000 was awarded to local programs for breast health assistance for uninsured and under-insured patients. There were 13 grantees that covered some or all of the three counties. Programs covered everything from education, screening, diagnosis and financial assistance to survivors going through treatment.

FBCCEDP

The Medicaid Treatment Act allows Florida to have the Breast and Cervical Early Detection Program (FBCCEDP, commonly referred to as BCCEP) at the Health Departments. This program is for uninsured women ages 50-64. The program has been funded in Florida since 1994. The Act has three options, and Florida is Option One. Option One states that a woman who qualifies for the program must begin her continuum of care in the program. The program will not accept patients who have been screened somewhere else during that year.

During the 2010-2011 grant cycle, the Central Florida Affiliate granted funds for screening to a BCCEP program in Seminole County that sees women from Seminole and Orange Counties between the ages 40-49. Orange, Osceola and Volusia Counties have BCCEP programs for women 50-64 who meet the qualifications. This is one of the most inclusive programs available to the Central Florida community with which the Komen Affiliate will continue to collaborate.

Key Informant Findings

Key Informant interviews indicated that the largest partnerships that exist in these three counties are funded by the Central Florida Affiliate of Susan G. Komen for the Cure. The larger programs at hospitals, and some organizations, utilize Komen funding to fill gaps in their programs with screening needs. It is important to note that many of the programs reviewed did not have a complete continuum of care. Many stop services after screening due to lack of funding.

The majority of Key Informants felt that more collaboration was needed in the communities as a whole because all of the different programs are difficult to navigate with regard to qualifying, and programs seem to duplicate services. It was clear across the board that the breast health community was not collaborating in a way that would improve the continuum of care by removing programs that are essentially duplicated and replacing them with programs that satisfy the next steps. Many Key Informants felt that the steps following screening, such as diagnostic testing, were being overlooked and were incomplete due to the multiple screening programs.

The BCCEP program in Seminole County, which sees Orange County patients, received Komen grant money to screen women aged 40-49 in previous years. As of January of 2010, the program saw 65,487 women in the entire state of Florida, requiring 112,611 mammograms (Florida Department of Health, 2010).

According to Key Informant interviews, large gaps lie in the program starting with a lack of knowledge about its existence, followed by eligibility requirements. In order to be eligible, poverty levels must be adhered to, and a woman must begin her continuum of care in the system. BCCEP does not accept patients who did not begin the process in their system.

Breast cancer was ranked as an extremely prominent health concern in all three counties with concerns that women cannot enter a continuum of care due to both a lack of knowledge about breast health and lack of financial resources. It was agreed that the current health care system is not successful at meeting needs for breast health in these communities. The main theme that was identified throughout all key informant interviews was the lack of collaboration among breast health programs in the communities, as well as the need for breast health education within minority communities.

Orange County Key Informants mentioned the need for minorities to enter into the continuum of care, as they often are overlooked, and the county is home to a large population of minorities.

Osceola County Key Informants felt that additional programs are necessary in the county as many patients have to travel to Orange County for services.

Key Informants from both Orange and Osceola Counties revealed that the need for diagnostic testing in many of the available programs was being overlooked. It was mentioned multiple times that there is still a need for funding for screening, but with knowledge of other community

programs, it may be that there is a need for education, not necessarily funding, freeing up funds for diagnostic testing. Biopsies have been in high demand in the two counties over the past few years, according to local programs.

Key Informants in Volusia County agreed with statistical data that highlighted the lack of basic education of breast cancer, specifically among the minority population. It was noted that many women in the county are not aware of the signs and symptoms of breast changes, and many do not see the importance of annual clinical exams resulting in low screenings.

All three counties were concerned with breast health navigation, stating that there is a lack of education on the available programs. This concern was not only for the general public but also for professional health care workers. Key Informants felt that many patients were not entering the correct programs, causing duplicate screenings and even disqualifying patients from a program that could save their lives.

Legislative Issues in Target Communities

Currently, the Florida Affiliates of Susan G. Komen for the Cure discuss, via a monthly teleconference, public policy issues in the state. At the Central Florida Affiliate, one board member, one employee and one volunteer are involved in the calls and action items.

