

Qualitative Data: Ensuring Community Input

Qualitative Data Sources and Methodology Overview

Methodology

After assessing the quantitative, systems and policy data, several breast health factors were identified for further qualitative investigation including: attitudes and beliefs, knowledge, utilization, access, transportation to each step of continuum, cost and other barriers, and knowledge of resources including patient navigation.

Because of the geographic range of the communities identified in previous sections of the assessment, key informant interviews and strategically placed focus groups were the most feasible options for qualitative data collection. Key informant interviews were used to gather breast health information within the geographic regions identified for further focus by quantitative data and systems and policy analysis. This method facilitated data collection from a limited number of well-connected and informed community leaders and professionals, and to shape an understanding of the attitudes and beliefs of survivors and co-survivors. Through interviews, respondents could openly discuss the identified topic, and add to our understanding of the statistics and how they are interpreted in the community. (Susan G. Komen, 2014)

Focus groups were used to investigate a range of ideas, beliefs and feelings about breast cancer, and to uncover factors that influence options and behavior of women in the service area. The data collected through focus groups clarified differences in perspectives between priority counties and identified barriers and ways to overcome them. Like the key informant interviews, this information, including the specific comments and language used by the participants, sheds light on the other data collected in this assessment.

Sampling

Komen Columbus staff and interns compiled lists of medical providers, current and past grantees, health departments, clinics, Federally Qualified Health Centers, support groups and other key contacts in each county. Each person was contacted by phone or e-mail, and invited to participate in a key informant interview. The interview incorporated skip-logic so that providers, survivors, and co-survivors each received customized, open-ended questions. For phone interviews, answers were entered into the interview form. When preferred, the interview was delivered via a format that allowed the informant to type their responses, while still maintaining the customized and open-ended nature of the interview. This assisted in efforts to reach and collect data from a desired number of informants. Each informant completed an electronic consent form before beginning the interview. All data was password protected on an internet server. Participants were informed that their information would remain confidential, and that all data would be reported in aggregate only, to protect anonymity.

The population of interest was community leaders and key stakeholders that encounter breast health issues or barriers to breast health through their personal experience or professional work. Snowball sampling was used by asking those who completed an interview to provide the names of colleagues or those in their network that might also be interested. This helped us include hard to reach members of the population, and helped us include people we had not heard from before. Convenience sampling was used by reaching out to existing contacts, including grantees, or participants from various educational or other programs we've held, and professional contacts in our network. This was an efficient method to reach a large number of informative contacts that would not be possible using probability techniques. The combination of these methods meant that we do not know that our sample was representative of the population. Convenience sampling means the sample may over represent and underrepresent some groups. (Susan G. Komen, 2014)

Due to small populations in many of the rural and Appalachian counties, every attempt was made to hold focus groups in a central location and recruit from surrounding counties. Despite significant recruitment efforts, throughout all three target communities, a limited number of focus groups could realistically be scheduled and conducted by Komen Columbus staff, resulting in low participation and small focus group count. Staff and interns scheduled, promoted, moderated and recorded focus groups. Participating community groups helped to promote and recruit participants.

Because much of the mission and key questions are aimed at women who have not yet been diagnosed with breast cancer, the population of interest was women, 40 years of age or older, residing in any of the target communities. However, after attempts to recruit diverse groups of non-survivor women 40 and older did not result in the number of participants needed, additional focus was placed on recruiting survivors. Convenience sampling was used to promote planned focus groups to survivors through the Komen Columbus survivor newsletter, flyers, e-mails to grantees and local support groups. Local organizations and businesses, including churches, book clubs, and women's groups were contacted about holding a group among their members, to some success. A local radio station that covered the suburban and metropolitan regions sent an invitation to its entire market research database, filtered to women 40 and older. Women who did not live in the area of focus completed a secondary survey, and that information is not reported here. Women who did live in the area of focus were invited to participate in a focus group. Throughout all recruitment efforts, snowball sampling was used by encouraging women to invite others to participate, adding some diversity and hard to reach individuals to the strength of the sample. However, these methods do not result in a representative sample and may over represent or underrepresent certain groups. Both survivors and women over 40 who have not had breast cancer are included, and contributed an insightful combination of experiences.

