COMMUNITY PROFILE REPORT

Susan G. Komen for the Cure® CHARLOTTE

2011

Disclaimer:

The information in this Community Profile Report is based on the work of the Charlotte 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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With heartfelt appreciation,
Mary Hamrick, Community Outreach Manager
Charlotte Affiliate of Susan G. Komen for the Cure

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Executive Summary

Introduction

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, which is the world's largest breast cancer organization and the largest source of nonprofit funds dedicated to the fight against breast cancer with more than $1.9 billion invested to date. For more information about Komen for the Cure, breast health or breast cancer visit www.komen.org or call 1-877-GOKOMEN.

The Charlotte Affiliate of Susan G. Komen for the Cure was founded by Penelope Wilson in 1992 and the first annual Susan G. Komen Charlotte Race for the Cure® was held on October 4, 1997. Each year, the Charlotte Affliate holds the Komen Charlotte Race for the Cure on the first Saturday in October. Through this and numerous other fundraising events hosted by organizations and individuals, the Affiliate has raised over $14 million for breast cancer research, education, screening and treatment. Seventy-five percent of net proceeds stay in the local service area to fund breast health programs. The remaining net twenty-five percent supports vital breast cancer research. Since 1997, the Affiliate has awarded over $8 million to local non-profits through community grants in the nine-county service area made up of: Cabarrus, Gaston, Iredell, Lincoln, Mecklenburg, Rowan, Stanly, and Union, NC, and York, SC. The Affiliate has also contributed nearly $3 million to the Komen National Award and Research Grant Program, funding groundbreaking breast cancer research, meritorious awards and educational and scientific programs around the world.

Overview of Breast Cancer Impact

Unless otherwise noted, the 2009 demographic and breast cancer statistics used to compile this Community Profile report was provided by the Healthcare Business of Thomson Reuters © 2009. The data uses 2009 estimates and was provided at the request of the Susan G. Komen for the Cure national organization. For the purpose of this report, the Community Profile team focused on mortality rates first, with the objective of reducing over time the number deaths due to a breast cancer diagnosis. Stanly County surfaced as the county with the highest mortality rates in the service area at 30.7 deaths per 100,000 female population, and Rowan County was close behind at 28.5 deaths per 100,000 female population. These rates are well above the service area average of 23.2 deaths per 100,000 female population. Additionally, Stanly County emerged as the county with the highest percentage of females without a mammogram in the past twelve months at 40 percent, followed closely behind by Gaston at over 39 percent and Rowan at 38.9 percent. The average percentage of females without a mammogram in the past twelve months was 36.7 percent.

Both Stanly and Rowan counties are rural areas suffering from financial hardships including a higher than average percentage of uninsured females and a higher than average percentage of families living below poverty. Additionally, both counties experienced many company closings and downsizing during the economic downturn.

Rowan County's 124,596 population is made up of 75.6 percent Caucasian, 16.0 percent African American, 6.3 percent Hispanic, 0.3 percent American Indian, 0.8 percent Asian, and 0.9 percent Other. Stanly County's 62,171 population is slightly less diverse at 82.4 percent Caucasian, 11.4 percent African American, 3.4 percent Hispanic, 0.3 percent American Indian, 1.6 percent Asian, and 0.9 percent Other.

High breast cancer mortality rates combined with low breast cancer screening rates and overall financial hardships, highlight the Community Profile team's decision to focus on Stanly and Rowan counties for the purposes of this report.

Overview of Health Systems Analysis

The team prepared asset maps to look at the mammography locations as well as the mortality rates of both Stanly and Rowan counties. In Stanly County, two mammography locations are available, one in Locust and the other in Albemarle at Stanly Regional Medical Center (SRMC). Within the last year, SRMC opened a new Breast Health Center featuring digital mammography, a breast health navigator, and new office space. SRMC has received a grant from the Affiliate for the past six years, providing education, screening, and diagnostics to un/under-insured individuals. Additionally, SRMC collaborates with other local organizations focused on serving un/uninsured populations to best meet the needs of these individuals.

In Rowan County, the sole mammography office is part of Rowan Regional Medical Center (RRMC) in Salisbury. Similarly to SRMC, RRMC recently opened a new Breast Health Center, featuring digital mammography, their first breast health navigator, and a new office space. Additionally, a mobile mammography van, operated by Carolinas Medical Center – NorthEast (CMC-NE) offers another mammography option in both of the target counties, and some residents of the counties travel to CMC-NE in Concord (Cabarrus County) for their breast health care.

Both county health departments have administered North Carolina Breast and Cervical Cancer Control Program (NC BCCCP) funds, which provide free or low-cost breast and cervical cancer screenings and follow-up to eligible women living in these counties. Women enrolled, screened and diagnosed with breast cancer through NC BCCCP may apply for Breast and Cervical Medicaid (BCCM) to cover the cost of treatment. However, women diagnosed with breast cancer, who would have qualified for NC BCCCP but were not enrolled at the time of diagnosis, are not eligible for BCCM.

The Rowan County Health Department (RCHD) recently learned that their NC BCCCP funding was reduced for the upcoming fiscal year, and this impacted their ability to run the program. These cuts combined with recent cuts in county funding, resulted in the loss of three positions, including a nurse. In turn, the RCHD Board of Health voted to eliminate the NC BCCCP program at the RCHD going forward. Additionally, the Stanly County Health Department (SCHD) is running short on NC BCCCP funds and anticipates funds will be depleted well before the current fiscal year ends on June 30, 2011.

Currently, there is a proposed cut to all available NC BCCCP funds for the state. If passed, NC BCCCP funds would be reduced 73% from $1.5 million to just $400,000 for the upcoming fiscal year. At the current level, NC BCCCP screens about seven to ten percent of the eligible population in NC. The success of the NC BCCCP program is integral to achieving the Komen mission, and the Affiliate is working diligently with other North Carolina Affiliates to ensure that NC BCCCP funds remain.

The Community Profile team conducted fifteen key informant (KI) interviews with experts from a variety of disciplines and organizations involved in the breast health continuum of care in Rowan and Stanly counties. Each interview was conducted over the phone and lasted approximately one hour. Several themes emerged from the interviews. Key informants (KIs) felt that the groups least likely to get screened for breast cancer were primarily those women uninsured or with little or poor coverage, and those with a low socioeconomic status (SES). Lack of financial resources was mentioned as a barrier to women seeking breast health services during almost every interview conducted. Another dominant theme that appeared during KI interviews was a knowledge deficit in regard to breast health and available resources. KIs shared that they believe fear of pain, fear of the procedure itself, and fear of a positive diagnosis also kept women from getting regularly screened. The majority of KIs were aware of both Komen grant money and NC BCCCP funds. The mobile unit was discussed in great depth during interviews and was perceived as an asset to these communities. KIs felt breast health educational and awareness programs are needed, as well as financial programs to cover transportation, screening and treatment. These themes reinforced the need for additional qualitative research to better understand perceived barriers that prevent women from seeking breast health services, as well as potential resources to encourage women to be more proactive about their breast health.

Overview of Breast Cancer Perspectives

A total of 44 women participated in four focus groups held in Stanly and Rowan counties. Focus group participants were recruited with the help of community gate keepers, who were familiar with routes to access the counties' population. The Community Profile team created a script and questionnaire to guide the group sessions. To help ensure data quality, each of the focus groups were facilitated by the same moderator and co-moderator. Additionally, when conversation ceased at the end of each question, the co-moderator read aloud the responses provided by participants to confirm accuracy of information and fill in any areas or answers that may have been missed. Hispanic participants responded in Spanish and a translator verbalized the responses in English during the session. All other participants were fluent in English. All results were analyzed to identify common themes present throughout the sessions. Initial analysis of the data revealed the following categories: pain, fear, support, breast health knowledge, outreach, access to facilities, finances, insurance, self, society, SES, and culture.

Analysis of the data from all four focus groups revealed consistency of three themes also identified during KI interviews: knowledge, access, and support. These areas were clearly identified as gaps in the system and are areas where intervention is needed. The

dominant theme of knowledge included the need for increased education and awareness related to the importance of mammograms, potential risk factors, procedures related to breast health, signs and symptoms, self breast awareness and available resources. Numerous participants agreed that there was a need for programs teaching the basics of breast health to females in general, and more specifically with younger female populations. The importance of access to educational pamphlets and information was highlighted as a deficit within the communities.

A secondary prominent theme found during the focus sessions was access. Within Rowan County, some participants reported preferring to travel outside of the county for health care. Comparatively, for Stanly County participants, transportation services were noted as a more significant issue. However, participants from both Stanly and Rowan counties emphasized the lack of available financial resources and lack of insurance coverage as barriers to breast cancer screening and care. Participants reported a high incidence of poverty, a large proportion of uninsured and elevated high school dropout rates each contribute to a poor SES among residents of both counties. Participants shared that minority populations suffered from additional culturally related barriers which inhibit access to breast health care, primarily in Hispanic and Hmong populations.

Finally, support from family, friends, providers, and the community was identified as another important theme with participants. Positive and negative support in various forms reportedly influenced the beliefs and perceptions of participants, and inhibited or encouraged female county residents to seek breast health services. Focus group members also mentioned that negative and positive experiences with nurses, providers, or a hospital shaped future visits and motivation for seeking care.

Conclusions

The Community Profile team hopes this report will provide a better understanding of specific gaps and barriers in the continuum of care, so that ultimately, the Affiliate and other interested parties and organizations may work together to better address the needs of these target areas. The Affiliate adopted the following Action Plan in an effort to meet the needs and gaps identified through the Community Profile process:

Priority 1 – Partner with community-based outreach/health organizations to effectively increase access to breast health information and services to women living in rural areas, with specific focus on Rowan and Stanly Counties.

Objective 1 – For FY 2012, amend the Affiliate's Statement of Need within the Request for Application (RFA) to include programs with proactive outreach, education, and patient support serving diverse groups throughout the Affliate service area with a focus on rural regions.

Objective 2 – By January 2012, research and partner with non-grantee community based health organizations to arrange at least one outreach opportunity within Stanly or Rowan County at an appropriate community event.

Objective 3 – For FY 2012, host an Affiliate "Best Practices" event for grantees and other interested organizations. Highlight successful education/outreach programs such as CMC-NE's "Breast Health Champions," Cancer Services of Gaston County's "Breast Health Education for Ninth Grade Students," or the Girl Scouts' Hornets Nest Council's "Scouting for the Cure."

