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An Inventory of Avon Foundation for Women Breast Cancer Patient Navigation Programs

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Abstract

An Inventory of Avon Foundation for Women Breast Cancer Patient Navigation Programs

By Sandte Stanley

The Avon Foundation for Women grantees provide breast cancer services through patient navigation. The purpose of this study is to explore the variation in the use and services of navigators, describe the audiences they serve, treatment completion, and evaluation mechanisms. Fifty-six Avon patient navigation programs funded since 2008 throughout the United States; 44 (81%) complete responses were received. Programs were racially and ethnically diverse mostly serving Hispanics (30%) and African Americans (31%). The age of clients was mostly in the 40-64 years old (64%) range. A majority of clients that PN programs (90%) served had an average income of less than \$30,000. Programs tended to serve either uninsured (50.7%) or clients with access to Medicaid (32.4%). PN programs were both community-based and hospital-based programs (22.5%) operating from safety-net settings (35.2%). All Avon Foundation for Women Grantees incorporate some type of navigation services within their programs. Patient navigators provided these types of services: diagnostic services such as breast imagining (e.g. mammography and breast ultrasound) and various types of therapy. Barriers to care within the Avon funded PN programs were consistent with barriers found in previous research, including issues of transportation, access to appointments, language barriers, and financial issues (e.g. cost of screening and treatment specifically for those uninsured). PN programs found ways to reduce multiple barriers through offering onsite services which help to negate multiple systems and social barriers. The purpose of this study is to explore the variation in the use and services of navigators, describe the audiences they serve, and evaluation mechanisms of these programs.

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Introduction

Chapter 1

Patient Navigation (PN) programs aim to assist patients in overcoming barriers to cancer services however, the methods used to achieve their goals may differ from program to program because no consensus exists on the role of patient navigators or what the PN programs entail.¹⁻² PN crosses all parts of the cancer continuum in order to serve patients at any point after their diagnosis they choose to enter the navigation system. As a result of the varying demographics of populations served, PN programming is broadly defined, the role of the navigators themselves also has a wide array of responsibilities especially in relation to breast cancer care. The role of patient navigators who specifically work with breast cancer patients vary from assisting patients with specific systems barriers, coping with diagnosis and treatment, educating patients on breast cancer topics, and psychosocial support.¹ Moreover, the work of patient navigators is completely dependent on which part of the cancer continuum is the primary focus of the PN program.² The distinctiveness of PN programming and navigator roles can be easily understood as being necessary in supporting the communities served.

Wells and colleagues conducted a literature review in an effort to better describe PN in terms of defining roles, qualifications, populations served, outcomes, services within the continuum and efficacy across varying types of cancer.¹ They found definitions of patient navigation that were associated with barrier-focused programming ranging from time limited individualized cancer related care, improvement in health services access, and improvement in time to cancer care services. Further, patient navigators were noted to work with varying populations (although most assisted patients disproportionately affected by poor health

outcomes) through a wide range of activities that included education, addressing patient and systems barriers, and psychosocial support. However, they noted a gap within literature regarding efficacy of PN programs which can be better understood through further research that accounts for limitations in clinical research pertaining to navigation.

PN outcome evaluations differ greatly depending on the part of the cancer continuum being addressed by the program. Systematic literature reviews specifically examining efficacy of patient navigation breast cancer programs revealed a pattern of programs with similar outcome variables such as evaluation of receipt of care and utilization of health services.^{1, 3-8} Evaluation of one such program, the Avon Foundation Community Education and Outreach Initiative Patient Navigation Program, examined strengths and weaknesses of programming and impact on its patient population.⁹ This particular evaluation found positive associations between patient navigators and their patients as well as improvements in areas such as: ability to ask questions, information support, emotional support and spiritual support. Robinson-White et al. (2010) found that although PN programs do improve varying aspects of cancer care, gaps in the literature still remain in regards to results of PN programs specific to patient demographics (e.g. race, income, disease stage, etc).¹⁰ Further, they found little research linking navigation efficacy and adherence to treatment.

Founded in 1955, Avon Foundation for Women is one of the leading non-profit organizations and funding entities that serves the needs of women who are specifically battling breast cancer. Overall goals for this organization include increasing breast cancer research as well as improvement to access to breast cancer care for women.¹¹ Through donations and fundraising activities Avon Foundation for Women funds programs that look towards the eradication or prevention of breast cancer. Programming that is funded by the Avon Foundation

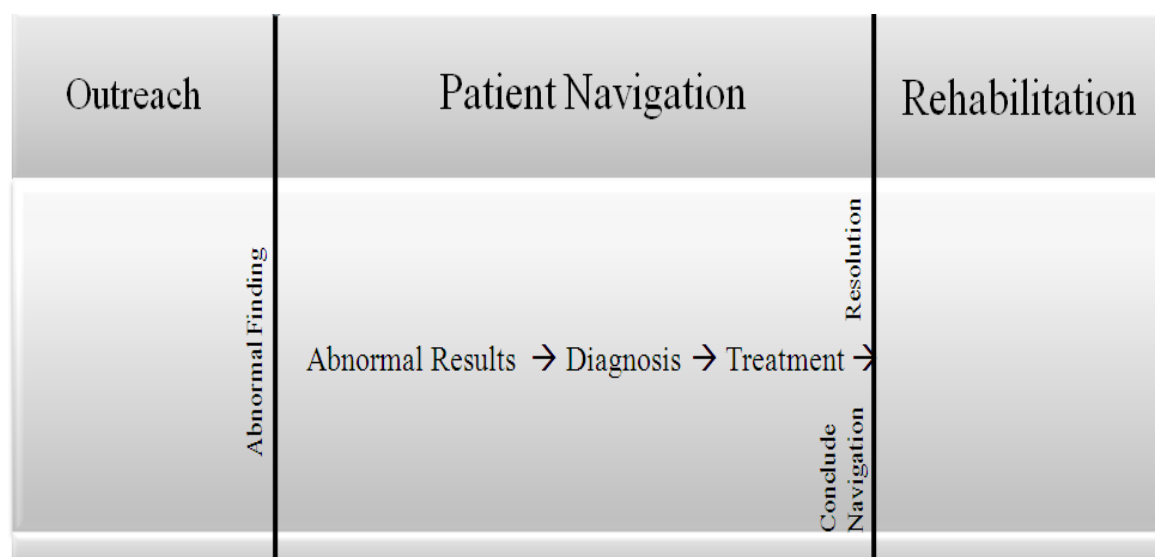
for Women includes safety net programs that help underserved populations gain improved access to health services. The Avon Foundation for Women emphasizes the importance of cancer prevention and intervention by funding scientific research that enhances the field and improves upon knowledge of cancer etiology and prevention. In conjunction with the Avon Foundation for Women, this study could help the development and implementation of PN programming by describing the navigation performed by the Avon Foundation grantees. The Avon Foundation for Women is a leader in the fight against breast cancer that has provided \$700-million in grants since 1992 to support breast cancer programs.

The purpose of this study is to explore the variation in the use and services of navigators across these programs, and describe the audiences they serve, the spectrum of cancer care services are offered, and evaluation of these programs. Although standardization of PN programs is not the goal of this study because of the understanding that every population is unique in its needs and resources, an inventory will be taken of methods used towards patient services and treatment completion in order to accomplish the goals of Avon Foundation for Women funded PN programs. This research will help to enhance the existing knowledge of patient navigation in regards to what is currently being done in designing and evaluating programs for varying populations.

The theoretical framework that serves as the foundation of this study comes from the Freeman Patient Navigation Model. The main focus of this model is the reduction of social and systems barriers to cancer care that manifest into health disparities.¹² Rather than focusing on patient navigators themselves this model focuses on programming and its role in assisting those with positive cancer findings to overcome system and social barriers in an effort to receive

adequate and timely care from diagnosis to treatment. This is done through providing assistance in navigating a complex health care system with an individually focused goal for that particular patient population. This model further emphasizes 3 specific goals: 1) cancer examination outreach and education, 2) increasing access to examinations and screenings, and 3) ensuring adequate time to diagnosis and treatment for those with positive cancer findings.¹²⁻¹⁴ For individuals who are underserved, underinsured, and are of marginalized populations, PN programs serve as a liaison between an often inaccessible health care system and the patient. As seen in Figure 1 PN begins after outreach is conducted and directly when abnormal findings are received by the patient. PN extends from abnormal test results through treatment, ultimately ending at the point of rehabilitation. The program and its prevention and intervention mechanisms serve as a factor in breaking down population barriers that prohibit health outcomes (e.g. prevention of breast cancer or entering into survivorship). This study will use this model to better define the mechanisms associated with the breakdown of specific population barriers and how navigation programs assist in reducing those barriers from diagnosis through treatment. The Avon Foundation for Women supports PN programs such as the ones depicted by the Freeman Patient Navigation Model.