Ethics

Each participant completed a consent form and was informed that all data would be reported in aggregate or de-identified, to protect anonymity. No names were attached to data collected in the focus groups. Data was stored on a password protected computer in a locked office. Each participant received a \$10 gift card as an incentive.

The use of focus groups with women (survivors and general population ages 40+) and key informant interviews with a variety of healthcare providers, health officials, civic leaders and community leaders allowed Komen Columbus to compare and contrast the different perspectives about the barriers to screening, diagnostics and treatment in the metropolitan, suburban and rural-Appalachian target communities. This triangulation confirmed the themes and concerns of individuals at the community level with those at the system level.

Qualitative Data Overview

The key informant interview was designed to take 20-30 minutes to complete with open ended questions in two main categories: "Attitudes and Beliefs", and "Education, Outreach, and Health Decision Making". These two categories were then followed up with specific questions tailored to survivorship, co-survivorship, and health care provider association. Key informants ranged from community members with no direct ties to breast cancer, to breast health navigators, medical providers and administrators, survivors, and co-survivors. Detailed demographic data describing the key informants interviewed is in Table 15.

All key informant interviews were transcribed into an online data collection form, which also scripted the interview. This collection method allowed for the most flexible use of online software

to filter, organize and analyze interview content, and allowed for skip-logic and consent to be integrated into one location.

Table 15. Key Informant Demographic Summary

Target Community	Status					Gender		Age		
	Survivor	Co-survivor	Medical provider	Administrative staff	Other	Male	Female	<44	45-64	65+
Total respondents										
Metropolitan 20.2% (19)	41.2% (8)	70.6% (12)	35.3% (2)	23.5% (4)	11.8% (2)	10.5% (2)	89.5% (17)	36.8% (7)	47.4% (9)	15.8% (3)
Suburban 21.3% (20)	12.5% (2)	75.0% (12)	18.8% (3)	18.8% (3)	6.3% (1)	20.0% (4)	80.0% (16)	30.0% (6)	65.0% (13)	5.0% (1)
Rural-Appalachian 57.4% (55)	12.5% (6)	60.4% (29)	14.6% (7)	10.4% (5)	33.3% (16)	3.6% (2)	96.4% (53)	34.5% (19)	58.2% (32)	7.3% (4)

Metropolitan counties: Franklin (19). Suburban counties: Clark (5), Fairfield (1), Licking (5), Madison (9). Rural-Appalachian counties: Guernsey (4), Hocking, (3), Marion (7), Meigs (11), Monroe (1), Morgan (4), Muskingum (10), Noble (1), Perry (7), Vinton (3), Washington (4). All counties in target communities represented by at least one key informant interview.

A list of questions and script for focus groups was developed from earlier parts of the needs assessment and using the Community Profile Guidebook. All focus groups were recorded for back-up, and extensive notes were taken by the moderator during the discussion. These notes and recordings, when back-up or clarification was needed, were used as the main source of focus group data. Notes provided great detail, and remained anonymous, while recordings were available for clarification of any missing or unclear documentation. Detailed demographic data describing the focus group participants is in Table 16.

Table 16. Focus Group Demographic Data

Target Community	Age Range			Survivor	Income Level			Race/ Ethnicity		
	<40	40-59	60+		<30,000	\$30,001-\$50,000	More than \$50,000	Black	White	Other
Total respondents										
Metropolitan 2.9% (8)	25.0% (2)	50.0% (4)	25.0% (2)	75.0% (6)	37.5% (3)	12.5% (1)	50.0% (4)	12.5% (1)	87.5% (7)	0.0% (0)
Suburban 11.3% (7)	0.0% (0)	42.9% (3)	57.1% (4)	85.7% (6)	0.0% (0)	42.9% (3)	42.9% (3)	14.3% (1)	85.7% (6)	0.0% (0)
Rural-Appalachian 75.8% (47)	4.3% (2)	27.7% (13)	68.1% (32)	34.0% (16)	25.5% (12)	12.8% (6)	36.2% (17)	4.3% (2)	91.5% (43)	2.1% (1)

Metropolitan counties: Franklin (8). Suburban counties: Licking, (2), Madison (5). Rural-Appalachian counties: Marion (22), Meigs (7), Muskingum (6), Washington (12). Note: All rows may not sum. Some questions were not answered or respondent selected "prefer not to disclose".