Objective 4 – For FY 2012, continue to build on current grantee partnerships and other collaborations in Rowan and Stanly Counties developed through the Community Profile. Work to further promote these services and grants within the community.

Priority 2 – Partner with local churches to effectively increase access to breast health information and services to women living in rural areas, with specific focus on Rowan or Stanly County.

Objective 1 – By September 2011, identify a local volunteer chair within Rowan or Stanly County to work with the Affiliate in engaging the faith communities as part of the Affiliate's Pink Sunday educational program held annually in April.

Objective 2 – By April 2012, through the help of volunteer chairs and committees, engage at least ten churches in Rowan or Stanly County to participate in the Affiliate's Pink Sunday program in 2012.

Priority 3 – Provide opportunities for enhanced networking for breast health professionals and organizations in the service area.

Objective 1 – For FY 2011, organize a task force to research local symposiums, meetings, conference and coalitions to clarify the purpose and goals of a regional networking / educational assembly. Begin initial planning phases of determined event with goal of delivering event in 12 – 24 months.

Priority 4 – Continue partnering with other North Carolina Komen Affiliates to advocate for NC BCCCP funds locally and federally while also identifying opportunities to partner and collaborate with other organizations with similar initiatives.

Objective 1 – In April 2011, send a minimum of two Affiliate representatives to attend and participate in the Komen National Lobby Days held in Washington DC.

Objective 2 – FY 2011, create a local Affiliate board position dedicated towards guiding the Affiliate's advocacy efforts. The new position will develop a robust and active committee to support the Affiliate's advocacy efforts.

Objective 3 – FY 2011, plan at least one annual trip, in conjunction with other North Carolina Affiliates, to meet with the Cancer Prevention and Control Branch at the NC Division of Public Health in Raleigh, NC.

Introduction

About Susan G. Komen for the Cure

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

Nancy G. Brinker (right); Susan G. Komen (left)

Affiliate History

Penelope Wilson (right); Annie Wingo (left)

The Charlotte Affiliate of Susan G. Komen for the Cure was also founded on a personal promise. In memory of Annie Wingo who lost her battle to breast cancer in 1992, Penelope Wilson recruited a passionate group of volunteers to organize the first annual Susan G. Komen Charlotte Race for the Cure® on October 4, 1997. Each year, the Charlotte Affliate holds the Komen Charlotte Race for the Cure on the first Saturday in October. Through this and numerous other fundraising events hosted by organizations and individuals, the Affiliate has raised over $14 million for breast cancer research, education, screening and treatment. Komen Charlotte is a grant making organization. Each year, 75 percent of the Affiliate's net proceeds stay in the local nine-county service area to fund breast health education, breast cancer screening and treatment programs. The remaining net 25 percent supports vital breast cancer research. Since 1997, the Affiliate has awarded over $8 million to local non-profits through community grants in the service area. The Affiliate has also contributed nearly $3 million to the Komen National Award and Research Grant Program, which funds groundbreaking breast cancer research, meritorious awards and educational and scientific programs around the world.

According to a 2010 Harris Poll, Susan G. Komen for the Cure was named the number one non-profit to which people are most likely to donate. Komen for the Cure was also named number one in Brand Equity, and second only to St. Jude's Research Hospital when ranked according to trust. In 2010, the Affiliate was named the winner of the Association of Fundraising Professional's Outstanding Philanthropic Organization in Charlotte, NC. The Affiliate also works diligently on advocacy and policy as part of the Komen Advocacy Alliance.

Organizational Structure

The Charlotte Affiliate employs four full-time staff members and one part-time staff person who are supported by volunteer committees (*see Figure 1*).

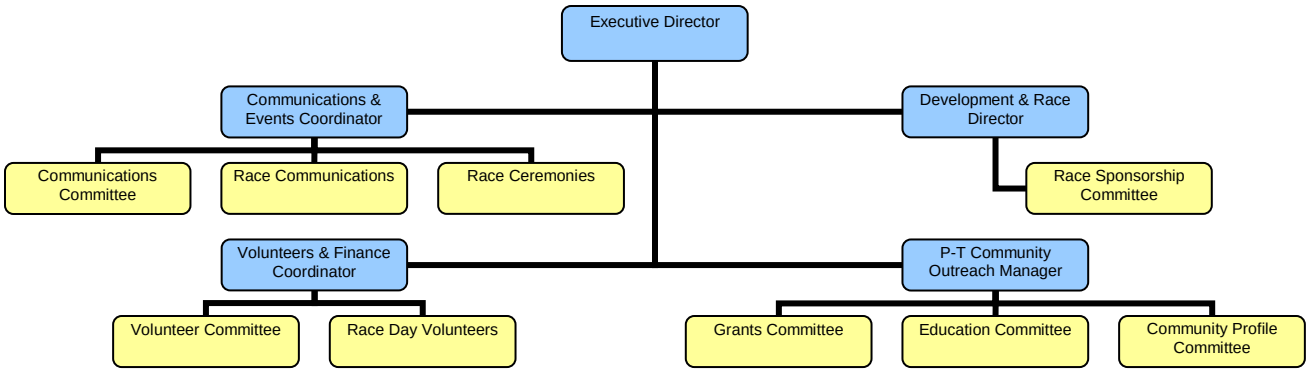

Figure 1: Organizational chart showing staff (blue) and volunteer committees (yellow).

The Affiliate is governed by a 13-member Board of Directors also supported by volunteer committees, and the Executive Director reports to the President of the Board (*see Figure 2).*

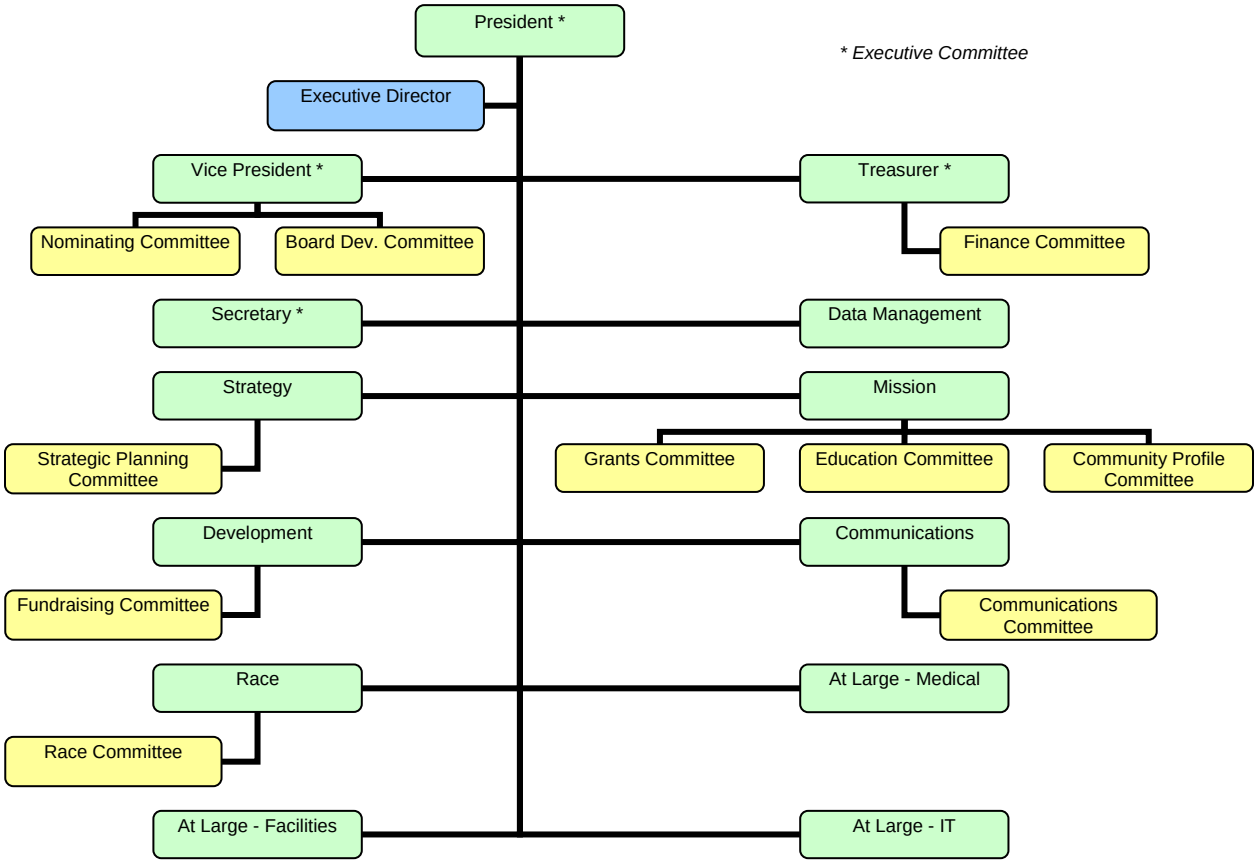

Figure 2: Organizational chart showing Board of Directors (green) supported by volunteer committees (yellow). Executive Director (blue) reports to President of Board of Directors.

Description of Service Area

The Affiliate service area includes the following nine counties: Cabarrus, Gaston, Iredell, Lincoln, Mecklenburg, Rowan, Stanly, and Union, NC, and York, SC. The Affiliate service area is highlighted in pink in the North Carolina map below *(see Figure 3).*

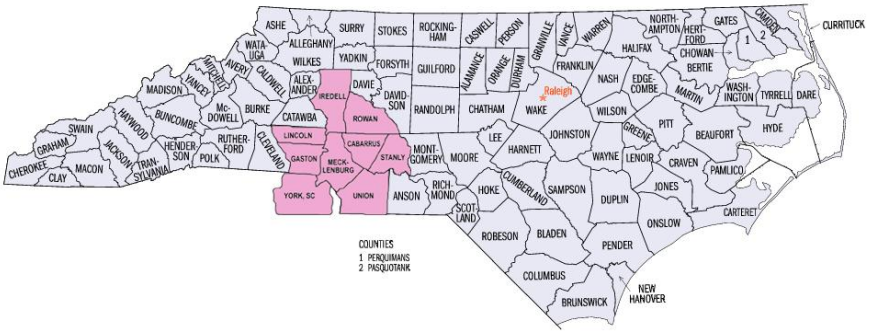

Figure 3: North Carolina map with the Affiliate nine-county service area highlighted pink.