Figure 1. Conceptual Freeman Patient Navigation Model¹⁴



Purpose Statement

The purpose of this research is to characterize the PN programs and services funded by the Avon Foundation and find the commonalities that exist among PN programs.

Research Questions

This study looks to provide answers to the following research questions:

1. What are the goals of the Avon funded PN programs and what populations do they serve?
2. What are population specific barriers to care and how are they being addressed to decrease health disparities?
3. How is social support being delivered in navigation services?
4. What are the PN services for programs focused on treatment of breast cancer and how is recommended treatment completion being tracked?
5. What is the extent of evaluation of PN programs?

Definition of Key Terms

Throughout this text some terms will be repeated often, in order to establish a framework of knowledge for the reader, these terms will be defined below.

1. Patient navigation: programming whose main focus is the reduction of social and systems barriers related to breast cancer services in an effort to eliminate health disparities.¹²
2. Underserved populations: those disproportionately affected by disease who include but are not limited to racial and ethnic minorities, low SES individuals, and immigrants.¹⁵

3. Health disparities: how the incidence, morbidity and mortality rates are affected by the differences between groups of people.¹⁶

Review of Literature

Chapter 2

The following literature will set the foundation for what is already known about PN programming and research in an effort to bring into focus the gaps in knowledge about PN programs that will be addressed through this study. Topics that will be addressed within this review of literature will include: breast cancer statistics, barriers to breast care services, patient navigator interventions, outcomes of PN interventions, PN's impact on barriers to breast care after abnormal screenings, and gaps in literature.

A key element of the Avon Foundation for Women programs is its emphasis on reaching underserved communities in an effort to address disparities in breast cancer. In terms of health disparities regarding breast cancer, White women have higher incidence rates than African American women; yet, a health disparity exists among mortality rates. As of 2005, there is a 37% disparity in breast cancer related mortality between White women and African American women.¹⁷ This disparity in mortality rates exists primarily because African American women are more likely to be diagnosed with late stage cancer.¹⁸ Late stage diagnosis is associated with a multitude of factors; however, delays in screening and follow-up procedures for breast cancer are the main pathways to increased risk of advanced cancer, inevitably putting these women at higher risk for death.

Breast Cancer Statistics

Breast cancer is one of the leading causes of death among African American women, the US mortality rate from 2002-2006 for African American women was 33.0 per 100,000 women;

comparatively White women had a mortality rate of 23.9 per 100,000 women.¹⁷ The five-year breast cancer survival rate for African American women is the lowest among all races, meaning that African American women have a 78% chance of surviving breast cancer five years after diagnosis compared to White women who have a 90% five-year survival rate.¹⁷ Disproportionate breast cancer mortality rates among African Americans may be attributed to time the wait time from development of breast cancer to diagnosis to initial treatment.⁴

Diagnosing breast cancer through abnormal mammography follow-ups at an early stage is the first step in improving health outcomes. In general women who have early stage localized breast cancer (e.g. cancer that has not spread to other areas of the body from where the cancer originally developed) have a 98% chance of surviving five years after diagnosis.¹⁷ The most important factor leading to health disparities among African American women are barriers that lead to infrequent use of breast cancer services. Tabar and colleagues conducted a 20-year follow-up study that found a 44% reduction in mortality through the use of timely mammography. While the Tabar study attributed reduction in mortality specifically to treatment of early staged tumors, other research has also found associations between decreased mortality and better treatment options and less aggressive therapy.^{19, 20} The importance of PN programs lies in the goal of increasing access to care for those who are disproportionately affected by this disease. Through making improvements in time to care and access to breast care services PN could serve as an additional resource for those effected by breast cancer disparities.

Barriers to breast cancer services

As lack of access to breast cancer services is a contributing factor to the development of and mortality from breast cancer, it is therefore critical to understand these barriers and address

them. Synthesizing all barriers to services would be difficult to do since every population has specific needs and faces varying challenges based on a number of factors. However, some barriers that have been determined to effect access to cancer services across multiple populations include: education, acculturation, socioeconomic status, perceived low risk, health insurance and time off from work, pain of exam, and fear of finding cancer, health literacy, and financial and transportation barriers.^{15, 20, 21}

Navigators often serve as a source of encouragement to patients recently diagnosed with cancer to seek medical care while combating individual barriers that these patients would face in an effort to seek medical assistance. For instance, in an effort to combat feelings of mistrust of the medical community that acts as a patient barrier to care, navigators are often recruited among the community to give a level of familiarity between patient and navigator.²⁰ Moreover, through an assessment of PN pilot programs, population specific interventions were noted as being essential in helping overcome access to services barriers.²² This finding developed from a survey administered to the East Harlem community to assess the specific barriers faced in regards to screening and prevention found education, acculturation, and socioeconomic status as having a direct impact on financial barriers prohibiting access to quality care.²²

Further, barriers can be counteracted by promotional factors that encourage screenings such as, having social networks who encourage screening behaviors.²¹ Tejada and colleagues took a population specific approach by examining impeding and promotional factors that influence participation in breast cancer screening among Mexican women in the United States. Jandorf examined a specific population and gave credence to the idea that not all populations are the same. In an assessment of East Harlem, although most women were of the same

socioeconomic status, issues such as acculturation which would not impact all racial and ethnic groups, serves as a major factor in the decision to participate in breast cancer screenings.²²

Patient Navigator Interventions

In spite of the declining mortality rates and improvements to breast health care, health disparities between racial and ethnic minorities and White women remain consistent in mortality and incidence rates. Current literature reflects the efforts of individual programs to reduce health disparities via patient navigation. However, patient navigators and their direct roles in increasing treatment completion that leads to a decrease in mortality disparities between racial ethnic minorities and White women are still unknown.

Parker and colleagues looked to pinpoint a concise description of PN and their work through directly observing navigators.² Much like previous literature, Parker observed that the variation in navigators was completely dependent on the objectives of the PN programs in which the navigators served. Further, a true assessment of outcomes could not be established when looking at these programs because of the lack of information provided that described specific activities of navigators and the multiple influencing outside factors; this left a gap in assessing the efficacy among navigators.

Wells and colleagues (2008) conducted a comprehensive review of PN literature to observe whether results from implemented PN programs had achieved their specific goals.¹ Programs described PN programming as being targeted at specific barriers, however, the means to which they tackle said barriers varied as to the methods navigators used to accomplish their goal. Moreover the description in regards to training of navigators was shown to be sparse across the literature. Wells recognizes that navigators range from lay health workers to trained health

professionals; however, the information did not describe what their specific training included and if the training of the navigator had an effect on interactions with their clients. Outcomes measured varied across program but specifically focused on efficacy of patient navigation in regards to adherence to health services, screening rates, stage of diagnosis, and improvement in treatment. Further, in regards to treatment adherence results varied from no significant increase in timely treatment adherence to some findings of an improvement between time to treatment and time of diagnosis. Although the literature brought several observations about PN programming to light, the question still remains whether efficacy exists among PN programming.

Steinberg and colleagues implemented an intervention where they described the recruitment mechanisms and expectations of patient navigators in the program.²³ Patient navigators were recruited and selected in order to guide cancer patients through the health care system to receive timely services. As with most navigation programs, navigators were expected to address specific barriers faced by their population, south central and south western Los Angeles women newly diagnosed with cancer, as well as providing additional information on participating in clinical trials, which traditionally do not include large samples of racial and ethnic minorities.²³ The lay navigators (e.g. those who have survived cancer) were recruited as a means to better connect with the personal barriers patients would face as well as provide assistance for those who spoke languages other than English. Steinberg emphasized the importance of community involvement in the development of the patient navigation program in order to gain a better understanding of the needs of the target community. This emphasis on community needs directly impacted the type of navigators that were recruited into the program. Although Steinberg and others gave a glimpse into the implementation of patient navigation

programming, the report lacked detail in the characteristics of patient navigators and how those characteristics impact the interaction and relationship between navigator and patient.

Outcomes of PN Interventions

Robinson-White et al. conducted a systematic review of breast cancer PN programs which included an examination of the outcomes of PN on breast care.¹⁰ In this literature review 31 articles were found that pertained specifically to PN programming, 12 of which were evaluative data-based articles. These studies examined interventions at varying parts of the cancer continuum. The results of the review showed that each of these PN programs varied in characteristics such as setting, design and method. Although these programs did differ in the fundamental ways they were designed, the outcomes that were revealed in their final analysis were similar in that patients had complied with treatment, adherence of those particular studies were at 90%. Activities such as patient participation in care and social support provided by navigators were seen across programs. One component that was not described in any of these interventions was the specific characteristics of the patient navigators in regards to how they developed their efforts to improve treatment adherence. Robinson-White and colleagues further call for more empirically based studies that measure the efficacy of navigation. The emphasis in navigation research should move towards providing evidence that navigation programming helps to reduce health disparities and the role navigators would play in assisting breast cancer patients in better accessing care.