Beginning with the key informant interview data, responses to each question were labeled with codes and those codes were organized into themes. Analysis was done by target community.

Each response could be tagged, and subsequent references to that code could be re-tagged. This process allowed for filtering and counting the number of times each code emerged. Then codes could be grouped into themes, resulting in overall themes captured in the data for each target community.

Table 17. Summary of Key Informant Interview and Focus Group Themes

Topic of interest	Metropolitan	Suburban	Rural-Appalachian
Available breast health services	<ul style="list-style-type: none"> Perceive many resources and services available, many places to get services without even going to hospital 	<ul style="list-style-type: none"> All have local hospital with screening and diagnostics Some other resources (especially reconstruction) have more options outside the area- works well to have a specialist travel to that county a few times a month to provide the service 	<ul style="list-style-type: none"> Health departments play larger role in this area. Less mention of local hospitals or providers, few options per area, small facilities Mobile units more relied on for mammography Lack of understanding about Komen grant process, (don't know they can apply for funding) and programs (that services are available and funded by Komen)
Barriers to care	<ol style="list-style-type: none"> Fear, pain/discomfort Education Time, convenience, Cost/ insurance/ connecting to a PCP (but seeing progress) Transportation 	<ol style="list-style-type: none"> Fear, pain/discomfort Education Cost/ insurance Time, child care, convenience, prioritizing self-care 	<ol style="list-style-type: none"> Time, transportation, convenience Cost/ insurance Fear Education, know risks <ul style="list-style-type: none"> Concern for women too young to be covered for mammograms Dislike of accepting free services
Distance to care and transportation	<ul style="list-style-type: none"> Majority don't leave county for care Rely on family and friends for transportation help, harder for those with language barrier Resources that help include: incentives, gas cards Public transportation and cabs available. Receiving patients from other counties coming here for care 	<ul style="list-style-type: none"> Many do leave county for at least some aspect of care, many prefer to stay local for their care or are limited by work schedules or transportation issues from going to Columbus for care if they wish to. Very limited public transportation. Hard to use/ connect available. Komen grants' travel vouchers are major source of help. 	<ul style="list-style-type: none"> Almost everyone leaves county for care out of necessity- some prefer facilities in Columbus due to perception of size and quality, while others would prefer to stay local if possible Transportation has much bigger impact than other areas. Gas prices and lack of public transportation combine with poverty level to make bigger barrier and harder to overcome than in other areas. Time off work and extra stress to drive long distances multiple times per week Limited resources available outside Komen programs Managed Medicaid offers transportation, some options for senior citizens.

Topic of interest	Metropolitan	Suburban	Rural-Appalachian
Mobile mammography	<ul style="list-style-type: none"> Promotion and advertising to participating groups is key Ability to accept "walk-ons" would help Reduces fear because in natural setting 	<ul style="list-style-type: none"> Doctor's order issues Strategic location and promotion make it a great tool for access Sometimes hard to fill schedule- many have impression it is only used for uninsured. Could be used more for access for insured 	<ul style="list-style-type: none"> Need more opportunities Some prefer a facility, but don't seem to understand the comparability of quality Some prefer the convenience of mobile
Outreach and education	<ul style="list-style-type: none"> Media, newspaper, TV, and internet are major source of information Partnerships with community groups are needed to reach underserved/ minorities Patient navigators (PN), providers, hotlines, mental health and social services, schools and churches suggested for disseminating information. Must be streamlined and simple Recommend outreach and literature for reaching younger girls, who can also reach their mothers 	<ul style="list-style-type: none"> Mobile units are visible reminders Report seeing progress but outreach is missing some groups Partnerships with community groups and health departments are emphasized Media, newspaper, TV and internet also used Providers, emphasized more as a source than metropolitan areas. Providers and health departments, helpline, churches, salons, stores, churches, pharmacies and local organizations suggested for dissemination. Navigators must be familiar with available local resources and systems. Personal relationships are drivers to action- individuals who outreach and speak to friends Focus needed on remaining population that isn't utilizing and hard to motivate (like tobacco cessation) Want more outside of October Promote Komen Ambassadors as resources available to community- create conversation Some concern over chemical exposure and air pollution as causes In general, good understanding of risk factors and family risk 	<ul style="list-style-type: none"> Health departments emphasized. Newspaper is a major source. Report seeing a lot of awareness but not sure of the outcomes. Free luncheons Less media and internet, especially for older women. Almost exclusive reliance on health departments for disseminating resource information. Little mention of providers or patient navigators. Help line would be good, but limit the "runaround". Attitude of not wanting to "bother the doctor" in small towns- survivors are visible and people ask them questions Outreach to younger girls to dispel myths and embarrassment Want more outside of October Deep belief in environmental causes of cancer (Fracking, heavy metal exposure, air pollution, local electric and power plants) Understanding of risk factors is mixed- belief in some myths Aware of genetic factors, but unclear understanding of BRCA and how family history works Perception that the area is plagued by greater cancer rates than other areas, and that it is being ignored More outreach to working women