As a collaborative, the Affiliates are currently looking at oral chemotherapy options with regard to health insurance and alternative screening options for women with dense breasts. Locally, efforts are being made to form partnerships and relationships with local political leaders. Komen Central Florida has taken the initiative to invite local politicians to larger events. Together, these efforts will result in a solid partnership between Komen and the state.

Many Key Informants felt it was necessary to educate the public on the changes in health insurance implemented by health care reform, as many patients do not understand the recent changes. Key Informants also felt policies dealing with age limits in certain programs were unjust, as cancer is known to strike at any age.

The FBCCEDP was frequently mentioned with regard to needing policy changes among Key Informants. Option One limits the number of patients who can be helped through the program.

A Public Policy Committee is currently being developed for the Central Florida Affiliate. The Affiliate recruits Komen Champions for the Cure at local health fairs and Komen events. The Board of Directors will also be asked to register as Champions. Both an employee and a Board member from the Central Florida Affiliate will attend Lobby Days in Washington, D.C. each year.

A Woman's Experience moving through the Continuum of Care

Insured Patient

Key Informants felt that insured women had the best chance to navigate the continuum of care, as recourses were available to them due to the fact that they have insurance. Many survivors felt that the doctors available to the community were excellent doctors with great experience. When there are little or no financial issues, Central Florida offers exceptional programs with a continuum of care in which women can receive service. It should be noted that even women with health insurance are still falling through gaps due to lack of knowledge on breast health.

Uninsured Patient

Uninsured patients have a more difficult time navigating the system due to financial restraints and qualifying factors for the available programs. Many survivors noted in surveys that once they were screened, the programs that helped them did not have a continuum of care in place, causing them to search for help in the diagnosis stage.

FBCCEDP Patient

The FBCCEDP is well received by patients who qualify and begin their continuum of care there. The amount of aid available to the women who enter this program is substantial. The continuum of care provided is an ideal model when understood and used correctly.

Undocumented Patient

Undocumented patients have the most difficult time going through the continuum of care. Many of these patients will not enter the available programs for fear of deportation. A common misconception in Orange, Osceola and Volusia Counties was that programs would only see citizens or permanent residents.

Conclusions

In conclusion, when the statistical data is compared to the responses from the Key Informant interviews, there is a correlation. Results were similar in most areas.

Orange County statistics reveal low numbers of screenings, high rate of late stage diagnosis, and a high mortality rate, specifically among blacks. Key Informants in this county saw a similar picture when describing the breast health community with which they were familiar.

Osceola County statistics were similar to Orange County: screenings were low, late stage diagnosis was high, as well as mortality rates. Key Informants made comments that agreed with the statistics, again focusing on the minority population and the need for education.

Volusia County Key Informants saw a need for additional education for residents, particularly minorities, about the importance of regular screenings.

Existing programs are trying to fill the gaps but need to improve the effectiveness of follow-up care and develop better partnerships in the community. It is also important for these programs to educate residents on which programs are right for them and the importance of a continuum of care.

Breast Cancer Perspectives in the Target Communities

After reviewing the statistical data, as well as talking to Key Informants in the breast health community, it is important to talk to the patients in the communities where concerns were found. It is necessary to be conscious of the specific issues these women have experienced.

Methodology

The Community Profile Team decided to do surveys and a focus group to reach out to the women going through the continuum of care.

- A focus group was done in Volusia County at Halifax Medical Center to examine the low clinical exam screening rates. The group consisted of fifteen survivors, one male and fourteen females. All were residents of Volusia County. The survivors were brought together by a Komen grantee.
- Surveys were disseminated via an e-mail blast, social media sites and other websites, as well as through grantees. They were sent to all nine counties, but results from Orange, Osceola and Volusia are the only results being reviewed for this Community Profile. While the surveys were available on the web, there was no specific number sent out. However, total response counts from all forms of the survey were 523 at the time that the information was collected.
- Surveys intended for survivors only were distributed in a similar method: e-mail blast to survivors, e-mail blast to community partners with a survivor database, and grantees distribution at support groups. Altogether, 92 responses were collected from survivors in the target communities.

Once the Community Profile Team felt an adequate number of responses had been submitted, results were sorted by counties and reviewed by two members of the team. The reviewers searched for common themes that were present multiple times.