PN's impact on barriers to Breast Cancer after abnormal screenings

Ell, Vourlekis, Lee and Xie described the role of patient navigators when intervening after abnormal mammograms.⁴ This study was one of the few designed to examine patient

navigation in a randomized control trial specifically, adherence rates after intervention implementation. Among women who participated in the Screening Adherence Follow-up (SAFe) program with PN were evaluated along with another group of women who received standard care or those not enrolled within the study. The SAFe program was designed to address individual follow-up barriers to abnormal mammography results using two methods first, through a control group which utilized health education counseling, appointment reminders and second, the experimental group which had a navigation team. Both groups revealed an increased in follow-up adherence rates to abnormal mammography results. The treatment group had a 90% adherence rate while the control group only showed an adherence rate of 66%. This study suggests that rigorous and multidimensional navigations should be implemented in order to effectively help provide patients the tools to overcome barriers to treatment adherence in breast cancer.

Gap in Literature

The currently published literature on PN describes in detail the importance of PN programming on the impact of various goals for multiple programs. However, no current research describes patient navigators and their characteristics in relation to one system that aims to prevent and treat breast cancer, in this case the Avon Foundation for Women. In order to gain a better understanding of the most effective way to aid newly diagnosed breast cancer patients in gaining more timely access to health care treatment, a general knowledge of what services and characteristics of the people providing these services needs to be attained. The Avon Foundation for Women provides an opportunity to examine a diverse group of programs throughout the United States.

The research provides a thorough overview of the barriers to accessing timely breast cancer care and treatment. However, there is a lack of consistency in assessing how these barriers to care are being addressed through the use of patient navigation programs and the characteristics of the navigators who assist these patients.

Methodology

Chapter 3

Methodology

Study Design

This was a cross sectional study where primary data were collected through a distributed online survey. Response bias was limited because of the autonomy that was given to the participants. Researchers for the study were not present for the administering of the survey, the only contact researcher had with participants was for the distribution of the survey. A census of Avon Foundation for Women programs funded since 2008 was the sample. Avon Foundation for Women provided a list of funded programs that were to be contacted for the purposes of this study.

Participants

The study consisted of 56 Avon patient navigation programs funded since 2008 throughout the United States. Only programs who received Avon funding were included in the study. Funded grantees were invited to participate in an online survey that assessed their goals and aspects of characteristics of their PN program. A list of the project directors and their contact information was provided by the Avon Foundation for Women and was used for recruitment. An email was distributed to potential participants informing them of the study and provided a link within the email for them to participate at that time. These particular programs were found to meet the qualifications of Avon Foundation for Women's objectives in helping garner access to breast cancer services for underrepresented populations.

Measures

This study aims to characterize the PN programs, explore commonalities that exist among PN programs and services to assist in treatment completion among breast cancer survivors. The survey includes a total of 48 multiple choice and short answer items. The survey was adapted from the 2007 Avon Foundation for Women Patient Navigators evaluation and studies of community health workers. The goal of this research was to describe the Avon Foundation PN programs in terms of activities they provided to help women access health services. The topic areas that are covered in the adapted survey include: population specific goals of PN programs, population specific barriers to care, social support of navigation programs, evaluation processes of navigation programs and treatment adherence tracking mechanisms.

There are several major sections of the survey that were used to better assess specific aspects of not only the functionality of the PN programs but also the navigators as well. Sections included characteristics of the population the program serves (e.g. racial and age distribution, languages spoken, income distribution, insurance status), characteristics of the Avon-funded program (e.g. program setting, services provided, affiliations for delivery of services), how navigation is structured in the program (e.g. whether programs describe employees as patient navigators, payment mechanisms, caseload), how navigation works within the program (e.g. referral process, recruitment of patients), and effectiveness of the program (e.g. evaluation processes). Open-ended questions pertained to goals, barriers to goals and mechanisms used to mitigate said barriers (e.g. what are the primary cultural, psychological, social or financial barriers to screening or treatment faced by your population and how are the population barriers you indicated being addressed by your program?)

Procedures

The researchers used Zoomerang to distribute an email invitation to the 48 item questionnaire to Avon funded breast cancer program directors (Appendix A). Surveys were distributed online and responses collected via Zoomerang, a web-based questionnaire system using a password protected data management system. Emails with links to the survey were sent out by the researcher in three waves. The first wave of emails informed them of the study and provided a link within the email for them to participate at that time. Attached to the email was a letter of endorsement from Avon Foundation for Women Executive Director (Appendix B). This letter requested voluntary participation in the survey and to direct any questions to the researcher. The second wave of emails had the same message but was sent only to organizations that had not yet completed the survey with the endorsement letter attached. The third wave of emails was a final reminder to complete the survey within 1 week with the attached endorsement letter.

Data Analysis

Responses from Zoomerang were entered into SPSS 17.0 to conduct data analysis including running descriptive statistics (e.g. frequencies and cross tabulations) of population descriptions (e.g. racial and age distributions, languages spoken, insurance status) and the structural aspects of patient navigation programs (e.g. cancer continuum focus of program, services provided, and how many are patients are served per navigator). Data for open ended questions such as “what are the primary cultural, psychological, social or financial barriers to screening or treatment faced by your population?” were analyzed by thematic analysis of major codes and will be reported as major and minor themes. Codes were established by listing

reoccurring phrases or key words from each response and checking each reoccurring phrase or key term each time it appeared in a response. Themes that appeared 5 times or more was an indication of a reoccurring theme. Most short answer responses reoccurred only 1-3 times, so in order to effectively narrow the list of themes the number 5 was chosen. These chosen themes were more comprehensive, reoccurring anywhere from 5 to 31 times.

Results

From the list provided by the Avon Foundation, there were a total of 56 Avon Foundation funded programs since 2008. Of these programs 2 programs were excluded, one was excluded because they had not begun serving their population at the time this study began and the second program did not provide accurate contact information. From those contacted we received 44 (81%) complete responses to the survey distributed via the Zoomerang website. Respondents included Program managers, Program Directors, Grants Directors and various other positions within the Avon funded PN programs throughout the United States.

1. Goals of the Avon funded PN programs and populations served

Table 1 indicates programs that serve racially and ethnically diverse populations that are mostly Hispanic (30%) and Black or African American (31%). The age of clients was mostly in the 40-64 years old (64%) range. A majority of clients PN programs (90%) served had an average income of less than \$30,000. Furthermore, a majority of the programs served a population that was either uninsured (50.7%) or had access to Medicaid (32.4%). Immigrants (47.9%) and uninsured (Medicaid eligible) clients were among the majority of special populations served. Moreover, clients mostly were served in urbanized areas (43.7%) which were defined as an area or place with a population over 50,000 residents. Further, as shown in Table 2, in describing the navigators, 43 programs indicated having someone serve in their

program with the title “patient navigator”. Navigator positions tended to be funded mostly by the Avon Foundation, however, other sources of funding from other organizations were indicated.

No navigation program indicated receiving reimbursement through insurance by having navigators as part of the programs. Programs indicated having requirements and training mechanisms for their navigators which included having a specific degree or licensure or a minimum years of experience as a navigator. Skills PN programs found to be essential for their navigators to have included interpersonal (e.g. listening skills) (41), communication (e.g. effectively communicating information to the client) (40), confidentiality (e.g. related to HIPPA) (38) and organization (33).

Table 1. Description of Navigated Patient Population (n=44)

Demographics	No. of Respondents (mean % of patients)
<i>Age</i>	
Under 40 years old	40 (14%)
40-64 years old	41 (64%)
65+ years old	41 (20%)
<i>Race</i>	
Hispanic	40 (30%)
Non-Hispanic White	39 (31%)
Black or African American	40 (31%)
Asian	40 (8%)
Native Hawaiian/PI	----
Native American/AN	----
Other Non-Hispanic	39 (3%)
<i>Income</i>	
Less than \$10,000	21 (29.6%)
\$10,001-\$20,000	23 (32.4%)
\$20,001-\$30,000	21 (29.6%)
\$30,001-\$40,000	10 (14.1%)
Greater than \$40,001	5 (7%)
<i>Insurance status</i>	
Medicare	13 (18.3%)
Medicaid	23 (32.4%)
Private coverage	8 (11.3%)

Uninsured	36 (50.7%)
Ineligible for Medicaid/Medicare	17 (23.9%)
<i>Special Populations</i>	
Immigrants	34 (47.9%)
Migrant workers	6 (8.5%)
Isolated rural residents	6 (8.5%)
Homeless	26 (36.6%)
Uninsured (Medicaid eligible)	40 (56.3%)
<i>Areas Served</i>	
Urbanized	31 (43.7%)
Urban area	2 (2.8%)
Rural area	1 (1.4%)
Both urban and rural areas	12 (16.9%)
Suburban area	8 (11.3%)

Table 2. Characteristics of Navigators (n=44).