Topic of interest	Metropolitan	Suburban	Rural-Appalachian
Survivor experience, survivorship services	<ul style="list-style-type: none"> • Varied experiences with provider communication. Mostly positive. • No delays in time to diagnosis/ follow-up • Lists of questions to ask and a “buddy” at the appointment are helpful 	<ul style="list-style-type: none"> • No delays in time to diagnosis/ follow-up 	<ul style="list-style-type: none"> • Mostly positive experiences. • When communication is poor, knowing what questions to ask is key tool- many would like record or written notes of visits • No delays in time to diagnosis/ follow-up • Feel abandoned after treatment is complete, concerned about diet and other health issues • Do not like getting news via phone call
Trust in providers and healthcare system	<ul style="list-style-type: none"> • Concerns are time spent with patient, costs, insurance and fear more than trusting providers. 	<ul style="list-style-type: none"> • Many have impression that they can access better facilities in Columbus, but generally trust providers and system. 	<ul style="list-style-type: none"> • Not many options to choose from for providers. • Some trust and have positive experiences, some don't trust. • Distrust centers around stories of mishandled cases. • Lack of specialty providers drives distrust in expertise/knowledge of provider. • Worry the system will be hard to work with if diagnosed • Distrust insurance • PCPs don't talk about breast health, screening recommendations and risk with patients • General perception that breast cancer is not a priority concern
Patient navigation experience	<ul style="list-style-type: none"> • Want help understanding diagnosis and options, locating support resources and coordinating appointments • Some had very positive experiences with navigators, some had never heard of a navigator and wanted to know why they weren't offered one 	<ul style="list-style-type: none"> • Want help understanding diagnosis and options, locating support resources and coordinating appointments • Those that had navigators were positive, had gone to Columbus health system 	<ul style="list-style-type: none"> • Need to be easily accessible, and communicative • Want help understanding diagnosis and options, locating support resources and coordinating appointments • Often discuss old American Cancer Society navigator program or other kinds of advocates- desire education about recovery, post treatment life and treatment options
Providers, tracking, CDC guidelines	<ul style="list-style-type: none"> • Follow USPTF, NCCN, ACS guidelines • Some implement tracking and reminder systems • See awareness of resources and connecting to facilities as barriers for women • Yearly reminder letters and making appointments for the following year at a visit seem helpful 	<ul style="list-style-type: none"> • Follow USPTF, NCCN, ACS guidelines • Unclear on tracking and reminder systems • See education about recommendations and scheduling as barriers for women • Note that a better connection to navigators or health department would be beneficial 	<ul style="list-style-type: none"> • Follow USPTF, NCCN, ACS guidelines • Some implement tracking and reminder systems • See fear and confusion about recommendations as barriers for women • Need help with follow-up diagnostics linkage and transportation • Confusion about when recommendations suggest a woman stop being screened due to age

Qualitative Data Findings

Limitations of the Qualitative Data

Certain implications of data collection methods limit capability of the findings to represent each target community accurately. The use of focus groups enabled in-depth data collection, stimulated individuals to share openly, strengthened relationship with the community, and was an efficient way to collect wide range of information in a short amount of time. The focus groups also provided information about needs, community attitudes and norms. However, the data collected in focus groups can be hard to analyze and present in a scientific manner. Most importantly, it was challenging to recruit enough participants or schedule enough focus groups in the large number of target counties to meet best practice standard of three or more groups per county. This makes it difficult to generalize the findings to the larger population. However, focus group saturation of themes was achieved, even without the ideal number of focus groups. Specifically, breast cancer survivors may be overrepresented in the focus group data, while the general population of women over 40 years of age and older may be underrepresented.