Review of Qualitative Findings

Surveys done in both Orange and Osceola Counties had an emerging theme: women were only getting screened once they found a lump in their breast or recognized some other major change. Orange County was more familiar with the local Komen Affiliate and was aware of other screening programs. Osceola County responses mentioned the lack of available services in their county.

The focus group at Halifax Health Medical Center was done to focus on education of breast health to determine if the low rates for screenings and clinical exams were due to a lack of general breast health knowledge. Before the focus group commenced, participants listened to a brief presentation about the purpose of the Community Profile, how their community was selected and how their responses would be used. Guidelines were established to ensure each participant would have input. Participants agreed on the guidelines.

Notes were taken by an Affiliate grantee and reviewed for accuracy and analysis. Upon review, commonly stated answers and statements were grouped together. If a response was frequently repeated, it was determined to be a common theme.

Themes that were found were as follows:

One: Not one survivor participating in the focus group could say that she/he felt that their physicians had taught them what was normal for their breasts in regard to changes over time, and most did not have regular clinical exams or mammograms.

Two: There is not enough information available to the public in this community on breast health. Better ways to distribute the information are through different forms of media and presentations.

Surveys done in Volusia County mirrored the themes found in the focus group and also portrayed a major theme of uncertainty in terms of where to turn for financial help, if in need. Responses revealed that the two most common reasons the respondents in this community felt women were not being screened or getting clinical exams on a regular basis was financial hardship and lack of education. Responses to a question asking where a person could turn to for financial help for breast health were an overwhelming “I do not know.” The local Komen Affiliate was the second most popular response.

Survivor surveys in all counties showed a significant need for financial assistance for patients going through treatment. When asked how the diagnosis affected their lives, financially was most commonly stated, followed by emotionally. Comments such as: “It ruined my life financially,” “I cannot afford anything,” “my family goes without because of me,” “devastating financially,” and “I have spent more time dealing with how I will pay my bills than focusing on my health” were popular responses.

Another emerging theme was that they wished they had been more educated on breast cancer before diagnosis. In response to a question about what survivors wished they knew before being diagnosed, answers were as follows: “I wish I knew it wasn’t an immediate death sentence,” “if I had of known my risk was higher because I am black, I would have paid more attention,” and “anyone can get it; I didn’t know that.”

Conclusions

After reviewing all three types of information (statistics, Key Informant interviews and surveys), the Community Profile Team was confident in the findings. Statistics matched what Key

Informants were seeing in their breast health communities, and surveys were echoing the Key Informant responses. Programs were evaluated equally across the board, and reoccurring issues were presented multiple times.

A lack of breast health education needs to be addressed in Central Florida, specifically for minorities. Early detection and the benefits it provides need to be addressed and taught to the public.

All counties need access to screening, particularly Orange, Osceola and Volusia. Orange and Osceola also need programs that will help with the late stage diagnosis problem that is evident in these areas. Funding for diagnostics has been requested and is supported by data.

In all areas of the Affiliate service area, financial assistance for survivors going through treatment stood out as a need. Poverty levels and the cost of health care are troublesome to the Community Profile Team.

Conclusions: What We Learned, What We Will Do

Review of the Findings

The Community Profile Team first identified three target communities by looking at statistical data. Statistics from Florida CHARTS, the U.S. Census Bureau and estimates from Thompson Reuters ©2009 were most frequently used and compared to one another. The Team was in agreement that the three target areas that stood out the most in terms of need were Orange, Osceola and Volusia Counties.

All three counties had the lowest screening rates in the Affiliate service area as well as low insurance rates. Both Orange and Osceola Counties had the highest late stage diagnosis and mortality from breast cancer. These statistics were taken from Florida CHARTS. They were dated 2007, but the Team felt they were more accurate than estimates.

Approximately 20-30% of women were not screened in the past year according to statistics. Survey results matched these numbers making the Community Profile Team feel comfortable with the statistics from 2007. There were similar correlations between the statistics for late stage 3 diagnosis and the counties in which survivors resided.

After statistics were reviewed and target areas were chosen, interviews, surveys and focus groups were done to see if there were more correlations between the statistics and responses. Nearly every finding in quantitative data was backed up by qualitative data. The information that was found reported that screenings were low in these areas due to lack of education, specifically for minorities. All areas were equally uninformed on the importance of early detection. The low screening rate is directly correlated to the high rates of late stage diagnosis and mortality.