	Term “Patient Navigator”	Funding	Reimbursement	Requirements & Training	Skills
Yes	43	----	0	36	----
No	1	----	44	7	----
Themes		Avon Foundation (41)		RN	Interpersonal (41)
		Internal (15)		Case management	Communication (40)
		Susan G. Komen (10)		Internal training	Confidentiality (38)
		Charitable organizations (6)		Navigator competency/certification	Organization (33)
		Other (4)		LCSW/MSW	Advocacy (32)
		State agency (3)		Years of experiences	Service coordinator (28)
		American Cancer Society (1)		Breast cancer/General knowledge	Cancer knowledge base (26)
					Bilingual (25)
					Teaching (23)

Table 3 describes PN programs as both community-based and hospital-based programs (22.5%) operating from safety-net settings (35.2%). Their services span the cancer continuum with programs focusing primarily on secondary care (21.1%). Further, 50% of PN programs offered onsite services, which included diagnostic services such as breast imaging (e.g. mammography and breast ultrasound) and various types of therapy. Only 5.6% of PN programs offered no onsite services. Other services that were offered related to breast health but were not offered onsite included, survivorship services (50.7%), breast health screening (49.3%), treatment (47.9%), and genetic testing (32.4%).

Table 3. Description of Patient Navigation Programs and Services (n=44)

Program Characteristics	No. of Programs (%)
<i>Program Type</i>	
Community-based	12 (16.9%)
Hospital-based	16 (22.5%)
Both	16 (22.5%)
<i>Safety-net</i>	
Academic medical center	25 (35.2%)
Community hospital	14 (19.7%)
Teaching hospital	8 (11.3%)
16 (22.5%)	
<i>Continuum focus</i>	
Primary	9 (12.7%)
Secondary	15 (21.1%)
Tertiary	13 (18.3%)
All of the above	28 (39.4%)
<i>Onsite services</i>	
Mammography screening	37 (52.1%)
Diagnostic mammography	36 (50.7%)
Breast ultrasound	36 (50.7%)
Breast MRI	29 (40.8%)
Breast surgeon/health center	36 (50.7%)
Medical oncologist	35 (49.3%)
Radiation therapy	29 (40.8%)
Other cancer-related services	23 (32.4%)
None of the above	4 (5.6%)

Regularly offered services

Outreach	41 (57.7%)
Breast health screening activities	35 (49.3%)
Genetic testing	23 (32.4%)
Breast cancer diagnostic services	34 (47.9%)
Breast cancer treatment	34 (47.9%)
Survivorship activities	36 (50.7%)

Table 4 lists the goals of these programs, which tended to focus on delivering timely access to services and care, providing education (e.g. education in breast health, medical information and resources that are available to cancer patients), providing or assistance in emotional support (e.g. counseling services and peer support), guiding patients through the system, removing systems barriers, and improving screening and quality of life (specifically in terms of survivorship).

Table 4. Goals, Thematic Barriers, and Mechanisms to Address Barriers of Patient Navigation Programs (n=44)

Goals	Barriers	Mechanisms to Address Barriers
Systems Goals	Systems Barriers	Education on breast health
Guide patients through system	Cost of screening/treatment; uninsured	
Timely access to services/care	Language	Interpreters/bilingual staff
Education (e.g. resources, medical)	Transportation	
Remove barriers	Health literacy (BC related)	Transportation
Improve screening		Financial support (e.g. vouchers, funding, counseling)
Treatment completion	Social Barriers	
	Child care	
Social Goals		Resource referrals
Emotional support (e.g. counseling)	Fear of undocumented or immigration status	
Outreach to community	Fear of mammography	Outreach events
	Culture (status as women, beliefs)	
	Lack of social support	

2. Addressing population specific barriers to care in terms of decreasing health disparities

Table 4 lists overarching themes (commentary that reoccurred 5 times or more) regarding barriers to care, which included issues of transportation, access to appointments, language barriers, and financial issues (e.g. cost of screening and treatment specifically for those uninsured). Themes that were not as frequently mentioned but still had reoccurring references were lack of child care, work schedule and employment conflicts, general lack of health literacy related to breast cancer, fears related to citizenship status and mammography, mental health and substance abuse issues, lack of social support, cultural beliefs and lack of a formal education. In spite of language barriers serving as a primary barrier data indicated that 47.9% of patient navigators do not speak the same language of the population they serve.

Reoccurring themes regarding services offered by PN programs to address population barriers included financial support services (e.g. providing vouchers, alternative funding, and financial counseling), offering free or discounted breast health services (e.g. screenings), counseling and emotional support (e.g. individualized peer counseling or group therapy and referrals), resource referrals, providing interpreters and having a bilingual staff, providing transportation, and community outreach events. Educating the community on breast health and providing interpreters and a bilingual staff were the most frequently reoccurring themes among ways to address barriers.

3. Delivery of social support in navigation services

Social support was defined by the researcher in terms of personal services outside of medical breast health services. These services were provided in terms of outreach/public education (57.7%). The top ranked skills specific that were required of navigators included

interpersonal skills (57.7%), communication skills (56.3%), and confidentiality (53.5%). Contact was maintained with client via navigators mostly through in person visits onsite (59.2%), telephone (57.7%), and accompaniment to medical and therapeutic appointments (47.9%).

4. PN breast cancer treatment services and tracking of treatment completion

Almost two-thirds of the PN programs had programming specific to the tertiary portion of the cancer continuum. 57.9% of these programs offered a method of tracking completion of recommended treatment. Programs indicated an average treatment completion ranging from 70%-99% of patients who complete recommended treatment. Specific follow-up mechanisms between patient and navigator had limited reoccurring themes. Call post-treatment was the most often mentioned follow-up mechanism. Other forms of follow-up included follow-ups regarding specific inquiries or concerns after cases are closed, follow-ups at annual screenings, letters, the clinic follows the patient and notifies navigator of changes, providing survivorship services, and follow-up intervals (e.g. follow-up call after 6 months and/or 1 year).

5. The extent of program evaluation

Thirty-three programs (75%) indicated that they had conducted some form of evaluation on their PN program in the past. Mostly 88% of programs indicated that they utilized in-house evaluation processes through having their own staff conduct the evaluations. Other mechanisms (27%) and college personnel (21%) outside of their program were also used to conduct evaluations. The topics of outcomes that were assessed included outcomes of programs (77%), outcomes of navigation (72%) and services (59%).

Discussion

Chapter 4

In this study, the focus for Avon Foundation for Women is to assist underserved populations, therefore a majority of their programs assisted lower income, racial and ethnic minorities as well as immigrants and the uninsured. We found the barriers within the Avon funded PN programs to be consistent with the barriers found in research both of which included transportation, language, and inability to afford screening and treatment due to under/uninsured status.^{15, 21, 22} Top reoccurring themes focused on providing education, providing emotional support, and delivering timely access to care which can be directly linked with those barriers which included providing better opportunities for individuals to gain access through connecting them with insurance or navigating them through the system. Although the goals were different in wording, ultimately they all were consistent in addressing the disparity having limited access to care creates.

The Avon PN programs were solely based in hospitals or communities. Therefore, many diagnostic services were offered to address screening and follow-up. The skills and services offered by the Avon PN programs included educating their population, managing individual cases, and increasing screening promotion, which were seen as issues among African American and Hispanic populations throughout the research.^{19, 22} Navigators were described as having skills related to interpersonal and communication skills which are important in relating to and understanding the clients they serve on a more personal level.^{13, 23} Familiarity with health systems may contribute to more efficient navigation through the medical system. Qualification

and training of navigators in both the literature and this study included field experience or having licensure in health fields such as nursing, social work, and navigator certification.¹

PN programs found ways to reduce multiple barriers through offering onsite services at discounted or reduced costs which helps populations who are under or uninsured and it impacts those who have limited transportation (e.g. travel from site to site for medical care would not be necessary). Further, offering these onsite services decreases the risk of facing communication issues because of language and limited health literacy barriers since most of the programs offered bilingual staff and interpreters.²¹ However, a conflicting finding was that some PN programs reported their patient navigators as not being able to speak the same language as the population they serve. It is not clear as to whether patient navigators are considered part of the staff; however, few programs required bilingualism as a criterion for their navigators.

A mechanism that is often overlooked is the social support aspect of PN programs. Social support was shown as a reoccurring theme which reflected the understanding of the navigation process as not only a systems issue but a social issue as well. There was an emphasis on social support being not solely about breast services but the major emotional impact that a diagnosis of cancer has on the individual and the toll that treatment can have on functioning. Moreover, the barriers faced by these women were indicative of some failure in social systems rather than medical or structural systems issues alone. Lack of child care, work conflicts and lack of social support from families were indicated by PN programs as barriers that have little to do with the medical field and more to do with the environment and support that the patient has before entering the system. Through providing services to help ease social barriers, patients are

provided with time to focus on screening follow-ups and treatment.²³ We also found that 50% of the programs addressed survivorship activities to support the full cancer continuum.