The use of key informant interviews allowed an exploration of topics in-depth and yielded detail-rich data and new insights. It allowed informants to clarify issues as needed and provided an opportunity to strengthen and build relationship with communities and new professional colleagues. It also gave investigators the flexibility to customize the interview to the individual and clarify questions. However, weaknesses of the data include the difficulty of selecting the “right” informants with appropriate diversity of backgrounds and viewpoints. There may be distortions in answers through recall error, selective perceptions or desire to please the interviewer. Due to the challenge of scheduling interviews, respondents were allowed a backup option of completing an automated version if necessary, which meant some interviews lack some of the flexibility of a traditional interview. In order to achieve a high standard of data, the goal was to complete eleven key informant interviews per county in each target community. This was achieved only in Franklin and Meigs counties. Due to much smaller population size and difficulty contacting key informants, less than best practice key informant sample sizes were achieved in all other counties. These issues make it difficult to generalize the results to larger population and hard to compare respondents. The data may be better used at the aggregate level, when looking at the counties grouped by target community.

The qualitative data collection represented several different income levels, insurance coverage types, survivors and non-survivors, age ranges, providers, knowledge and education levels. However, the data may not represent Hispanics and Latina, Asian Americans, young survivors or male survivors specifically. Due to the number of counties in the Rural-Appalachian community, data presented in aggregate may over represent women living in those areas.

Barriers to care

In Metropolitan and Suburban communities, fear of diagnosis, misconceptions about pain or discomfort of screening, and a lack of education about resources, risk or recommendations emerged as the top barriers to care. These concerns were followed by costs and insurance issues, and general access issues like child care, convenience, and the struggle of many women to prioritize their health over competing family needs. Transportation was not nearly as concerning in these areas as it was in Rural-Appalachian areas, where it was the top barrier. After transportation, time and convenience, fear and education emerged as important.

Fear

Fear was again cited as a common reason to not seek care among all communities. In addition to being fearful of the procedure and results, women reported nervousness about discomfort or pain during mammography as a possible concern. Participants

stated that individuals are scared of finding out their test results and would rather not know the truth than face a cancer diagnosis. However, fear was also a motivating factor for one woman to get screened who said that “being a single parent, I have to stay alive for this child”. All areas noted that education about mammography, risk, breast abnormalities and breast cancer, and misconceptions would help to combat this issue.

Insurance/ Cost

Participants noted that coverage definitely affects whether or not a woman seeks care, but were encouraged by the effects of the Affordable Care Act and Medicaid expansion in making screening more available. Awareness of the available resources and insurance options, as well as how to use that insurance, was important in all communities. All areas reported seeing higher deductibles in their insurance coverage. Costs remained a more critical issue in the Rural-Appalachian areas, especially non-medical costs and transportation-related costs.

Transportation/ Access/ Time

Transportation was overall less of an issue for women in counties that were within one hour of Columbus and in Columbus, most women do not have any need to leave the county for care and the public transportation system is more comprehensive. Throughout the service area, women rely on family and friends for help with transportation, which is complicated by costs, language, disability or other issues. Helpful tools vary by area, but all areas report gas cards, extended hours and mobile mammography are helpful.

Though women in Metropolitan areas stay local for their care, many noted that providers should be aware that women may be traveling to the area for care from Suburban and Rural-Appalachian areas.

In Suburban areas, transportation was an issue as many participants frequently traveled to Columbus for treatment at the Ohio State University Wexner Medical Center, Grant, Mount Carmel, and Riverside Methodist. Scheduling was an issue for women travelling to Columbus because they would have to either miss half a day or work or attempt to schedule the appointment early enough to make it on time. One individual had to request a note from her doctor to miss work because of exhaustion due to travel. While individuals in the focus group were able to provide their own transportation they hypothesized that many residents of their county do not have access to get to a hospital.