Mecklenburg County, located in the middle of the service area, is the most populous county in North Carolina and is by far the most populous of the nine counties with 909,674 residents. As expected, Mecklenburg County offers the greatest number of breast health provider options, and in some cases, residents of other counties may come into Mecklenburg County for their breast health needs. In 2010-11, the Affiliate awarded 40 percent of the community grant funds to partners within Mecklenburg County. This mirrors the population distribution, as 42 percent of the individuals in the Affiliate service area live in Mecklenburg County, while individuals living in the remaining eight counties combine to make up 58 percent of the population.

Purpose of Report

The goal of the Community Profile is to gather information about the Affiliate nine-county service area for the purpose of identifying gaps in services and populations most in need of breast health care. The results of this project are instrumental in guiding activities such as:

- Establishing focused granting priorities
- Creating targeted educational programs
- Strengthening the need for fundraising
- Guiding inclusion efforts in the community
- Driving public policy efforts
- Establishing directions of marketing and outreach
- Aligning the Affiliate strategic and operational plans

Additionally, this information can be used by other organizations for program planning and service delivery, grant writing, and finding opportunities for expanded referrals and interagency collaborations.

Breast Cancer Impact in Affiliate Service Area

Methodology

Unless otherwise noted, the 2009 demographic and breast cancer statistics used to compile this Community Profile report was provided by the Healthcare Business of Thomson Reuters © 2009. The data uses 2009 estimates and was provided at the request of the Susan G. Komen for the Cure national organization.

Overview of the Affiliate Service Area

Breast Cancer Mortality

For the purpose of this report, the Community Profile team focused most heavily on breast cancer mortality rates, with the objective of reducing over time the number of deaths due to a breast cancer diagnosis. Stanly County has the highest breast cancer mortality rates in the service area at 30.7 deaths per 100,000 female population. Rowan and Gaston counties are close behind at 28.5 and 27.4 deaths per 100,000 female population respectively (*see Figure 4*).

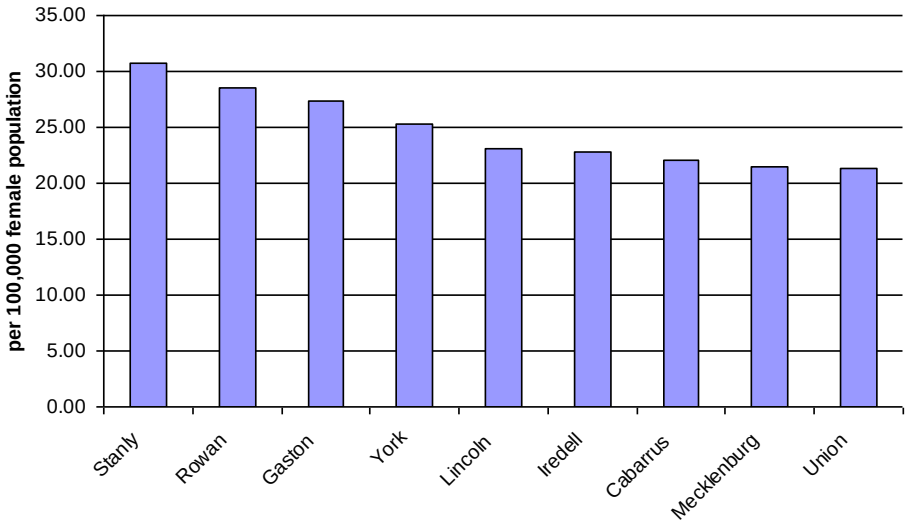

Figure 4. Breast cancer mortality rates for the Affiliate service area.
Thomson Reuters © 2009.

When looking at breast cancer mortality rates by race, Caucasian women have the highest rates in Stanly, Rowan and Gaston counties at 31.49, 29.03, and 28.92 per 100,000 female populaton respectively. While African American women have the highest breast cancer mortality rates in Rowan, Lincoln, Iredell and Stanly ranging from 31.23 to 30.76 per 100,000 female populaton.

Late Stage Diagnosis

The majority of female breast cancer cases in the service area are diagnosed at Stage I, but an average of 8.0 percent of breast cancer cases are diagnosed in Stage III and IV.

Based on the data below, Mecklenburg has the highest percentage of breast cancer cases diagnosed at Stage IV followed by York and Rowan counties (*see Figure 5*).

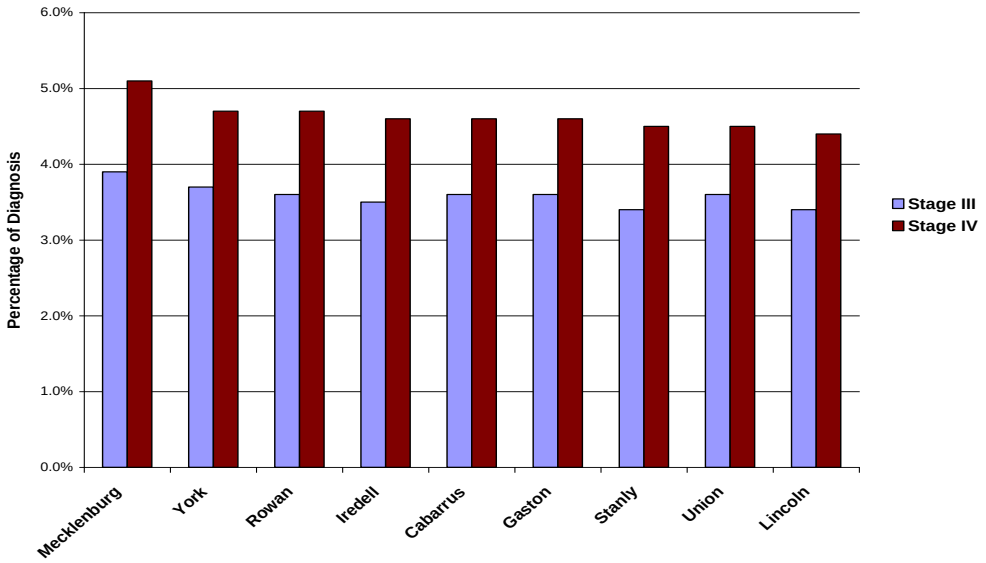

Figure 5. Late stage breast cancer incidence rates by county.
Thomson Reuters ©2009

When looking at late stage diagnosis by race, it becomes evident that African American women are more likely to be diagnosed at late stage, or Stage IV, breast cancer at 8.0 percent per 100,000 females, than Caucasian women and all other ethnicities who are diagnosted at late stage breast cancer at 4.2 percent per 100,000 females (*see Figure 6*).

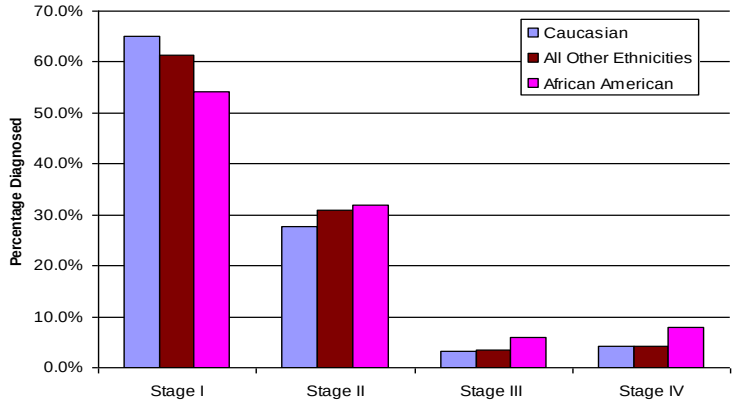

Figure 6: Breast cancer incidence rate by ethnicity and stage.
Thomson Reuters ©2009

African American women make up approximately 21% percent of the female population within the Affiliate service area equating to 234,899 individuals. Among African American women, the causes of higher mortality rates, more frequent late-stage diagnosis, and poorer survival rates are complex and not completely understood. Aggressive tumor characteristics linked to poorer prognosis appear to be more common in African American women and may contribute to lower survival rates. However, even

when controlling for these factors, African American women have poorer survival rates. This can be explained in part by unequal receipt of prompt, high quality treatment for African American women compared to Caucasian women. (ACS, 2009).

Mammogram Screening

Approximately 38 percent of female residents in the service area aged 40 and over have not had a mammogram in the past 12 months. Stanly County has the highest percentage of females without a mammogram at 40.1 percent followed closely behind by Gaston at 39.7 percent and Rowan at 38.9 percent *(see Figure 7).*

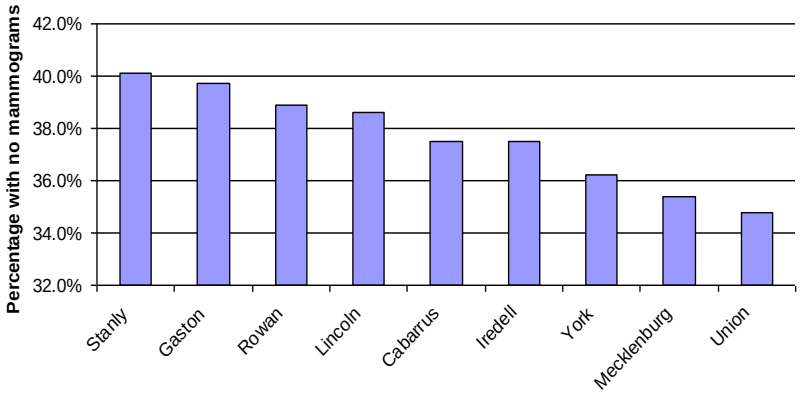

Figure 7. Females aged 40+ with no mammogram in the last twelve months.
Thomson Reuters ©2009

Communities of Interest

After the initial review, the Community Profile team determined two areas to explore more thoroughly.

1. Stanly County - Due to high mortality rates, low screening rates, and overall financial hardships of the county.
2. Rowan County - Due to high mortality rates, low screening rates, and overall financial hardships of the county.

North Carolina Comprehensive Assessment for Tracking Community Health (NC CATCH) is an epidemiological surveillance tool used and compiled by health departments in North Carolina. After review using NC CATCH, the available data further supported the decision to focus on Stanly and Rowan counties with similar rates and needs in regard to breast health and breast cancer. http://www.epi.state.nc.us/SCHS/catch/

Both Stanly and Rowan counties are rural areas suffering from financial hardships including a higher than average percentage of uninsured females and a higher than average percentage of families living below poverty. Additionally, both counties experienced many company closings during the economic downturn including but not limited to Phillip Morris and Cannon Mills, as well as downsizing at Freightliner and numerous other large and small companies.