Although programs did track treatment completion and indicated it to be part of their cancer continuum focus, few programs indicated adherence to treatment to be an overarching theme. Program goals focused more on activities that lead up to treatment without addressing the completion of treatment. Programs who did track treatment completion indicated positive outcomes in their patients who worked with navigators.^{4, 10} However, no information was provided on whether or not the treatment they received was timely enough to be effective. Previous literature found that measurable outcomes pertained to adherence.⁴ No specific responses were given to indicate what type of information was collected regarding navigation and services outcomes within the Avon funded PN programs. However, we know that the goals of these PN program are directly linked with the types of outcomes that are measured.¹⁰

Limitations included difficulty matching goals to specific populations in order to interpret program specific goals and means of addressing said goals given the data analysis methodology. Quantitative and qualitative results could not be easily matched together in a way that would allow for a comparative analysis. Only inferences could be made between the reoccurring themes from the qualitative results (e.g. those who indicated language barriers being a primary concern) and quantitative results (e.g. populations largely non English speaking as their clients). There was a broad range reported for PN programs whose patients completed recommended treatment. PN programs ranges were between 70-99% which created an over inflation of the numbers represented. Another limitation is that this is a cross sectional snapshot on each program at 1 point in time. Depending on what time period was observed, results could differ. Additionally,

data was based on self-report by grantee Program Directors which may not have been completely accurate since they may not have direct access to all the information needed for the survey.

Finally, because there was only one coder used for the qualitative data analysis, the inter-rater reliability is limited.

All Avon Foundation for Women Grantees incorporate some type of navigation services within their programs. These services range across the cancer continuum. In spite of the recognition of some barriers and the methods to address them, there are still larger issues that prohibit access to care. We see throughout the literature that transportation and language services are barriers to care and although they were addressed by Avon grantees, those issues still remained as top ranked reoccurring themes for barriers that are still faced. Moreover, there are many methods to increase access to care for women seeking services; however, through examining this one national program, we see that many of the methods utilized are the same. For example, many of the programs chose to provide financial services because their populations were lower income. Finally, efficacy among PN programs cannot be fully understood until patients and navigators are also interviewed and surveyed through follow-up.⁹ Those who were assessed within this survey were managers of programs and not necessarily those who have direct access to patients. The most valuable resource to utilize when trying to understand whether or not a program is helping its population, are the people being served and the individuals who are directly serving them.

Further research should be conducted on different populations such as immigrants and how health disparities are impacted by patient navigation. Also, analysis that includes individuals being navigated in regards to whether or not specific barriers are being addressed would be

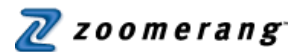
valuable to compare to the goals of PN programs. More research on the spectrum and role of navigation programs will strengthen our understanding of how they can impact cancer care.

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Appendix A



Avon Foundation Programming Survey

Avon Foundation Programming Survey



Page 1 - Question 1 - Open Ended - One or More Lines with Prompt

[Mandatory]

Organization Information

- Contact person name
- Title
- City
- State
- Phone number
- E-mail

Page 2 - Heading

Characteristics of the population your program serves

Page 2 - Question 2 - Open Ended - One or More Lines with Prompt

What is the age distribution of participants in your program (estimate percentages)?

- % under 40 years old
- % 40-64 years old
- % 65+ years old

Page 2 - Question 3 - Open Ended - One or More Lines with Prompt

What is the racial and ethnic distribution of participants in your program (estimate percentages)?

- % Hispanic
- % Non-Hispanic White
- % Non-Hispanic Black or African American
- % Non-Hispanic Asian
- % Non-Hispanic Native Hawaiian/Pacific Islander
- % Non-Hispanic American Indian/Alaska Native
- % Other Non-Hispanic

(specify)

Page 2 - Question 4 - Open Ended - One Line

What percentage of participants in your program speak English as their primary language?

Page 2 - Question 5 - Choice - Multiple Answers (Bullets)

Are there any special populations that your program serves?

- Immigrants
- Migrant workers
- Isolated rural residents
- Homeless
- Uninsured (Medicaid eligible)
- Other, please specify

Page 2 - Question 6 - Choice - Multiple Answers (Bullets)

What is the yearly income of the participants in your program?

- Less than \$10,000
- \$10,001-\$20,000
- \$20,001-\$30,000
- \$30,001-\$40,000
- Greater than \$40,001

Page 2 - Question 7 - Choice - Multiple Answers (Bullets)

What type of insurance do your participants primarily have?

- Medicare
- Medicaid
- Private coverage
- Uninsured
- Ineligible for Medicaid or Medicare

Page 2 - Question 8 - Choice - Multiple Answers (Bullets)

What methods do you use to recruit clients? (Please mark all that apply):

- We have no formal recruitment effort
- We advertise using media outlets (e.g. radio, TV, newspapers)
- We ask churches, associations and other nonprofits to identify new clients
- We send out patient reminders
- We conduct outreach activities, such as health fairs, community events, etc
- We conduct screening programs through individual or group education
- We mail or post flyers/posters/brochures

- We use a mobile unit
- We use referrals from clients
- We use referrals from other agencies/providers
- We use door-to-door inquiries
- Word-of-mouth
- Other, please specify

Page 2 - Question 9 - Open Ended - Comments Box

What are the primary cultural, psychological, social or financial barriers to screening or treatment faced by your population? Please list below and be specific.

Page 2 - Question 10 - Open Ended - Comments Box

How are the population barriers you indicated being addressed by your program? Please list below and be specific.

Page 2 - Question 11 - Open Ended - Comments Box

What is the largest need or challenge faced by your patients currently? Please describe below.

Page 3 - Question 12 - Choice - One Answer (Bullets)

Is your program community based or hospital based? (please check one)

- Community-based [Skip to 5]
- Hospital-based
- Both community and hospital-based

[Mandatory]

Page 4 - Question 13 - Choice - Multiple Answers (Bullets)

Which of the following describe the hospital? (please check all that apply)

- A safety-net hospital (one that provides a significant level of care to low-income, uninsured and vulnerable populations)
- An academic medical center
- A community hospital
- A teaching hospital

Page 5 - Question 14 - Open Ended - One Line

What year was your program established?

Page 5 - Question 15 - Choice - Multiple Answers (Bullets)

Which of the following services does your program offer? (please check all that apply)

- Outreach, public education or awareness services related to breast health
- Breast health screening activities
- Genetic testing services related to breast health
- Diagnostic services related to breast cancer
- Treatment related to breast cancer
- Survivorship activities related to breast cancer such as education, support groups or clinical activities

Page 5 - Question 16 - Choice - Multiple Answers (Bullets)

With whom do you partner to deliver health services? Groups with whom your program is formally affiliated (or partnered) to deliver services. (please mark all that apply):

- Agency/organization's location
- Community-based agency/organization
- Community college
- Faith-based group
- Hospital/medical clinic
- IHS/Tribal organization
- Local health department
- Local housing authority
- Non-profit organization
- School or school district
- State health department
- State Medicaid program
- University/medical school
- Other, please specify

Page 5 - Question 17 - Choice - Multiple Answers (Bullets)

The area served by this program is (please mark all that apply):

- An urbanized area (an area or place with a population >50,000)
- An urban area (an incorporated or unincorporated area or place with a population >2500 but less than 50,000)
- A rural area (an area or place with a population <2500 and low population density)
- Both urban and rural areas (the program serves both types)
- A suburban area (a place that is adjacent to or included in an urbanized area)

Page 5 - Question 18 - Choice - One Answer (Bullets)

[Mandatory]

Does anyone in your program provide a service that has come to be called "patient navigation"?

- Yes [Skip to 7]
- No
- Not sure

Page 6 - Question 19 - Choice - One Answer (Bullets)

[Mandatory]

Is there someone in your program-perhaps a provider, case manager, community outreach worker, advocate or volunteer-who helps a woman who has an abnormal screening or a new breast cancer diagnosis complete all the steps she needs to take to get through the healthcare system?

- Yes
- No [Skip to End]

Page 7 - Heading

From now on we will be referring to those who provide healthcare navigation services to patients in your program as "patient navigators".

Page 7 - Heading

How navigation is structured in your program

Page 7 - Question 20 - Open Ended - One Line

How many individuals provide breast-related navigation for your program?

Page 7 - Question 21 - Open Ended - One Line

How many are paid?

Page 7 - Question 22 - Open Ended - One Line

How many volunteer?

Page 7 - Question 23 - Open Ended - One Line

What is your caseload per navigator? (i.e. how many patients does each navigator serve per month)

Page 7 - Question 24 - Choice - Multiple Answers (Bullets)

Are any of your navigator positions funded by the following sources? (please check all that apply)

- Avon Foundation
- Internal

- Susan G. Komen for the Cure
- American Cancer Society
- Another foundation or charitable organization
- State agency
- Federal agency
- Other, please specify

Page 7 - Question 25 - Yes or No

Does your program receive any kind of reimbursement for its navigators, such as insurance or other third-party payments?