Transportation is a more complex and difficult barrier in the Rural-Appalachian community than other areas. Gas prices and lack of public transportation combine with the prevalence of poverty to make transportation issues harder to overcome. Women noted that they did not have time to seek screening services and that there is a lack of convenience associated with breast health screening, which deters women from getting care. Women are unable to take time off work for screening, and many locations do not offer flexible hours.

For women undergoing diagnostics or treatment, leaving the county becomes necessary in many Rural- Appalachian counties. There is a perception that a bigger town or facility will have better technology or training, which is why women may desire to travel farther for services. Worrying about finances and time off work adds an additional layer of stress that is very frustrating for patients.

The available resources in Suburban and Rural-Appalachian areas are difficult to access, and often only available for senior citizens or through Managed Medicaid. Komen Community Grants provide gas assistance, and these are noted as one of the few sources of help available.

Outreach and education

Media, newspaper, TV and internet are major sources of information across all communities. Many women report they see progress in the education being done in their areas, but doubt the success of that education in motivating women to take action, or suspect specific groups are not being reached. In all areas, women note that partnerships with other community groups to target and reach specific groups would be beneficial. All areas emphasized churches, social work or civic organizations and schools as potential sources of outreach. Suburban areas also mentioned local businesses like salons and pharmacies. The Rural-Appalachian area mentioned local media and matching survivors with others to provide support and education. In the Metropolitan and Rural-Appalachian communities, targeted and sensitive outreach to younger girls during health classes in school was suggested as a way to dispel myths, create a healthy foundation for girls as they approach an age when they will be at risk, and to also bring education to their mothers.

In the Rural-Appalachian community with an aging population, internet is not used or as readily available as in other areas. There is almost exclusive reliance on health departments, as opposed to health care providers, for information. Health departments were emphasized much more in Suburban and Rural-Appalachian areas as a resource where women look for information. Personal relationships were emphasized in both areas as crucial to getting women to take action. Survivors are held up as examples in these communities. Survivors and Komen Ambassadors were recommended as source of education. Both areas emphasized wanting more activity outside of October, Breast Cancer Awareness Month, and were concerned about “awareness” versus “education”.

Understanding of Risk

There are significant misconceptions about risk and breast cancer in the Rural-Appalachian area. One participant had a mammogram following identification of a lump during a breast exam and did not understand what difference it would have made if it was found earlier during an annual exam. Rural-Appalachian county residents held a deep belief in environmental circumstances affecting their risk for cancer. Environmental conditions included fracking, heavy metal exposure, chemical and electrical plants being in the vicinity, living near “big power lines”, and air pollution. Personal characteristics that contribute to being at risk include alcohol, drugs, smoking, chemicals in processed foods, the amount of red meat eaten, and stress. Increased calcium levels and lacking certain hormones were also probably causes. One participant worried that because she accompanied a friend to a radiation treatment she caused her own tumor to grow. There is a deep distrust for the chemical plants in the Mid-Ohio Valley. Respondents agree that they are a cause for cancer but because they provide employment for many residents in the county the issue is not addressed. Another woman believed that having a short hit to the breast or a fall could be a cause of cancer. There is a strong perception that the area is uniquely affected by high rates of cancer and that the problem is being ignored.

Similar beliefs were reported in the Suburban community, though are not held as deeply or as widely. Participants cited environmental issues such as air quality and chemical exposures (“sprayed fields”), as a reason for being at an increased risk for breast cancer. In some aspects, Suburban participants demonstrated an accurate

understanding of risk factors like age, stress, diet and weight. Overall, Suburban participants were skeptical to pinpoint an exact risk factor for the cause of cancer due to a lack of trust in the media, and personal experience with the disease without any known risk factors. “These days they tell you anything can cause cancer.” And in response to media reports for associated risk factors one participant stated that it should be “taken with a grain of salt”.

Understanding of family history and genetic factors varies widely. Participants in all communities were aware of the relationship between family history and genetic factors and breast cancer risk. There was confusion over what constitutes a family history, but a there was a general understanding that a family history increases risk and there was dissent over how the BRCA gene works. One participant wanted to be tested for the gene because her brother had prostate cancer and was upset to find that a local provider did not recommend the procedure. Another stated that because she and her sister had breast cancer her daughter was “going to get it”. Other participants discussed having the gene as a reason to seek a prophylactic mastectomy before a diagnosis.