Stanly County

Stanly County is largely rural with farms, mountains and small towns. The total population is 62,173, with 50.4 percent females. Out of the nine counties in the service area, Stanly County has the smallest population. The largest city is Albemarle with a total population of approximately 16,000. Following is the ethnic breakdown for the county:

- 2009 Total Population: 62,171
- Caucasian: 82.4 percent
- African American: 11.4 percent
- Hispanic: 3.4 percent
- American Indian: 0.3 percent
- Asian: 1.6 percent
- Other: 0.9 percent

The following statistics highlight the need for breast health programs and services within Stanly County:

- *Breast Cancer Mortality Rate* - Highest breast cancer mortality rate at 27.3 per 100,000 female population, compared to the overall service area rate of 23.3 per 100,000 female population. The NC state average is 24.7 per 100,000 female population, and a national average of 24.0 per 100,000 female population.
- *Breast Cancer Screening* - Lowest breast cancer screening rates at 40.1 percent of women not having a mammogram within the past twelve months, compared to the service area rate of 36.7 percent.
- *Age of Female Population* - 15.5 percent of the female population is 65 or older, compared to 10.6 percent of overall service area.
- *Average Family Income* - Lowest average family income is $42,368, compared to the overall service area income of $53,051.
- *Uninsured Females* – The second highest percentage of uninsured females (age 18-64) in the service area at 20.9 percent, compared to the service area rate of 17.0 percent.

Rowan County

Rowan is a rural county with a population of 124,617 consisting of 50.8% females. Salisbury, the largest city in Rowan County, has grown nearly 22 percent over the past ten years from 26,462 residents to just of 32,000 residents (Salisbury Post http://www.salisburypost.com/News/091010-salisbury-population-census-qcd). Rowan County is a bit more diverse than Stanly with the following ethnic breakdown:

- 2009 Total Population: 124,596
- Caucasian: 75.6 percent
- African American: 16.0 percent
- Hispanic: 6.3 percent
- American Indian: 0.3 percent
- Asian: 0.8 percent
- Other: 0.9 percent

The following statistics highlight the needs within Rowan County:

- *Breast Cancer Mortality* - High breast cancer mortality rate at 28.5 per 100,000 female population, compared to the service area rate of 23.3 per 100,000 female population.
- *Breast Cancer Screening* - Low breast cancer screening rates, with 38.9 percent of women not having a mammogram within the past twelve months, compared to the service area rate of 36.5 percent.
- *Age of Female Population* - 14.2 percent of the female population is 65 or older, compared to 10.6 percent of overall service area.
- *Poverty* - 8.5 percent of the families living in Rowan County are living below poverty level, compared to the service area percentage of 6.9 percent of families.
- *Average Family Income* - Average household income is $45,582, which is less than the average family income of $53,015 for the service area.
- *Uninsured Females* - High rate of uninsured females aged 18-65 at 20.1 percent, compared to the service area rate of 17.0 percent.

Conclusions

High breast cancer mortality rates combined with low breast cancer screening rates and overall financial hardships, highlight the need to concentrate on Stanly and Rowan counties for the purposes of this report. Incidentally, these counties were also identified as target areas by the 2009 Community Profile team due to similar statistics. The goal of the 2011 report is to further explore the gaps in service and potential areas for intervention by more thoroughly reviewing the health systems and legislative issues, as well as gathering observations from provider sources and the targeted communities. The report will provide a better understanding of the specific gaps and barriers throughout the continuum of care, so that ultimately, the Affiliate and other interested parties and organizations may work together to better address the needs of these target areas.

Also of interest, Gaston County ranked in the top three for several of the concerning breast health categories reviewed, as well as in the area of financial hardships. For these reasons, the Community Profile team recommends Gaston County as a potential target area to explore further in future Community Profile reports. Additionally, the team also recommends looking more specifically at African American women in future reports, as African America women are diagnosed at late-stage, or Stage IV, breast cancer at nearly twice the rate of other ethnicities in the service area.

Health Systems Analysis of Target Communities

Overview of Continuum of Care

The breast cancer continuum of care can help us understand potential gaps, barriers and issues present for women at each phase. It also helps recognize that many factors throughout the continuum can influence the statistics within the service area (*see Figure 8*).

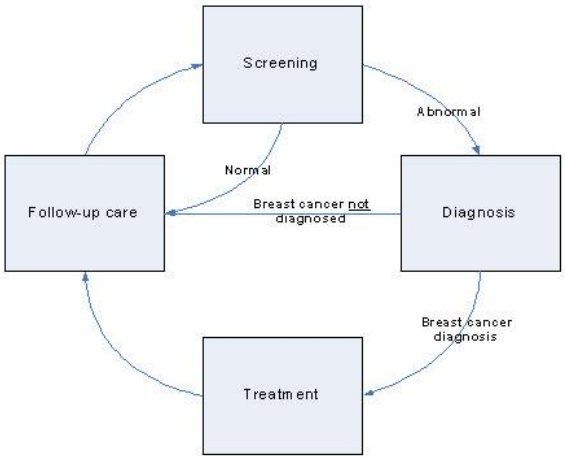

Figure 8: Diagram of the breast cancer continuum of care.

Methodology

Asset Maps

Asset maps of the Affiliate's nine-county service area and two target communities, Stanly and Rowan counties, were created using MapPoint software by a senior financial analyst in financial planning and analysis at Novant Health. Mammography locations were identified through the U.S. Department of Health and Human Services – U.S. Food and Drug Administration site: http://www.accessdata.fda.gov/scripts/cdrh/cfdocs/cfMQSA/mqsa.cfm.

Key Informant Interviews

Fifteen key informant (KI) interviews were conducted with experts in the breast health field within Stanly and Rowan counties. Interviewees represented a variety of disciplines and organizations including three hospitals, two free clinics, two county health departments, one OB/GYN practice, one oncology practice, and two churches. Individual roles at these organizations included nurse navigator, executive director, faith community nurse, oncology nurse, physicians assistant, nurse practitioner, community outreach manager, and oncology program coordinator.

Each interview was conducted over the phone and lasted approximately one hour. A graduate student intern created the questionnaire with input from a qualitative data professor who has experience collecting community data. The Affiliate's community outreach manager conducted all of the interviews and the conversations were recorded. The intern transcribed the notes, and the Community Profile team reviewed the data collected from the interview responses to identify key themes.

Legislative Issues in Target Areas

The North Carolina Breast and Cervical Cancer Control Program (NC BCCCP) provides free or low-cost breast and cervical cancer screenings and follow-up to eligible women in North Carolina. NC BCCCP services are offered at most local health departments as well as some community health centers, hospitals and private physicians' offices across the state. Approximately 102 local health agencies work in cooperation with physicians, hospitals, and other health care facilities to provide services to eligible North Carolina women.

NC BCCCP provides services to North Carolina women who are uninsured or underinsured, are without Medicare Part B or Medicaid, are between ages 40 - 64 for breast screening services, and have a household income at or below 250 percent of the federal poverty level. Currently, there are approximately 162,162 NC BCCCP program eligible women in NC. Between July 1, 2009, and June 30, 2010, NC BCCCP screened 16,387 women, including 15,193 breast cancer screenings and 8,071 cervical cancer screenings. There were 207 breast cancers diagnosed, with 141 of those being invasive. NC BCCCP currently only screens about seven to 10 percent of the eligible population in NC. This is based on the lack of funding to screen all that would be eligible.

To be eligible to apply for Breast and Cervical Medicaid (BCCM), a woman must be enrolled, screened (NC BCCCP funds pay for all or part of the cost of screening services) and diagnosed with breast and/or cervical cancer through NC BCCCP. BCCM pays for surgical intervention and other treatment of diagnosed breast and cervical cancers. NC BCCCP and Medicaid collaborate to approve applications for women applying for BCCM. Both entities have a role in the approval process. NC BCCCP will screen undocumented individuals; however, a woman must be a documented U.S. citizen to be eligible for BCCM.

Unfortunately, there are instances of women who would qualify for NC BCCCP but are not enrolled because they or their physician are unaware of the program. This is particularly devastating for women who are diagnosed with breast cancer and would have qualified for BCCM to pay for their treatment but are not screened under NC BCCCP. These women do not have insurance and cannot cover the high costs of treating breast cancer. Some uninsured patients may get assistance from hospital charity care if available or pro-bono work from physicians and surgeons; however, this is not a guarantee and does not cover the mountain of expenses incurred with a breast cancer diagnosis.

Regrettably, the NC BCCCP funding within NC is shrinking. In 2007, $2.0 million in NC BCCCP funds were initially allocated for the state. Of that, $500,000 was reallocated for smoking cessation, leaving $1.5 million for NC BCCCP. For the upcoming fiscal year of July 1, 2011, through June 30, 2012, there are proposed cuts of $1.1 million, which would leave just $400,000 in NC BCCCP funds. This proposed 73 percent cut in funding would be devastating to the women in need of the vital screening services. In January 2011, the four Komen North Carolina Affiliates each sent representatives to meet with the Assistant Branch Head of Cancer Prevention and Control Branch at the NC Division of Public Health. These Affiliates are working diligently together to save the NC BCCCP funds through various lobbying efforts including letters, phone calls and visits with the

state senators and local representatives. This will continue to be a priority of the Affiliate, as success of the NC BCCCP program is integral to achieving the Affiliate's mission. NC BCCCP is funded by the U.S. Centers for Disease Control and Prevention with the purpose of reducing cancer deaths through early detection. The North Carolina program is administered by the Division of Public Health – NC Department of Health and Human Services. For more information about NC BCCCP or to find a local NC BCCCP provider, call (919) 707-5300 or 1-800-662-7030.

The Affiliate also serves York County, South Carolina which is the only county in the service area not located in North Carolina. South Carolina's Best Chance Network (BCN) provides free breast and cervical cancer screenings for medically underserved women living there. The criteria to qualify for BCN services include the following three conditions: the woman must lack insurance or have insurance that only covers hospital care, she must be between the ages of 47 to 64, and she must meet certain income guidelines which are listed on the South Carolina Department of Health and Environmental Control website (http://www.scdhec.gov/health/chcdp/cancer/bcn.htm). BCN services include mammograms, clinical breast exams, pap tests, pelvic exams, diagnostic procedures, case management, and community education on breast/cervical cancer and early detection. North Family Medicine in Rock Hill, SC is the only BCN Provider in York County. Women can call the American Cancer Society's Cancer Resource Network Division Service Center at 1-888-227-6333 for more information regarding Best Chance Network providers in their area.