- Yes
- No

Page 7 - Question 26 - Yes or No

In order to be eligible to serve as a patient navigator, does your program have any requirements that must be met? (e.g. education, training, credentials, previous diagnosis of cancer)

- Yes
- No

Page 7 - Question 27 - Open Ended - Comments Box

Please describe required training or eligibility for patient navigators below.

Page 7 - Question 28 - Choice - Multiple Answers (Bullets)

Please mark skills that are required of navigators prior to hire/volunteer with your organization/agency:

- Advocacy skills
- Bilingual skills
- Capacity building skills
- Communication skills
- Confidentiality skills
- Interpersonal skills
- Cancer content knowledge base
- Organizational skills
- Service coordinator skills
- Teaching skills
- Other skills (specify)

Page 8 - Heading

The questions below ask about the highest level of training, education or other credentials held by navigators in your program. For each level, please indicate the number of full-time, part-time and volunteer navigators for whom this is the highest level they have achieved.

Page 8 - Question 29 - Open Ended - One or More Lines with Prompt

How many full-time navigators completed the following levels of training/education/credentials?

- No high school diploma, GED or equivalent _____
- High school diploma, GED or equivalent _____
- Nursing - LPN (diploma) _____
- College degree _____
- Graduate degree _____
- Other (please describe) _____

Page 8 - Question 30 - Open Ended - One or More Lines with Prompt

How many part-time navigators completed the following levels of training/education/credentials?

- No high school diploma, GED or equivalent _____
- High school diploma, GED or equivalent _____
- Nursing - LPN (diploma) _____
- College degree _____
- Graduate degree _____
- Other (please describe) _____

Page 8 - Question 31 - Open Ended - One or More Lines with Prompt

How many volunteer navigators completed the following levels of training/education/credentials?

- No high school diploma, GED or equivalent _____
- High school diploma, GED or equivalent _____
- Nursing - LPN (diploma) _____
- College degree _____
- Graduate degree _____
- Other (please describe) _____

Page 8 - Question 32 - Choice - One Answer (Bullets)

Do your navigators speak the languages of those they serve?

- All languages
- Some languages
- None

Page 9 - Heading

How navigation works in your program

Page 9 - Question 33 - Open Ended - Comments Box

What are the primary goals of your patient navigation program? Please list below.

Page 9 - Question 34 - Choice - Multiple Answers (Bullets)

What part of the cancer continuum does your patient navigation program fall under? (check all that apply)

- Primary (e.g. screening/early detection) [Skip to 11]
- Secondary (e.g. detection/diagnosis) [Skip to 11]
- Tertiary (e.g. treatment)
- All of the above

[Mandatory]

Page 10 - Question 35 - Open Ended - One Line

How many patients (on average) complete the recommended course of: chemotherapy, radiation, surgery, hormonal therapy?

Page 10 - Question 36 - Yes or No

Do you have a method of tracking recommended treatment completion?

- Yes
- No
- If yes, what is your method of tracking completion of recommended treatment?

[Mandatory]

Page 11 - Question 37 - Choice - Multiple Answers (Bullets)

Is navigation offered for the following? (check all that apply)

- Outreach and screening
- Patients with abnormal breast screening
- Patients who have received a diagnosis of breast cancer
- Patients who need to receive treatment

Page 11 - Question 38 - Choice - Multiple Answers (Bullets)

What type of services are offered by your patient navigation program? (check all that apply)

- Assistance in gaining access to medical services
- Assistance in gaining access to social services

- Case management
- Referrals/direct contact for medical services
- Referrals for social services
- Scheduling appointments
- Transportation to appointments
- Accompaniment to appointments
- Counseling
- Education on health issues
- Emotional support
- Social support
- Directly contacting family
- Interpretation
- Determine eligibility for services
- Enroll in health insurance programs
- Records keeping

Page 11 - Question 39 - Choice - One Answer (Bullets)

How many breast cancer patients are navigated by your program annually?

- 1-100
- 101-250
- 251-500
- 501-750
- 751-1000
- 1001-2500
- 2501-5000
- 5001 or more

Page 11 - Question 40 - Choice - Multiple Answers (Bullets)

In what locations do your navigators routinely support patients? (please check all that apply)

- By telephone
- In person at your program site
- Visit patient's home
- At medical/therapeutic appointments
- At social service agencies, court, etc. (non-medical visits)
- Other (describe)

Page 11 - Question 41 - Choice - Multiple Answers (Bullets)

How do your navigators become aware of patients who need their services? (please check all that apply)

- Navigator reviews lab data
- Navigator reviews appointment schedules
- Navigator reviews referral log
- Referral from primary care provider
- Referral from cancer care provider or a diagnostic service provider

- Referral from other research project staff
- Referral from family member or friend who has heard about navigation
- Use of a pager provided by the site?
- Other (describe)

Page 11 - Question 42 - Choice - Multiple Answers (Bullets)

Which of the following types of cancer-related services are available directly on site in your program? "On site" refers to services available in the same complex. It does NOT include mobile mammography screening vans. A clinical facility in another building that an ambulatory patient could walk to counts as "on site." Please check all that apply.

- Mammography screening
- Diagnostic mammography
- Breast ultrasound
- Breast MRI
- Breast surgeon/breast health center/general surgeon who does breast surgery
- Medical oncologist
- Radiation therapy
- Other cancer-related services directly (please list)
- None of the above

Page 12 - Question 43 - Open Ended - Comments Box

Once patients complete your program is there a follow-up process? If so please, describe below.

Page 12 - Heading

Effectiveness

Page 12 - Question 44 - Yes or No

Does your program conduct a formal evaluation to assess its success and/or progress in addressing the program's objectives?

- Yes
- No

Page 12 - Question 45 - Choice - Multiple Answers (Bullets)

If your program is conducting or has conducted an evaluation, who is conducting or has conducted it?

- College or university personnel
- Program staff
- Private consultants

Other (specify)

Page 12 - Question 46 - Choice - Multiple Answers (Bullets)

What do you collect data on (check all that apply)

- Navigators training
 - Navigators themselves
 - Clients/families served
 - Community/system
 - Outcomes of navigation
 - Outcomes of program
 - Quality of life
 - Policy
 - Services
 - Other (specify)
-

Page 12 - Question 47 - Open Ended - Comments Box

Do you have any other comments you would like to share about your program? If yes, note comments.

Appendix B

Hello,

I am Sandte Stanley a Master of Public Health (MPH) student from Emory University. Dr. Marc Hurlbert of the Avon Foundation approved my outreach to you (as noted in the attachment) and asks that you please respond to the questions that follow.

I am collecting data for my thesis as well as for the Avon Foundation that involves this brief survey of Foundation funded programs. The purpose of this survey is to better understand the complex and unique ways that cancer navigation programming works to help diverse populations. The results of this survey will potentially lead to understanding how navigation programs are implemented and evaluated. The survey should take no more than 30 minutes to complete, once you start the survey you will not be able to access the survey a second time so please complete to the best of your ability.

Please complete the survey by February 1, 2011.

If you would like to participate please follow the link to the survey:
<http://www.zoomerang.com/Survey/WEB22BJ3T7DJ5C/>

Thank you for participating! I look forward to your feedback.

Appendix C

This article will be submitted to Cancer (Journal of American Cancer Society).

INTRODUCTION

As of 2009, an estimated 192,370 women have died of breast cancer. Among these women the most disproportionately affected are racial and ethnic minorities. Specifically, African American women and those of lower socio economic status (SES) bear the heaviest burden.²⁴ The health disparity in mortality rates between White and African American women is reflected in data which show that breast cancer is one of the leading causes of death among African American women. The U.S. mortality rate from 2002-2006 for African American women was 33.0 per 100,000 women; comparatively White women had a mortality rate of 23.9 per 100,000 women.¹⁷ Those of lower socio economic status experience higher cancer death rates which can be attributed to multiple access to care barriers including being under or uninsured and financial barriers.²⁵ The gap of time between diagnosis and treatment is applicable to many racially and economically diverse populations and can be attributed to multiple access issues.

Barriers to care often result in late stage diagnosis which is associated with delays in screening and follow-up procedures regarding breast cancer that serve as main pathways to increased risk of advanced cancer, inevitably putting these women at higher risk for death.^{17, 19} Diagnosing breast cancer through abnormal mammography follow-ups at an early stage is the first step in improving health outcomes. In general, women who have early stage localized breast cancer (e.g. cancer that has not spread to other areas of the body from where the cancer originally developed) have a 98% chance of surviving five years after diagnosis.¹⁷ Access alone

cannot guarantee positive outcomes after a breast cancer diagnosis it is timely access to care which can help lead to healthier outcomes.