Quality of Care

Recommendations and guidelines

Respondent providers use a variety of recommendations for screening, including United States Preventive Task Force, National Comprehensive Cancer Network, and American Cancer Society recommendations. A few referred to “breast self-exam”. Some providers reported using reminder and tracking systems, though the types varied, and the provider sample is not representative. Women reported that yearly reminders are very effective at encouraging routine screening, and missing a reminder has resulted in a missed mammogram. One woman said that setting up her next annual appointment while she was leaving her current appointment was very helpful. Delays in diagnosis or treatment were not a concern among participants, though in additional work done through the Susan G. Komen Columbus Survivorship Steering Committee, 40 percent of participating providers were reported that they were not familiar with the Center for Disease Control guidelines for time to diagnostic and treatment resolution. Screening facilities in the Metropolitan area have tracking and reminder software that communicates with the electronic medical records of the referring primary care provider, though it is unclear how many facilities are using this tool.

Patient-provider communication

Respondents from all areas have a mixture of experiences with providers. Though most report positive experiences with providers and recommendations, some women did not feel like their provider communicated with them effectively about their care. Women emphasized that communication with providers is better when the patient is prepared and is aware of questions to ask pertaining to their care. One participant reported bringing a list of questions to her doctor and then requested that she be called or emailed with the responses at a later date. One survivor felt that the doctor relayed the information to her in the office very well but once she returned home she realized that she understood less than she thought. Communication is also improved if the patient has a “buddy” that is able to ask questions and take notes. Though some resources are available with questions to ask the doctor, women were not aware of them. Rural-Appalachian respondents placed a greater trust in having a written report or notes from their appointment. Important pieces of the survivor experience included education about their treatment options at diagnosis, cooperative insurance and workplaces, family support and exercise and other classes.

Many women value second opinions very highly. Survivors noted they appreciate honesty and a balance of reality and positivity when communicating with their provider. Some also felt that their doctor wanted to keep them uplifted and wasn't entirely forthcoming about recurrence statistics.

More information was requested about lifestyle changes after diagnosis such as exercise patterns and dieting recommendations. Almost no women in any area received survivorship care plans, and a few did not feel informed about their reconstruction options.

Trust in providers and healthcare system

Among Metropolitan respondents, concerns about trust centered on the time spent with a patient by a provider, costs and fear, more than distrust of the actual provider. In the Suburban areas, many women have the impression that they can access better facilities and care in Columbus, but generally, respondents reported trusting their providers and the healthcare system.

In the Rural-Appalachian area, word of mouth plays a critical role, and one negative experience with a provider leads to distrust within the whole system. Participants in the Rural-Appalachian community reported having less trust in providers than they used to because of all the information that they now have access to online, and because the provider is not always familiar with their entire family. Participants feel as if providers' "hands are tied" in a power struggle with insurance companies and this affects the care they receive leading to more patient-provider distrust. A lack of specialty providers in the area drives many to distrust the expertise or knowledge of their provider, and many reported concern that the system will be hard to work with if they are ever diagnosed. Many didn't feel their primary care providers were concerned or discussed breast health and risk enough.

Mobile mammography

Mobile mammography was generally seen as a critical tool in each community, though reasons varied. Throughout all communities, promotion and strategic partnerships with groups reaching target populations were seen as key to the success of mobile mammography. Among the Metropolitan group, the ability to accept "walk-on" patients for screening was seen as a way to increase the impact of mobile mammography. One of the strengths of mobile mammography was that it takes place in a natural setting and thus reduces fear.

In Suburban areas, referring physicians' orders and filling the schedule of the mobile unit were seen as struggles that reduce its effectiveness. However, it is seen as a great tool for access, with proper promotion and partnerships with local churches, senior centers, and civic groups.