Overview of Community Assets

Service Area Highlights

The following map highlights provider locations, Affiliate grantees, and mortality rates within the Affiliate's nine-county area *(see Figure 9):*

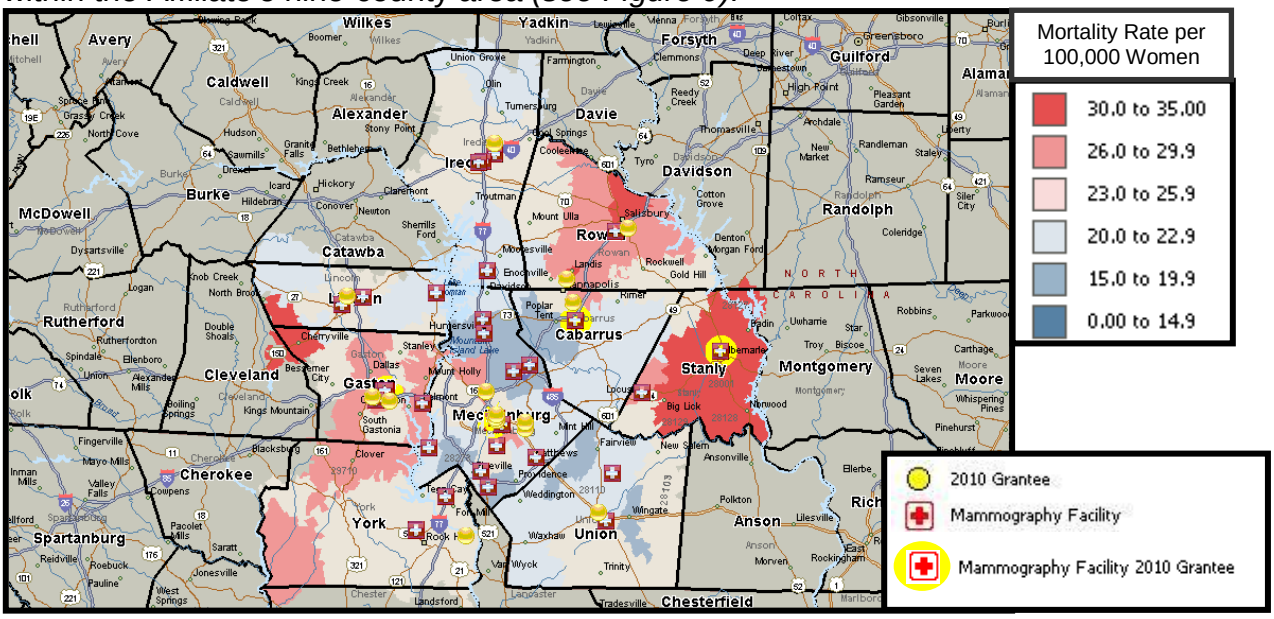

Figure 9: Nine-county service area highlighting Affiliate grantees, mammography facilities and mortality rates.

When looking at provider locations, Mecklenburg County offers 15 mammography sites, the most in the Affiliate's nine-county service area. Six of the remaining eight counties have at least two mammography locations, and Rowan and Cabarrus counties each have one location. Rowan County recently decreased from two locations when Rowan Regional Imaging absorbed Piedmont Radiology, and the remaining mammography site is located near Rowan Regional Medical Center (RRMC) in Salisbury.

Like Rowan, Cabarrus County has just one mammography site which is located near Carolinas Medical Center–NorthEast (CMC-NE) in Concord. However, CMC-NE also operates a mobile mammography unit which provides mammography access to numerous women in Cabarrus, Rowan, Stanly, Mecklenburg and Iredell counties. The mobile unit is dispatched to churches, businesses, colleges, medical facilities as well as special events taking place in the community. Women without insurance are easily and quickly screened for the CMC-NE screening grant provided by the Affiliate. A system is also in place for any women without primary care providers. CMC-NE has designed a yearly calendar for CMC-NE Physician Network, Logan and McGill Community Health Centers as well as Cabarrus County Community Free Clinic. Radiology scheduling contacts one of these clinics to insure a medical visit within a few days. They schedule the mammogram at the same time as the medical visit. Last year the CMC-NE Mobile Mammography unit performed 3,374 screenings.

Charlotte Radiology, an imaging group with 11 breast centers located throughout Mecklenburg, Union and York Counties, debuted their state-of-the-art mobile breast center in January 2011. The van provides mammography services to residents in Mecklenburg and surrounding counties. This new mobile option will be an asset to the service area. For additional information visit www.charlotteradiology.com.

Stanly County Highlights

The following map highlights Stanly County's two mammography locations, Affiliate grantees, and the high breast cancer mortality rates across the region (*see Figure 10*).

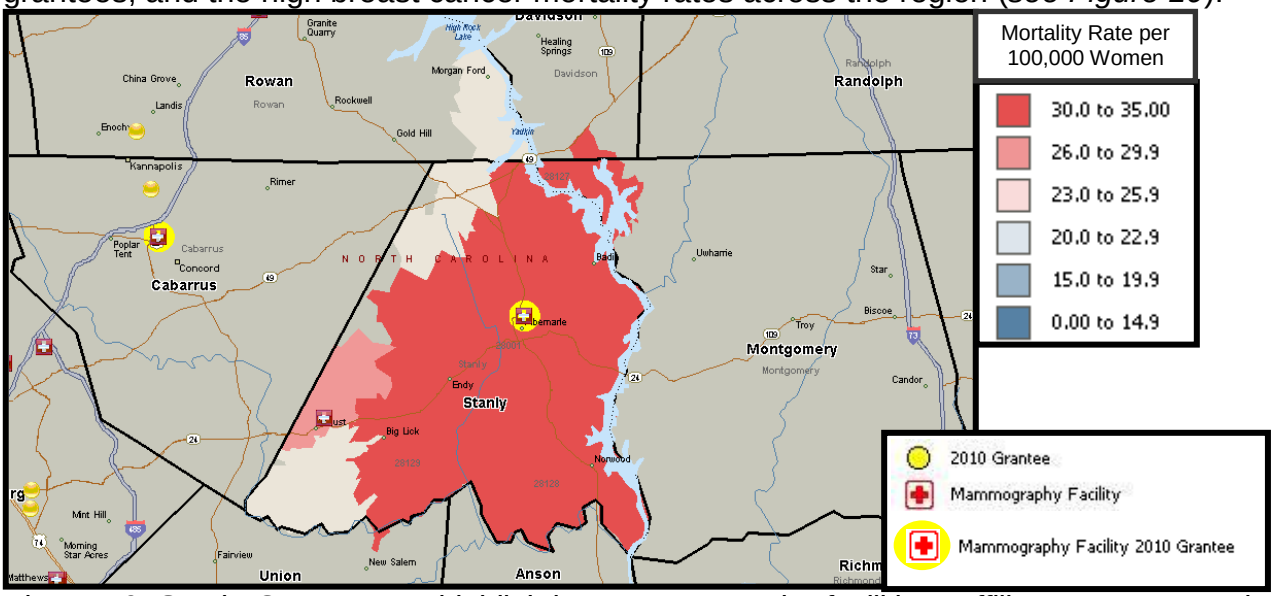

Figure 10: Stanly County map highlighting mammography facilities, Affiliate grantees and high mortality rates across the region.

The two mammography sites are the Breast Health Center at SRMC in Albemarle and West Stanly Imaging in Locust. Within the last 12 months, SRMC opened their new Breast Health Center featuring digital mammography, a breast health navigator, and a new office that is both comfortable and inviting. For the past six years, SRMC has provided breast health services (education, screening and diagnostic procedures) to un/under-insured individuals through a Komen Charlotte grant. Additionally, SRMC collaborates with the Community Care Clinic and the Stanly County Health Department (SCHD), both who refer many patients in need of the grant. SCHD offers NC BCCCP services to those who qualify in Stanly County. More NC BCCCP funds are needed, as SCHD ran out of funds in January 2011 and the NC BCCCP year end is June 30, 2011.

Rowan County Highlights

The following map provides a closer look at the mammography locations, Affiliate grantees and mortality rates within Rowan County, the other target county for this report. *(see Figure 11).*

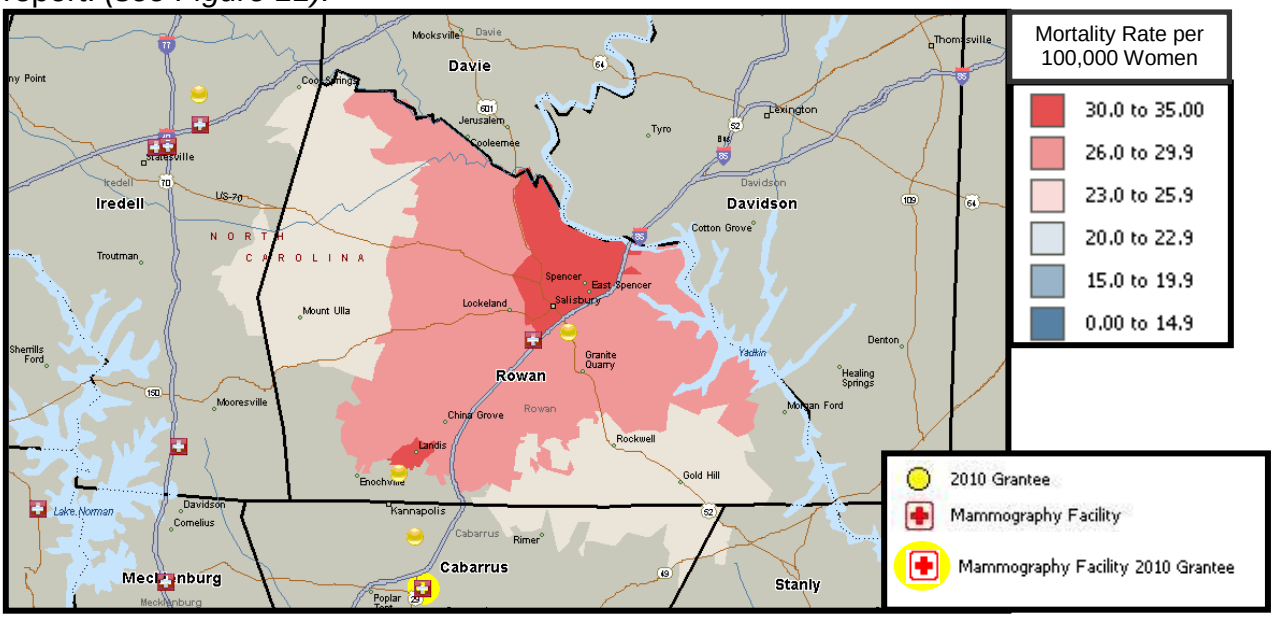

Figure 11: Map of Rowan County highlighting mammography facilities, Affliate grantees and mortality rates.