Patient navigation (PN) is a tool that is being utilized as a mechanism to help people overcome access and social barriers to health care. Specifically, breast cancer PN is leading the way in the evolution of navigation programming. Patient navigation serves as a mechanism to help these populations overcome individual system and social barriers in an effort to reduce the cancer burden among communities. Barriers that patient navigation services address include: alleviating financial burdens, transportation issues, communication issues, and finding quality care all in an effort to improve the likelihood of women receiving screening and timely treatment.^{20,21} PN helps fill the gap that health disparities leave by providing population specific help in reduction of these barriers that prevent women from seeking and accessing breast health care.² PN programming varies widely in the recruitment and background of navigators that are used.¹ Sparse data exists which describes training of navigators and mechanisms to which barriers are addressed among PN clients.² Further, research on the effectiveness of PN programming has assessed receipt of care, utilization of services and strengths and weaknesses of programming.^{1,3-9} However, since the important mechanism of PN in terms of improving patient outcomes lies within timely access, navigation efficacy and treatment completion has been sparsely researched.¹⁰

Founded in 1955, Avon Foundation for Women is one of the leading non-profit organizations and funding entities that serves the needs of women who are specifically battling breast cancer. Programming that is funded by the Avon Foundation for Women includes safety net programs that help underserved populations gain improved access to health services. The

Avon Foundation for Women emphasizes the importance of cancer prevention and intervention by funding scientific research that enhances the field and improves upon knowledge of cancer etiology and prevention.

This study will develop a better understanding of how Avon Foundation for Women grantees provide breast cancer services through patient navigation. The purpose of this study is to explore the variation in the use and services of navigators across these programs, and describe the audiences they serve, the spectrum of cancer care services offered, and evaluation of these programs.

MATERIALS AND METHODS

Avon Foundation for Women Patient Navigation programs funded since 2008 were invited to participate in a cross-sectional, online survey that assessed their goals and aspects of patient navigation. An email was distributed to potential participants informing them of the study and providing a link within the email for them to participate at that time. These particular programs were found to meet the qualifications of Avon Foundation for Women's objectives in helping garner access to breast cancer services for underrepresented populations. This study was approved by Emory University's Institutional Review Board.

Instrument

The survey includes a total of 48 multiple choice and short answer items. The survey was adapted from the 2007 Avon Foundation for Women Patient Navigators evaluation. There are several major sections of the survey that were used to better assess specific aspects of not only the functionality of the PN programs but also the navigators as well. Sections included characteristics of the population the program serves (e.g. racial and age distribution, languages

spoken, income distribution, insurance status), characteristics of the Avon-funded program (e.g. program setting, services provided, affiliations for delivery of services), how navigation is structured in the program (e.g. whether programs describe employees as patient navigators, payment mechanisms, caseload), how navigation works within the program (e.g. referral process, recruitment of patients), and effectiveness of the program (e.g. evaluation processes). Open-ended questions pertained to goals, barriers to goals and mechanisms used to mitigate said barriers. Some examples of these questions were: “What are the primary cultural, psychological, social or financial barriers to screening or treatment faced by your population?” and “How are the population barriers you indicated being addressed by your program?”.

Responses from Zoomerang were entered into SPSS 17.0 to conduct data analysis including running descriptive statistics (e.g. frequencies and cross tabulations) of population characteristics (e.g. racial and age distributions, languages spoken, insurance status) and the structural aspects of patient navigation programs (e.g. cancer continuum focus of program, services provided, and number of patients served per navigator). Data for open ended questions such as “what are the primary cultural, psychological, social or financial barriers to screening or treatment faced by your population?” were analyzed by thematic analysis of major codes and were reported as major and minor themes.

RESULTS

From the list provided by the Avon Foundation, there were a total of 56 Avon Foundation funded programs since 2008. Of these programs 2 programs were excluded: one was excluded because they had not begun serving their population at the time this study began, the second program did not provide accurate contact information. There were 44 (81%) responses to the online survey which included Program managers, Program Directors, Grants Directors and

various other positions within the Avon funded PN programs throughout the United States. In describing the navigators, 43 programs indicated having someone serve in their program with the title “patient navigator”. Navigator positions tended to be funded mostly by the Avon Foundations, however, other sources of funding from other organizations were indicated. No navigation program indicated receiving reimbursement through insurance by having navigators as part of the programs. Programs indicated having requirements and training mechanisms for their navigators which included having a specific degree or licensure or a minimum years of experience as a navigator. Skills PN programs found to be essential for their navigators to have included interpersonal (e.g. listening skills) (41), communication (e.g. effectively communicating information to the client) (40), confidentiality (e.g. related to HIPPA) (38) and organization (33).

Goals of the Avon funded PN programs and populations served

Table 1 indicates programs that serve racially and ethnically diverse populations that are mostly Hispanic (30%) and Black or African American (31%). The age of clients was mostly in the 40-64 years old (64%) range. A majority of clients PN programs (90%) served had an average income of less than \$30,000. Furthermore, a majority of the programs served a population that was either uninsured (50.7%) or had access to Medicaid (32.4%). Immigrants (47.9%) and uninsured Medicaid eligible (56.3%) clients were among the majority of special populations served. Moreover, clients mostly were served in urbanized areas (43.7%) which were defined as an area or place with a population over 50,000 residents.

Table 2 describes PN programs as both community-based and hospital-based programs (22.5%) operating from safety-net settings (35.2%). Over 39% of programs provided care across the cancer continuum. Navigation programming tended to cover most diagnostic services onsite.

These services included, mammography screening, diagnostic mammography, breast ultrasound and breast surgeon/health center. Services that were offered regularly included outreach, breast health screening activities, and genetic testing.

Table 3 lists the goals of these programs, which tended to focus on delivering timely access to services and care, providing education (e.g. education in breast health, medical information and resources that are available to cancer patients), providing or assistance in emotional support (e.g. counseling services and peer support), guiding patients through the system, removing systems barriers, and improving screening and quality of life (specifically in terms of survivorship).

Addressing population specific barriers to care in terms of decreasing health disparities

Table 3 lists overarching themes (commentary that reoccurred 5 times or more) regarding barriers to care, which included issues of transportation, access to appointments, language barriers, and financial issues (e.g. cost of screening and treatment specifically for those uninsured). Themes that were not as frequently mentioned but still had reoccurring references were lack of child care, work schedule and employment conflicts, general lack of health literacy related to breast cancer, fears related to citizenship status and mammography, mental health and substance abuse issues, lack of social support, cultural beliefs and lack of a formal education. In spite of language barriers serving as a primary barrier data indicated that 47.9% of patient navigators do not speak the same language of the population they serve.

Reoccurring themes regarding services offered by PN programs to address population barriers included financial support services (e.g. providing vouchers, alternative funding, and financial counseling), offering free or discounted breast health services (e.g. screenings),

counseling and emotional support (e.g. individualized peer counseling or group therapy and referrals), resource referrals, providing interpreters and having a bilingual staff, providing transportation, and community outreach events. Educating the community on breast health and providing interpreters and a bilingual staff were the most frequently reoccurring themes among ways to address barriers.

Further, 50% of PN programs offered onsite services, which included breast imaging (e.g. diagnostic mammography and breast ultrasound), mammography screenings, and breast surgeons/health centers/general surgeons. Only 5.6% of PN programs offered no onsite services. Other services that were offered related to breast health but were not offered onsite included, survivorship services (50.7%), breast health screening (49.3%), treatment (47.9%), and genetic testing (32.4%).

Delivery of social support in navigation services

Social support was defined by the research team in terms of personal services outside of medical breast health services. These services were provided in terms of outreach/public education (57.7%). The top ranked skills specific to social support that were required of navigators included interpersonal skills (57.7%), communication skills (56.3%), and confidentiality (53.5%). Contact was maintained with client via navigators mostly through in person visits onsite (59.2%), telephone (57.7%), and accompaniment to medical and therapeutic appointments (47.9%).

PN breast cancer treatment services and tracking of treatment completion

Almost two-thirds of the PN programs had programming specific to the tertiary portion of the cancer continuum. 57.9% of these programs offered a method of tracking recommended treatment completion. Programs indicated an average treatment completion ranging from 70%-99% of patients who complete recommended treatment. Specific follow-up mechanisms between patient and navigator had limited reoccurring themes. Call post-treatment was the most often mentioned follow-up mechanism. Other forms of follow-up included follow-ups regarding specific inquiries or concerns after cases are closed, follow-ups at annual screenings, the clinic follows the patient and notifies navigator of changes, providing survivorship services, and follow-up intervals (e.g, follow-up call after 6 months, 1 year).

The extent of program evaluation

Thirty-three programs (75%) indicated that they had conducted some form of evaluation on their PN program in the past. Mostly 88% of programs indicated that they utilized in-house evaluation processes through having their own staff conduct the evaluations. Other mechanisms (27%) and personnel from colleges (21%) outside of their program were also used to conduct evaluations. The topics of outcomes that were assessed included outcomes of programs (77%), outcomes of navigation (72%) and services (59%).