The topic of mobile mammography elicited mixed responses from participants in Rural-Appalachian areas. A few respondents felt that a mobile unit would not be used because they prefer an actual screening facility. However, this concern seemed to bring up that education may be needed about the quality of mobile mammography and the process for follow-up with abnormal screenings. Myths about mobile mammography would need dispelled to increase its use. Other participants believed that, like in other communities, with appropriate hours, promotion and partnerships, a mobile unit would be more convenient than seeking services in an office location. Suggestions for mobile units and community outreach locations included the library, county fair, and schools.

Discussion about mobile mammography highlighted a unique issue in the Rural-Appalachian community- the attitude that women will overcome barriers if something is important enough to them. This sentiment emerged several times.

Patient navigation experience

Experiences with patient navigators (PNs) varied from extremely positive to non-existent. Most women in all three communities had never hear of a PN, including survivors. Those who had reported positive experiences. Most wished that the PN was also in contact with family for additional information and support. In all areas, women desired help in understanding a diagnosis and treatment options so they could make the best decisions, locating support resources (including disability, insurance and non-medical financial assistance), and coordinating appointments.

Among Metropolitan respondents, women were largely unfamiliar with patient navigation services and did not know if they would be assigned a navigator or if this was something they should have requested. Among Suburban respondents, those who interacted with a PN reported positive experiences throughout care. “I know I wasn’t the only patient but she treated me like I was”. In Rural-Appalachian focus groups, patient navigation was not directly discussed, but participants suggested that there should be someone in the doctor’s office that can provide information and educate patients. Washington county participants suggested having a personal trainer to help provide individualized recovery programs. One survivor was issued a navigator through her insurance company but was worried “she was getting in my business so I was hesitant to talk to her”. The individual instead turned to friends and family for answers about the “little things” that doctors did not tell her. Women in Marion County differentiated between a PN and a patient advocate. The term “advocate” elicited more positive feelings and associations within the health care setting than did the word “navigator”. Women who were unfamiliar with patient navigation (or advocate) services agreed that having this type of service would be a wonderful tool to help make sure women are educated about their diagnosis and receive appropriate support. Women recognized the importance of factors like weight, exercise and diet in recurrence, but wanted more information on how to implement risk reducing behaviors.

Komen Columbus’s Survivorship Steering Committee identified patient navigation as a topic of focus for education and programming in its January 2014 meeting and subsequent committee work. Survivors reported varied quality of interactions with PNs and PNs were identified as crucial points in the system where education about various topics could greatly enhance a patient’s experience throughout the continuum of care.

Interviews with PNs highlighted a wide range of experience, from cardiology to acute care to palliative care to neonatal to oncology. Most PNs were trained in nursing, but a minority were trained in a different field, like social work (refer to PN Key Informant Interview summary attachment). More than 30 percent reported no patient navigation training whatsoever. Within the group who received training, over 22 percent reported general training that was not breast specific. Fifty three percent reported there is no uniform training within their hospital or health system. The navigators were from seven different counties, including rural, Appalachian, suburban and metropolitan settings, and represented 13 hospitals in central and southeastern Ohio. Eighty four percent of respondents had experience as a PN greater than four years. Sixty nine percent reported patients don’t receive a survivorship care plan yet, indicating a need for integration of that tool into their training. Sixty one percent reported they were not familiar with the Oncology Nursing Society’s Nurse Navigator Core Competencies. Discussions revealed that many existing trainings are available at unreasonable costs.

Conclusions

Qualitative data affirmed the findings of the health systems analysis, which identified gaps in follow-up care, patient navigation, survivorship services and transportation in suburban and Rural-Appalachian communities. Those in the Metropolitan area enjoy a wider variety of services, which are more easily accessible. Those in suburban and Rural-Appalachian communities must travel farther to screening, though that distance and difficulty varies widely, and lack the variety of options offered in Columbus. Health departments play a much more critical role in the Rural-Appalachian counties as a source of information and clearinghouse for resources than in other areas. Providers are relied on less directly than in other areas, and awareness of Komen grant funding opportunities and services offered is poor.

References

- Susan G. Komen. (2014). Community Profile Toolkit. Dallas, TX. Retrieved from Advantages and Disadvantages of Sampling Techniques.
- Susan G. Komen. (n.d.). Community Profile Toolkit. *Qualitative Data Collection Methods- Strengths and Limitations*. Dallas, TX.