It was found that in Orange and Osceola Counties, a woman did not inquire about a screening until she noticed a lump or change in her breast, which meant she was more likely to be in

need of diagnostics and at risk for a late stage diagnosis or even mortality. When early screening is not practiced, it can lead to the more aggressive stages of breast cancer.

Survivors of breast cancer made a large statement with regard to financial assistance for patients going through treatment. Many of the comments heard about this topic were upsetting to the Community Profile Team. There is an obvious need for financial support to patients undergoing treatment.

Conclusions

Conclusions can be made based on the evidence examined for this report that the three target areas (Orange, Osceola and Volusia Counties) are most in need of breast health services to help correct the devastating statistics. This in no way discounts the need in the other counties in the service area. There is still a need in all areas; these counties simply had needs that were more prominent.

The Community Profile Team feels that the root of the problems found can be addressed by starting with education on breast health. Many women were not getting screened annually, due to financial restraints, lack of knowledge on facilities, and the importance of regular screenings. By educating the public about breast health and existing programs, the continuum of care will more likely improve a woman's life and change the statistics for Central Florida.

Not receiving an annual screening and the high minority population in Orange and Osceola Counties is directly related to the high rate of late stage diagnosis and mortality. By informing this population on the importance of screening before problems exist, they will be less likely to experience such a high rate of stage 3 and 4 breast cancer patients and in turn, will have fewer deaths due to the disease.

Because Florida was hit so hard during the recent recession, poverty rates are high, less people have insurance and unemployment is high, it is not surprising that survivors going through treatment are struggling to make ends meet. Women spoke of losing their homes, families going without basic needs, and the stress that the financial burden from the disease put on them.

Programs do exist that can help patients going through a regular screening mammogram or even treatment. The lack of marketing and information prevents patients from being in the programs that are best for them. Over the next year, Komen Central Florida will work to improve the amount of education available, increase the number of programs that exist, and develop new programs that will better serve the community.

Action Plan

The goal for the next two years will be to focus on the areas of concern brought up in this Community Profile. This will be done by setting the following priorities:

1. **Problem:** Low screening rates among women in Central Florida, specifically in Orange, Osceola and Volusia County, and a lack of screening programs for women ages 40-49.
Priority: Provide screening services for patients between the ages 40-49 in Central Florida with a heavy focus on Orange, Osceola and Volusia County.
Objective 1: Look into funding breast health services on a mobile mammography bus by the grant cycle of 2012-2013 that can cover all of Central Florida.
Objective 2: Work with current grantees to expand their services to patients outside of their county by the next grant cycle.
Objective 3: Increase educational information on the importance of regular screenings in the form of community presentations (two per year) and monthly social media videos and articles highlighting available programs.
2. **Problem:** Women in Osceola and Orange County are being diagnosed at later stages and having a higher mortality rate from breast cancer, specifically black women.
Priority: Increase access to diagnostic testing for patients in Orange and Osceola Counties with a large focus on black women while educating them on the importance of early detection.
Objective 1: Work with current screening programs and develop a continuum of care by implementing assistance for diagnostic testing by January 2012 and then implementing next steps.
Objective 2: Increase education on the importance of early detection for women in these counties by being involved in two educational events during the next year. The goal will be to get these patients to the doctor before a lump is found.
Objective 3: Fund more diagnostic testing in Orange and Osceola Counties by the 2012-2013 grants cycle.
3. **Problem:** Survivors going through breast cancer treatment are experiencing financial hardship due to the cost of treatment.
Priority: Aid survivors that are at 200% of the federal poverty level with expenses such as, but not limited to, medical co-pays and living expenses.
Objective 1: Fund grants to assist with financial hardships for patients going through treatment.
4. **Problem:** Minorities and the younger population are less likely to be educated on breast health and also less likely to seek screenings.
Priority: Increase breast health education in places that are heavily populated by minorities and a younger population.
Objective 1: Develop specific marketing strategies by August 2012 that will target minorities and youth and inform them of breast health.
Objective 2: Implement strategies and develop programs on breast health specific to minorities and youth by October 2012.
Objective 3: Fund educational programs on breast health for minorities and youth by the 2012-2013 grants cycle.