Discussion

Chapter 4

In this study, the focus for Avon Foundation for Women is to assist underserved populations, therefore a majority of their programs assisted lower income, racial and ethnic

minorities as well as immigrants and the uninsured. We found the barriers within the Avon funded PN programs to be consistent with the barriers found in research both of which included transportation, language, and inability to afford screening and treatment due to under/uninsured status.^{15, 21, 22} Top reoccurring themes focused on providing education, providing emotional support, and delivering timely access to care which can be directly linked with those barriers which included providing better opportunities for individuals to gain access through connecting them with insurance or navigating them through the system. Although the goals were different in wording, ultimately they all were consistent in addressing the disparity having limited access to care creates.

The Avon PN programs were solely based in hospitals or communities. Therefore, many diagnostic services were offered to address screening and follow-up. The skills and services offered by the Avon PN programs included educating their population, managing individual cases, and increasing screening promotion, which were seen as issues among African American and Hispanic populations throughout the research.^{19, 22} Navigators were described as having skills related to interpersonal and communication skills which are important in relating to and understanding the clients they serve on a more personal level.^{13, 23} Familiarity with health systems may contribute to more efficient navigation through the medical system. Qualification and training of navigators in both the literature and this study included field experience or having licensure in health fields such as nursing, social work, and navigator certification.¹

PN programs found ways to reduce multiple barriers through offering onsite services at discounted or reduced costs which helps populations who are under or uninsured and it impacts those who have limited transportation (e.g. travel from site to site for medical care would not be

necessary). Further, offering these onsite services decreases the risk of facing communication issues because of language and limited health literacy barriers since most of the programs offered bilingual staff and interpreters.²¹ However, a conflicting finding was that some PN programs reported their patient navigators as not being able to speak the same language as the population they serve. It is not clear as to whether patient navigators are considered part of the staff; however, few programs required bilingualism as a criterion for their navigators.

A mechanism that is often overlooked is the social support aspect of PN programs. Social support was shown as a reoccurring theme which reflected the understanding of the navigation process as not only a systems issue but a social issue as well. There was an emphasis on social support being not solely about breast services but the major emotional impact that a diagnosis of cancer has on the individual and the toll that treatment can have on functioning. Moreover, the barriers faced by these women were indicative of some failure in social systems rather than medical or structural systems issues alone. Lack of child care, work conflicts and lack of social support from families were indicated by PN programs as barriers that have little to do with the medical field and more to do with the environment and support that the patient has before entering the system. Through providing services to help ease social barriers, patients are provided with time to focus on screening follow-ups and treatment.²³ We also found that 50% of the programs addressed survivorship activities to support the full cancer continuum.

Although programs did track treatment completion and indicated it to be part of their cancer continuum focus, few programs indicated adherence to treatment to be an overarching theme. Program goals focused more on activities that lead up to treatment without addressing the completion of treatment. Programs who did track treatment completion indicated positive

outcomes in their patients who worked with navigators.^{4, 10} However, no information was provided on whether or not the treatment they received was timely enough to be effective. Previous literature found that measurable outcomes pertained to adherence.⁴ No specific responses were given to indicate what type of information was collected regarding navigation and services outcomes within the Avon funded PN programs. However, we know that the goals of these PN program are directly linked with the types of outcomes that are measured.¹⁰

Limitations included difficulty matching goals to specific populations in order to interpret program specific goals and means of addressing said goals given the data analysis methodology. Quantitative and qualitative results could not be easily matched together in a way that would allow for a comparative analysis. Only inferences could be made between the reoccurring themes from the qualitative results (e.g. those who indicated language barriers being a primary concern) and quantitative results (e.g. populations largely non English speaking as their clients). There was a broad range reported for PN programs whose patients completed recommended treatment. PN programs ranges were between 70-99% which created an over inflation of the numbers represented. Another limitation is that this is a cross sectional snapshot on each program at 1 point in time. Depending on what time period was observed, results could differ. Additionally, data was based on self-report by grantee Program Directors which may not have been completely accurate since they may not have direct access to all the information needed for the survey. Finally, because there was only one coder used for the qualitative data analysis, the inter-rater reliability is limited.

All Avon Foundation for Women Grantees incorporate some type of navigation services within their programs. These services range across the cancer continuum. In spite of the

recognition of some barriers and the methods to address them, there are still larger issues that prohibit access to care. We see throughout the literature that transportation and language services are barriers to care and although they were addressed by Avon grantees, those issues still remained as top ranked reoccurring themes for barriers that are still faced. Moreover, there are many methods to increase access to care for women seeking services; however, through examining this one national program, we see that many of the methods utilized are the same. For example, many of the programs chose to provide financial services because their populations were lower income. Finally, efficacy among PN programs cannot be fully understood until patients and navigators are also interviewed and surveyed through follow-up.⁹ Those who were assessed within this survey were managers of programs and not necessarily those who have direct access to patients. The most valuable resource to utilize when trying to understand whether or not a program is helping its population, are the people being served and the individuals who are directly serving them.

Further research should be conducted on different populations such as immigrants and how health disparities are impacted by patient navigation. Also, analysis that includes individuals being navigated in regards to whether or not specific barriers are being addressed would be valuable to compare to the goals of PN programs. More research on the spectrum and role of navigation programs will strengthen our understanding of how they can impact cancer care.

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Table 1. Description of Navigated Patient Population (n=44)

Demographics	No. of Respondents (mean % of patients)
<i>Age</i>	
Under 40 years old	40 (14%)
40-64 years old	41 (64%)
65+ years old	41 (20%)
<i>Race</i>	
Hispanic	40 (30%)
Non-Hispanic White	39 (31%)
Black or African American	40 (31%)
Asian	40 (8%)
Native Hawaiian/PI	----
Native American/AN	----
Other Non-Hispanic	39 (3%)
<i>Income</i>	
Less than \$10,000	21 (29.6%)
\$10,001-\$20,000	23 (32.4%)
\$20,001-\$30,000	21 (29.6%)
\$30,001-\$40,000	10 (14.1%)
Greater than \$40,001	5 (7%)
<i>Insurance status</i>	
Medicare	13 (18.3%)
Medicaid	23 (32.4%)
Private coverage	8 (11.3%)
Uninsured	36 (50.7%)
Ineligible for Medicaid/Medicare	17 (23.9%)
<i>Special Populations</i>	
Immigrants	34 (47.9%)
Migrant workers	6 (8.5%)
Isolated rural residents	6 (8.5%)
Homeless	26 (36.6%)
Uninsured (Medicaid eligible)	40 (56.3%)
<i>Areas Served</i>	
Urbanized	31 (43.7%)
Urban area	2 (2.8%)
Rural area	1 (1.4%)
Both urban and rural areas	12 (16.9%)
Suburban area	8 (11.3%)

Table 2. Description of Patient Navigation Programs and Services (n=44)

Program Characteristics	No. of Programs (%)
<i>Program Type</i>	
Community-based	12 (16.9%)
Hospital-based	16 (22.5%)
Both	16 (22.5%)
Safety-net	25 (35.2%)
Academic medical center	14 (19.7%)
Community hospital	8 (11.3%)
Teaching hospital	16 (22.5%)
<i>Continuum focus</i>	
Primary	9 (12.7%)
Secondary	15 (21.1%)
Tertiary	13 (18.3%)
All of the above	28 (39.4%)
<i>Onsite services</i>	
Mammography screening	37 (52.1%)
Diagnostic mammography	36 (50.7%)
Breast ultrasound	36 (50.7%)
Breast MRI	29 (40.8%)
Breast surgeon/health center	36 (50.7%)
Medical oncologist	35 (49.3%)
Radiation therapy	29 (40.8%)
Other cancer-related services	23 (32.4%)
None of the above	4 (5.6%)
<i>Regularly offered services</i>	
Outreach	41 (57.7%)
Breast health screening activities	35 (49.3%)
Genetic testing	23 (32.4%)
Breast cancer diagnostic services	34 (47.9%)
Breast cancer treatment	34 (47.9%)
Survivorship activities	36 (50.7%)

Table 3. Goals, Thematic Barriers, and Mechanisms to Address Barriers of Patient Navigation Programs (n=44)

Goals	Barriers	Mechanisms to Address Barriers
Systems Goals Guide patients through system Timely access to services/care Education (e.g. resources, medical) Remove barriers Improve screening Treatment completion	Systems Barriers Cost of screening/treatment; uninsured Language Transportation Health literacy (BC related)	Education on breast health Interpreters/bilingual staff Transportation Financial support (e.g. vouchers, funding, counseling)
Social Goals Emotional support (e.g. counseling) Outreach to community	Social Barriers Child care Fear of undocumented or immigration status Fear of mammography Culture (status as women, beliefs) Lack of social support	Resource referrals Outreach events