As discussed, Rowan Regional Medical Center (RRMC) operates the sole mammography site in Rowan County. Similar to recent breast health improvements at SRMC, RRMC recently opened a new state-of-the-art Breast Health Center near the hospital and featuring services from screening through treatment and the entire continuum of care. Additionally, RRMC recently hired their first breast health navigator, providing more individualized care and support to each woman diagnosed with breast cancer.

The Rowan County Health Department (RCHD) provides breast screening services to women of Rowan County who are un/under-insured and at or below 200 percent of the poverty level. RCHD receives referrals from the Rowan County Community Care Clinic, the Good Shepherd Clinic, and RRMC when clients who need screenings do not have insurance or income to cover these services. However, NC BCCCP funds for the RCHD

were reduced for the upcoming fiscal year (July 1, 2011 through June 30, 2012), and this impacted their ability to run the NC BCCCP program. These cuts combined with recent cuts in county funding, resulted in the loss of three positions, including a nurse. In turn, the RCHD Board of Health voted to eliminate the NC BCCCP program at the RCHD going forward.

Key Informant Findings

During the KI interviews, the team primarily spoke with community members involved in the breast health continuum of care. KIs felt that the women who were least likely to get screened for breast cancer were primarily uninsured or with little or poor coverage and with a low SES. Minority status and a lack of knowledge about available resources were other characteristics that KIs believed were present in women not being screened.

The KIs mentioned several locations during the interviews where women in the designated counties go to seek breast health services including screening, treatment and information. Primary providers, OB/GYNs, and the Breast Health Centers located in both Stanly and Rowan counties were all mentioned numerous times as places where insured women could go when seeking breast health services. The health department, Breast Health Centers, and community clinics or free clinics were listed as locations where women who are un/under-insured would go when seeking breast health services.

Lack of financial resources was mentioned as a barrier to women seeking breast health services during almost every interview conducted. Another dominant theme that appeared during KI interviews was the community's knowledge deficit in regard to breast health and available resources.

Breast health services that work well in the communities were gauged during the KI interviews. Most of the KIs felt that word of mouth and outreach efforts for education and exposure worked very well through the use of advertisements and events. The CMC-NE mobile unit was mentioned as an asset numerous times during the KI interviews as well as during the focus groups which will be discussed later in this report.

KIs and community leaders who are involved with breast health care should be knowledgeable of the financial resources available for patients and what may be required for eligibility. During the KI interviews, the team asked about financial assistance programs that are currentlyl available in the communities. Komen grant money was mentioned in all but one KI interview. The NC BCCCP funds, discussed earlier in this report, were also mentioned in the majority of interviews. Other financial resources mentioned included charity care through the local hospitals, small grants from other sources, and indigent programs.

One of the final KI topics focused on desired programs to help aid and promote breast health. The majority requested were educational in nature. Several informants also mentioned the need for financial programs to cover transportation, screening, and treatment.

Finally, KIs shared perceptions of economic reasons that had a negative impact on the community's ability to practice good breast health. Most notably were loss of jobs and insurance coverage, and limited finances due to the economy's downfall. The addition of the Breast Health Centers and the breast health navigator position were mentioned as having positive impacts on the community's breast health and access to services.

Conclusions

Overall, several themes emerged during the KI interviews. The importance of finances and insurance coverage was made apparent. Informants believe that lack of transportation, lack of or low amount of insurance coverage, or the inability to pay for screening or subsequent treatment after a positive diagnosis prevented women from seeking screening. A knowledge deficit, in regard to breast health and available resources, was also described by several KIs during the interviews. KIs believed that promoting education and resources through advertisements would help to increase screening participation and breast health knowledge. The CMC-NE mobile unit was discussed in great depth during interviews and was perceived as an asset to the communities. Finally, a lack of education about the resources available, fear of the procedures, and fear of pain were also mentioned several times as hindering female county residents from seeking breast health services.

These themes reinforced the need for additional qualitative research to better understand perceived barriers that prevent women from seeking breast health services, as well as resources that may encourage women to be more proactive about their breast health. With these aims in mind, results from the KI interviews were used to shape and guide a focus group tool for further investigation into community beliefs and perceptions. Ultimately, this research will assist in the development of an action plan to serve the target counties and the surrounding areas.

Breast Cancer Perspectives in the Target Communities

Methodology

Following the health systems analysis, a total of four focus groups were conducted to seek essential information from residents of Stanly and Rowan counties in an effort to address knowledge gaps which were otherwise unobtainable. Emphasis was placed on further exploring findings from KI interviews to gain insight regarding breast health from residents of the target areas. The focus groups also afforded an opportunity to explore information about residents' attitudes, beliefs, and practices related to breast health care. In addition, the focus groups provided vital information to help identify possible reasons affiliated with the high mortality rates and lack of mammography screenings in the two targeted areas of Stanly and Rowan counties.

Focus group participants were recruited with the help of community gate keepers who were familiar with routes to access the counties' population. Breast health navigators, parish nurses, and KI participants helped identify locations and populations from which participants were recruited. In an effort to recruit a diverse population to help represent the targeted counties, few limitations to participation existed. These included being a woman eighteen years of age or older who lived in either Stanly or Rowan County. Flyers detailing information regarding the time, date, and location of the focus groups, as well as contact information for additional questions or concerns, were distributed and displayed in various community locations, such as the health department, the community free clinic, and in church bulletins. The contact person was the Affiliate's community outreach manager and leader of the Community Profile effort. Various incentives, depending on the location, were offered for focus group participants. Dinner was provided during two of the focus group meetings, while each of the remaining participants received either a $10 gas card or a $10 Walmart card. Upon completion of the focus groups, all participants received a small gift bag from the Affiliate which provided information about breast health care. The two Rowan County focus group sessions were held in Rockwell, NC and Kannapolis, NC, and the two Stanly County focus group sessions were held in Albemarle, NC. The locations of the gatherings were church halls, a community center, or an oncology office and were arranged by the gate keepers who helped with recruitment.

Informed by KI results, scientific articles, consultant recommendations, and sample questions from the Susan G. Komen Community Profile guide, qualitative data experts, and other key members of the Community Profile team created a script and questionnaire for use during the group sessions. The semi-structured interview guide consisted of 11 open ended questions designed to learn about perceptions, emotions, beliefs, and experiences which may prevent or encourage women to seek breast cancer screening and treatment. The design was used to elicit the desired information while permitting the moderator flexibility to facilitate the flow of the conversation or to clarify responses.

The questions were developed using a "step ladder" approach following the guidelines described by (Krueger & Casey 2009) and the outline in the Community Profile guide. The approach involved used an opening question to promote participant comfort,

followed by introductory questions introducing the topic. Transition questions came next to link the introduction questions to the key questions, which focused directly on the main areas of concern. Lastly, final questions were designed to reinforce key question content and provide participants an opportunity to add any additional information, express concerns, or ask any questions not addressed.

During each of the four focus groups the opening question was basic and used to encourage participants to relax and communicate within the group. The introductory questions introduced the topic of breast cancer. In the case of the Community Profile, we were most concerned with breast cancer awareness and breast cancer screening. Thus, we asked focus group participants what came to mind when someone said “mammogram” and “breast health”. The transition questions were, “How do you feel about mammograms?” and “How do you feel about breast cancer treatment?” We also asked questions addressing where a person residing in the community would go for breast health services including education, screening, and treatment.

The key questions addressed the areas of primary interest, which was to determine perceptions of barriers or enablers which prevent or promote breast health in the target counties. In addition to perceived barriers to breast health services, information was sought regarding participant ideas for change, intervention, and improvement to breast health and treatment. The final questions afforded an opportunity to re-visit concepts presented in the key questions thus reinforcing the main areas of concern. In addition, the questions provided an opportunity for reflection and analysis on the preceding discussion (Krueger & Casey 2009)

To help ensure data quality, each of the focus groups were facilitated by the same moderator and co-moderator. Upon receiving verbal consent from participants, all sessions were audio recorded and themes or notes were documented by at least two persons present during each session. The moderator was the head of the Community Profile project and guided the sessions with the help of a graduate MSPH student who served as co-moderator. The co-moderator read aloud the responses provided by participants at the end of each question to confirm accuracy of information. Following the session, moderators and note takers met to debrief and discuss the responses.

A total of 44 women participated in four focus groups conducted within the target communities. Within Rowan County, four African American and 18 Caucasian women participated, and within Stanly County two Hispanic, four African American, and 16 Caucasian women participated. Eleven of the participants from Stanly County identified themselves as breast cancer survivors, and two of the participants from Stanly County stated that they had a background in nursing. Each group discussion lasted approximately 90 minutes. Hispanic participants responded in Spanish and a translator verbalized the responses in English during the session. All other participants were fluent in English.

All results were analyzed to identify common themes present throughout the sessions. Initially the moderators, note-takers, and qualitative data expert read and re-read the

data. The data was color coded to identify significant responses and then grouped into categories which were common within the groups. Initial analysis of the data revealed the following categories: pain, fear, support, breast health knowledge, outreach, access to facilities, finances, insurance, self, society, SES, and culture.

Three overarching themes emerged from the data: knowledge, access, and support. Each of the themes revealed numerous sub themes as described below. To enhance reliability of findings moderators and note-takers independently coded and grouped the data into categories. The team met on three occasions to compare and discuss coding techniques. Consistency was reached regarding the categories and final themes.

Review of Qualitative Data

Theme 1: Knowledge

The first theme was a lack of knowledge related to breast health among community members. Although women in both target communities expressed a level of awareness regarding an annual recommendation for mammogram screenings, they also expressed confusion regarding the recommended screening schedules for women of both average and high risk. The survivor group in Stanly County reported being confused about "when to go and when to start" mammograms. Many of the community members, who have medical insurance, were unaware if their policies covered mammograms and when they were eligible for coverage. A lack of understanding regarding effectiveness of mammograms for large breasted women, amount of radiation exposure during the procedure, risk factors, and signs and symptoms of breast cancer were expressed. The risk of breast cancer related to familial history, as well as screening recommendations for this group, remained a grey area for participants. Within one of the Stanly focus group, there was a woman who was unfamiliar with the term mammogram. Most women expressed an awareness of breast-self exams (BSE) but felt unsure of how to perform them and what they were looking for. Participants reported that health care providers usually assume women know about BSE and do not provide adequate instruction or explanation.

Participants felt strongly that BSE instruction should also focus on absolving the stigma or cultural taboo of touching one's own body. One member mentioned, *"There is a taboo of women looking at and getting to know their nude body."* Breast health instruction should reinforce the appropriateness and necessity of being aware of your body and noticing any changes that may occur.

Discussions about low education level and high dropout rates were offered by members as reasons for higher rates of breast cancer in the target areas. Community members suggested introducing breast health education much earlier in the school systems as a means of raising awareness and increasing knowledge. Within Rowan County a CNA certification program currently exists within the public high school system, and coursework includes teaching girls to do breast self-exams every three months. Stanly County participants expressed a desire for similar breast health awareness programs at a high school level. One of the Rowan groups suggested the need for and an

application option on cell phones as a means of communicating with a younger generation.

Participants expressed a desire for breast health education materials to be available in visible public areas including health departments, clinics, Department of Social Services (DSS) and churches. Members identified parish nurses, health care providers, Komen, and medical facilities such as health departments, clinics, CMC-NE and the Breast Health Center at SRMC as primary providers of breast health information. Participants suggested a wide list of local community events where breast health awareness and educational materials could be provided.

Theme 2: Access

Members identified a lack of financial resources as reasons for not receiving mammogram screenings and clinical breast exams. Women expressed a concern of receiving a diagnosis and then not receiving care due to lack of insurance or being "dropped" by insurers if they had coverage. In general, they expressed a need for more financial assistance programs like Komen and charity care. However, some women do not take advantage of the free screening programs because if something is found, there is no money for treatment or follow-through. This may prevent the initial screening. A participant commented, "*Some people wait until they qualify for MediCare and then seek treatment."*

location of facilities.

Within Rowan County, the majority of focus group participants reported traveling outside of county lines to seek breast health screening and treatment, although facilities and services are available within the county. Incidentally, the focus groups were held in both Kannapolis and Rockwell, and these are located at approximately an equal distance between CMC-NE in Concord, NC and RRMC in Salisbury, NC. Additionally, participants mentioned the use of a mobile van unit, but there was some question about whether or not it was still in working order.

Stanly County participants reported positive experiences with the new Breast Health Center at SRMC, as well as with the new breast health navigator on staff. However, transportation to and from facilities is reportedly insufficient. Much confusion was reported about the county transportation service (SCUSA) with regards to cost of service, times of operation and service area. Other than SCUSA no public transportation, such as taxis or buses, is available in Stanly County. Members mentioned that the hospital previously offered volunteer transportation service, but this was recently cut. Additionally, it was reported that many minority women such as Hispanics are unable to drive and depend on their husbands for transportation. Participants remarked, *"In Stanly County, people walk as much as fifteen miles to their appointments," and "People will wait for hours before and after appointments hoping for a ride."*

Hours of operation for certain departments were deemed as inadequate and did not accommodate working women or families where the husband works and is the sole source of transportation. Group members suggested after hours or weekend breast health services be made available. Also recommended was an increase in the opportunity to access mammography through mobile vans at employment locations or churches.

beliefs and perceptions.

Pain and fear were identified as barriers to seeking breast health care. Pain and discomfort related to receiving a mammogram and breast cancer treatments were commonly expressed by members in the four groups. A small number of women addressed how mammograms have "changed over the past 10 years," indicating digital mammograms were improved and receiving one was proactive. Fear of the unknown, including procedures for screening, a positive cancer diagnosis, and losing their insurance after a diagnosis are immobilizing for persons and contribute to poor access. Fatalism was expressed as a reason to avoid screenings. Comments included, *"I don't want to know if I got it. It is too late. I'd just rather not know, especially with my family history,"* when referring to screenings. Feelings of anxiety and a need for "mental preparation" were identified when women considered receiving a mammogram. Perceptions of "long waits" to hear results of mammograms further contributed to the anxiety levels. A stigma remains present when considering breast care, and one women shared that, "*mammograms made her feel small and embarrassed*".

The women shared a general unawareness about the details surrounding free screening programs and believed that a more personal contact from a trusted member in the community inviting people to attend would promote participation. Displaying written information in health departments, free clinics, and public areas at church and shopping locations where residents frequent were also identified as possible ways to increase participation in screenings. A need for information to be located where services are already accessed by a lower socioeconomic group, such as food kitchens and clothing distribution areas was identified.

Women in both counties identified CMC-NE and Stanly as places where they would seek breast health services. Their choice was primarily influenced by where previous generations of families received care, and a lack of knowledge regarding the breast health care services offered within Rowan County. One participant commented, "*Where a person's parents went determines where they will go. It's a history thing."*

Participants suggested that both Rowan and Stanly host breast health fairs at their hospitals. Members of Rowan County noted that their health department did not have an OB/GYN on staff. Within Stanly County, it was mentioned that only one primary care physician was female. Additionally, members perceived a large amount of turnover among primary care physicians, as well as a very small number of available physicians making it harder to get an appointment.

Most people believed OB/GYNs and primary care providers should send a reminder by mail about their annual mammogram screening. Women perceived professional support by nurses, physicians, and breast care navigators as vital to promoting access. On the other hand, poor communication skills and condescending remarks from care providers compounded barriers to seeking screenings. When asked about breast cancer treatment one woman responded, *"It is very scary – you do not know what's happening and what it's all about if you can't understand the big words the doctor is using."* Women also feared being chastised by health care providers if they had not followed the recommendations for breast cancer screening. Interruptions in continuum of care were often the result of loss of insurance, income, or a negative experience with a previous mammogram.

cultural influences.

Cultural influences were evident in both groups. Women identified themselves as the primary caregivers in the family, often placing their own health care needs as a low priority. Predominant feelings in the smaller, more isolated communities were a lack of trust towards health care providers. A participant noted, *"Their illnesses may be more of a personal matter that isn't shared with family or outsiders."* A need for providers to access persons in the comfort of their community or cultural setting was suggested. Several women in the group reported that husbands may not support breast screenings or treatment due to their personal beliefs. This was particularly noted among Hmong and Laotian cultures. One health care professional noted, *"I've had patients' husbands refuse treatment for them, often in the Hmong and Laotian populations."* Additionally, participants shared that some cultures have a fear of diagnosis because the outcome will be an altered body image.

Theme 3: Support

Support from family, friends, providers, and the community was identified as being another important theme with participants. Support in various forms reportedly inhibited or encouraged female county residents to seek breast health services. Positive and negative personal support strongly influenced the beliefs and perceptions of participants.

personal support.

Personal support from family and friends was found to be helpful in encouraging women to seek breast health screenings and treatment. Many mentioned that it was easier to go for a mammogram appointment if someone went with them. Various members mentioned, *"You need the support of 'true' people,"* and *"When someone gives a caring comment like, 'It would mean a lot to me if you came' that can really encourage a person to get a mammogram."*

professional support.

Support from providers, nurses, and other health care representatives was mentioned often during the focus group sessions. Positive interactions and a healthy patient-provider relationship was deemed important in seeking screenings and discussing breast health information. The support nurses provided during clinic visits was frequently emphasized by breast cancer survivors as a positive influencing factor in completing their treatment. Comments included, *"Nurses were wonderful and helped us*

get through it," and *"They were so positive and weren't being doom and gloom."* Women who have not yet been diagnosed or are newly diagnosed also have a nurse navigator in each of the two counties that is present throughout the continuum of care to provide support, education, and guidance. A participant mentioned, *"The nurse navigator is a true resource for supporting these women."*

The breast health navigator is a newly adopted position in both Stanly and Rowan County Breast Health Centers, and it appears to be a positive addition to the overall breast health resources available. As described by a nurse navigator interviewed, "The aims of the nurse navigator is to provide access to screening mammography for all women, and when an abnormality is found, the navigator ensures the patient will receive further diagnosis and treatment in a timely manner." Participants indicated a desire to attend open houses at the new breast centers in both counties.

community support.

Participants noted their desire for the hospital, medical providers, and organizations like Komen to come into their community to share breast health education and resources. Opportunities exist at local community events ranging from festivals to tractor pulls which are popular among residents.

Many women identified churches as a good avenue for breast health outreach in both Rowan and Stanly counties. People feel comfortable in their faith community and rely on their place of worship to access health information. One participant suggested, "*Get a person to speak to church heads and talk to these churches. There are over 60 churches right in this area*."

Focus groups mentioned that doing fun things at a community level such as spa nights, girls night out and roundtable discussions, encouraged discussion about mammograms and breast health. One person commented, "*We need groups like this focus group talking to give hope to others and encourage screening*."

Conclusions

Analysis of the qualitative data through KI interviews and all of the focus groups revealed consistency of the three themes identified: knowledge, access, and support. These three main themes are areas where intervention is needed and were clearly identified as gaps in the system.

The targeted counties shared similar demographics and issues, as well subtle differences. The dominant theme discussed during focus sessions was the need for increased education, knowledge and awareness related to breast health. Breast health knowledge encompasses the importance of mammograms, risk factors, procedures related to breast health, signs and symptoms, breast self awareness and available resources. Numerous participants agreed that there was a need for programs teaching the basics of breast health to females in general, and more specifically with younger female populations. The importance of access to educational pamphlets and information

was highlighted as a deficit within the communities. Opportunities for public awareness were identified by participants as numerous community events, churches and high traffic public locations such as WalMart, YMCAs, as well as through newspaper advertisements, billboards, and television PSA's.

A secondary prominent theme during the qualitative analysis was access. Issues with access manifested in different forms between the two counties. Within Rowan County, participants reported travelling outside of the county for health care. Comparatively, for Stanly County participants, transportation services were noted as a more significant issue. However, participants from both Stanly and Rowan counties emphasized the lack of available financial resources and lack of insurance coverage as barriers to breast cancer screening and care. Additionally, participants reported a high incidence of poverty, a large proportion of uninsured, and an elevated high school drop out rate all contribute to a poor SES among residents of both counties further compounding access issues. Participants reported minority populations suffering from additional culturally related barriers inhibiting access to breast health care, among namely the Hispanic and Hmong groups.

Finally, support from family, friends, providers, and the community was identified as being another important theme with participants. Support in various forms reportedly inhibited or encouraged female county residents to seek breast health services. Positive and negative personal support strongly influenced the beliefs and perceptions of participants. Focus group members also mentioned that negative and positive experiences with nurses, providers, or a hospital shaped future visits and motivation for seeking care.

Conclusions: What We Learned, What We Will Do

Review of the Findings

In a review of the Affiliate service area breast cancer statistics, Stanly County surfaced as having the highest breast cancer mortality rates at 30.7 deaths per 100,000 female population, followed closely by Rowan and Gaston Counties at 28.5 and 27.4 deaths per 100,000 female population respectively. When considering mortality rates by race, Stanly, Rowan and Gaston counties have the highest mortality rates for Caucasian women at 31.49, 29.03, and 28.92 per 100,000 female populaton respectively. While African American women have the highest mortality rates in Rowan, Lincoln, Iredell and Stanly ranging from 31.23 to 30.76 per 100,000 female populaton. Approximately 38 percent of female residents in the service area aged 40 and over have not had a mammogram in the past 12 months. Stanly County has the highest percentage of females without a mammogram at 40.1 percent followed closely behind by Gaston at 39.7 percent and Rowan at 38.9 percent. Following the initial overview a decision was made to focus on Rowan and Stanly as Komen's target counties for the 2011 Community Profile.

A health systems analysis was conducted to identify gaps, needs, and barriers throughout the continuum of care which may contribute to the alarming statistics in the target communities. Within Rowan County, a recent merger of two mammography facilities reduced the number of available sites within the county from two to one. The new mammography site within Rowan County is at the RRMC Breast Health Center featuring services from screening through treatment and the entire continuum of care. A mobile mammography van, from CMC-NE in Cabarrus County, also provides services within Rowan in addition to three other counties. During the qualitative research portion of the study, various participants shared that some Rowan residents travel outside of county lines to receive breast health services.

Stanly County has two mammography locations. These locations are spread out within the county, allowing for nearby access in all areas. One of the mammography sites within Stanly County is the SRMC Breast Health Center featuring services from screening through treatment and the entire continuum of care.

Fifteen KI interviews were conducted and lack of financial resources was identified as the prominent barrier to women seeking breast health services. In addition to lack of financial resources, another dominant theme that appeared during KI interviews was a knowledge deficit in regard to breast health and available resources. KIs shared that they believe fear of pain, fear of the procedure itself, and fear of a positive diagnosis kept women from getting regularly screened.

During KI interviews, the team sought to determine available health resources that were available to community members for education and health screening, in addition to those identified through asset mapping. We discovered health information came mainly from providers, the health department, and Breast Health Centers within the

communities. The CMC-NE mobile unit was also discussed at length and KIs perceived it as an asset in these communities.

KIs believe that several opportunities for intervention are needed including educational programs, community outreach, advertisements, and various financial assistance programs. KIs felt women who were least likely to get screened were women with financial barriers who were either uninsured or underinsured. Additionally, women with a lack of knowledge about available services and resources are also less likely to participate in annual screening. Nearly all participants identified Komen as an available financial resource to help women get screened and many also mentioned NC BCCCP as a resource. Few alternative financial resources were mentioned.

The next step in understanding community perspectives towards breast health services and breast cancer was to conduct focus groups. Identification of the focus group population and questionnaire design flowed from the KI interviews. A total of 44 women participated in four focus groups in Rowan and Stanly counties. Following analysis, knowledge, access and support emerged as the overarching themes.

Similar to the KI interviews, the dominant theme identified during the focus sessions was the need for increased education related to breast health awareness. Participants expressed a need for education focusing on the importance of mammograms, available financial services, location of breast health care services, as well as risk factors, signs and symptoms of breast cancer, and breast self awareness in general. Group members also requested greater access to written educational materials. Suggestions for improving public awareness included providing health information at numerous community events and high traffic public locations, such as Walmart and YMCAs, as well as through churches, newspapers, billboards and television PSA’s.

Issues related to a lack of financial resources and insurance coverage were identified as barriers to accessing breast health services. Focus group sessions supported findings from KI interviews and consistently identified financial resources and lack of insurance as major barriers to seeking breast cancer screenings. Financial resources as a barrier could potentially include lack of transportation, lack of or a low amount of insurance coverage, or the inability to pay for screening or treatment. Culturally related barriers may also exist among Hispanic and Hmong residents further contributing to poor access.

Finally, support from family, friends, professional providers and the community was recognized as a factor which either inhibits or encourages women to participate in the breast health continuum of care. Positive and negative support strongly influences the beliefs and perceptions of participants, and also shapes the likelihood of women seeking breast health care.

Conclusions

Komen Affiliates were charged by the Susan G. Komen for the Cure national organization to focus on mortality rates among their service areas. Review of the nine counties in the Charlotte Affiliate led the 2011 Community Profile team to select Stanly and Rowan counties as target areas for this report.

Qualitative research proved consistent in identifying the need for breast health education, financial assistance, improved awareness of community facilities providing breast health care, as well as programs emphasizing the importance of support (personal, community, and professional).

Lack of knowledge, regarding breast health awareness, remains at the forefront of educational needs. By providing breast health information to the community, providers and community leaders can dispel common myths surrounding mammography and help reduce feelings of anxiety and fear. Information regarding availability of financial resources and healthcare facilities, risk factors, and self breast awareness are indicated. Education programs designed to target women at a younger age and emphasizing the importance of early detection will help improve the continuum of breast care.

Due to the higher rate of late stage diagnosis among African American women in the target counties, increased educational programs and improved access to screenings remain a priority. An effort to understand cultural perceptions and experiences of ethnic minorities including African American, Hispanic, Hmong and Laotian populations regarding barriers to breast health screenings should be explored. Further study is needed to address husband beliefs, as possible barriers, are indicated. An effort should be made by all levels of breast health education providers to recognize husbands as valuable sources of support to reduce women's mortality rates due to breast cancer.

Lack of financial resources to access breast health care is prevalent. Members of isolated rural communities also noted problems with ineffective public transportation as an additional barrier to accessing breast health care. In light of a downward economy, and the high uninsured population in Rowan and Stanly counties, the need for programs or grants that support screenings, early detection, and breast cancer treatments will continue to escalate. The NC BCCCP funds (which provide free or low-cost breast or cervical cancer screenings and follow-ups to eligible women in North Carolina) is shrinking, and regrettably the current proposal of a 73% cut in NC BCCCP funding could result in a drastic increase into the number of un/under-insured women in need of mammography services. The seriousness of these budget cuts was also echoed by KIs who continuously identified financial resources and lack of insurance as major barriers to seeking breast cancer screenings. Financial resources, lack of transportation, lack of or a low amount of insurance coverage, or the inability to pay for screening or treatment each contribute to inadequate financial resources. The North Carolina Affiliates are working diligently to continue lobbying through visits, phone calls and letters to ensure the funds remain available.

The Rowan County Health Department (RCHD) recently eliminated their NC BCCCP program due to a reduction in their funding amount combined with cuts from their county funding. The Stanly County Health Department (SCHD) is running short on NC BCCCP funds and anticipates funds will be depleted well before the fiscal year ends on June 30, 2011.

Continued outreach efforts by Komen, churches, community-based health organizations providers, and community groups to educate women and their families, and provide free screenings to women remain essential to improving the breast health continuum of care and reducing mortality. Newly formed breast health navigators, who coordinate all aspects of breast care, leave a positive impression on community members. Additional efforts by providers to accommodate after hour screenings and breast health fairs were identified as possible means to enhance breast health awareness. A greater presence to address breast health awareness and gaps in knowledge are indicated, specifically in rural communities in NC.

Action Plan

The Affiliate adopted the following Action Plan in an effort to meet the needs and gaps determined through the Community Profile process:

Priority 1 – Partner with community-based outreach/health organizations to effectively increase access to breast health information and services to women living in rural areas, with specific focus on Rowan and Stanly Counties.

Objective 1 – For FY 2012, amend the Affiliate's Statement of Need within the Request for Application (RFA) to include programs with proactive outreach, education, and patient support serving diverse groups throughout the Affliate service area with a focus on rural regions.

Objective 2 – By January 2012, research and partner with non-grantee community based health organizations to arrange at least one outreach opportunity within Stanly or Rowan County at an appropriate community event.

Objective 3 – For FY 2012, host an Affiliate "Best Practices" event for grantees and other interested organizations. Highlight successful education/outreach programs such as CMC-NE's "Breast Health Champions," Cancer Services of Gaston County's "Breast Health Education for Ninth Grade Students," or the Girl Scouts' Hornets Nest Council's "Scouting for the Cure."

Objective 4 – For FY 2012, continue to build on current grantee partnerships and other collaborations in Rowan and Stanly Counties developed through the Community Profile. Work to further promote these services and grants within the community.

Priority 2 – Partner with local churches to effectively increase access to breast health information and services to women living in rural areas, with specific focus on Rowan or Stanly County.

Objective 1 – By September 2011, identify a local volunteer chair within Rowan or Stanly County to work with the Affiliate in engaging the faith communities as part of the Affiliate's Pink Sunday educational program held annually in April.

Objective 2 – By April 2012, through the help of volunteer chairs and committees, engage at least ten churches in Rowan or Stanly County to participate in the Affiliate's Pink Sunday program in 2012.

Priority 3 – Provide opportunities for enhanced networking for breast health professionals and organizations in the service area.

Objective 1 – For FY 2011, organize a task force to research local symposiums, meetings, conference and coalitions to clarify the purpose and goals of a regional networking / educational assembly. Begin initial planning phases of determined event with goal of delivering event in 12 – 24 months.

Priority 4 – Continue partnering with other North Carolina Komen Affiliates to advocate for NC BCCCP funds locally and federally while also identifying opportunities to partner and collaborate with other organizations with similar initiatives.

Objective 1 – In April 2011, send a minimum of two Affiliate representatives to attend and participate in the Komen National Lobby Days held in Washington DC.

Objective 2 – FY 2011, create a local Affiliate board position dedicated towards guiding the Affiliate's advocacy efforts. The new position will develop a robust and active committee to support the Affiliate's advocacy efforts.

Objective 3 – FY 2011, plan at least one annual trip, in conjunction with other North Carolina Affiliates, to meet with the Cancer Prevention and Control Branch at the NC Division of Public Health in Raleigh, NC.