

Avon/Pfizer Metastatic Breast Cancer Grants Program White Paper





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Acknowledgements:

Author: Kristine De La Torre, PhD

Edited by: Carolyn Ricci, Dana Huber

Designed by: Corrine Ellsworth Beaumont, MFA PhD

INTRODUCTION

An estimated 150,000-250,000 women currently live with metastatic breast cancer (MBC) in the United States, and they have a median survival of 2 to 3 years after diagnosis that varies dramatically depending on the subtype of MBC.¹ Patients living with MBC manage complex and difficult medical treatments (e.g., chemotherapy, targeted therapy, radiation, surgery) from diagnosis through the balance of their lives.

MBC patients also face other challenging non-medical issues that impact their quality of life (QOL). These issues may include: limited support, education and understanding of MBC; poor access to nutritious food; language and geographic barriers; desire for and access to complementary medicine; legal matters; financial concerns; palliative care needs and end-of-life matters. Patients with MBC have unique concerns associated with their reality that are different from patients with earlier-stage disease. MBC patients often feel ignored, misunderstood, and left out of the “feel good” war on breast cancer that often emphasizes the experiences of survivors.¹ Specific initiatives and support that address a patient’s holistic needs are urgently needed for those living with MBC, their families, caregivers and communities.

MBC is when breast cancer cells spread from the breast to other parts of the body. MBC is also called advanced breast cancer, Stage IV, or secondary breast cancer. Secondary breast cancer means that the cancer was first in the breast and months—or even years—later appeared in another organ. A diagnosis of MBC is especially daunting to patients and families who are medically underserved (i.e., those with barriers to accessing care). Barriers to care may include: insufficient income, limited education and health literacy, lack of or inadequate insurance, limited English proficiency, and distance to care from rural areas. Minority and medically underserved populations may also have different tumor biology, more co-morbidities, underuse of adjuvant therapies, and difficulties communicating with medical professionals.²

1. Advancedbc.org. Silent Voices: Women with Advanced (Metastatic) Breast Cancer Share Their Needs and Preferences for Information, Support and Practical Services. Available at: <http://advancedbc.org/node/26>

2. Bickell et al., 2006; Blackman and Masi, 2006; Daly and Olopade, 2015; Darby et al., 2009.

Programs that were part of the 1-year MBC Grants Program increased access to services, information, and education specific to MBC patients; increased cultural competency of cancer care providers; and reduced disparities in access to care in medically underserved populations. Collectively, the 23 organizations funded by the MBC Grants Program designed and implemented programs that addressed various topics, including nutrition support, complementary and integrative medicine (CIM), psychosocial support, education and information, identification of MBC-specific clinical trials, assistance in accessing medication, and patient navigation. Improved access to such services through these programs can improve medical care, patient outcomes, QOL, and provide a better “today”. Lessons learned from these pilot programs will be documented as best practices and are thus expected to continue to improve QOL and address specific gaps and barriers in vulnerable, underserved populations (Table 1).

Over the course of the year, these 23 funded programs helped more than 32,800 individuals through efforts including nutrition counseling, patient navigation, education and complementary care.

Nearly 230 caregivers also benefitted from grantee initiatives, and many more families and community members were supported by this work. In addition, some programs included online content, reaching more than 14,000,000 people with information on MBC.

Medically underserved population	Solutions to remove barriers to care
Low income	Access to affordable, consistent health insurance; financial, housing, transportation, food assistance; assistance obtaining medication; navigation through treatment and palliative care
Low education	Linguistically accessible information; access to and education about complementary and integrative medicine; patient navigation
Limited English skills	Access to services, assistance, and information in the client's preferred language; culturally sensitive information and psychosocial support; navigation
Rural populations	Transportation assistance; access to remote support through the use of technology
Cultural and ethnic minorities	Increased access to clinical trials; education about personalized tumor assessment and treatment; culturally sensitive information
Men and young women	Increased support for patients in these sub-groups with MBC; improved public awareness, physician awareness, and research funding

Table 1. Reasons that patients are medically underserved and solutions implemented or suggested by programs funded by the MBC Grants Program



The goals of the MBC Grants Program are to:

- Implement programmatic solutions to challenges that will improve the QOL of underserved women and men with MBC
- Address gaps in services and information for the MBC community; and
- Address barriers to care, information, and services

7 AREAS OF NEED

were funded in 23 programs



FOOD INSECURITY & NUTRITION

Food insecurity and nutrition: 2 programs

Accessing nutritious food is often difficult for underserved MBC patients, who have varying needs depending on their health at a given moment. Patients that live in food deserts, or areas where grocery stores and farmers' markets are few and far between, are especially vulnerable to food insecurity, and many perceive that there is a stigma attached to not being able to afford and prepare one's own food.



COMPLEMENTARY MEDICINE (CIM) & PALLIATIVE CARE

Complementary and integrative medicine (CIM) and palliative care: 2 programs

MBC patients will endure a number of various treatments as their condition changes over time. Many of these treatments are difficult on the body, and eventually, medical interventions will no longer work. Many MBC patients incorporate additional regimens, including palliative care, into their treatment plans to help relieve pain, build strength and improve overall health.



PSYCHOSOCIAL SUPPORT

Psychosocial support: 8 programs

MBC patients endure challenges different from those diagnosed in earlier stages of breast cancer. Many seek support from peers and other families with similar experiences. Programs provide MBC-specific social, psychological, emotional, and functional support to medically underserved clients that are sensitive to their reality. Psychosocial support removes the sense of isolation that many people with MBC feel.



EDUCATION & INFORMATION

Education and information: 5 programs

Much of the available patient education is focused on the early stages of breast cancer, excluding the needs of MBC patients. Patient education on MBC should be concise, easy to understand, evidence-based, personalized, and linguistically, spiritually, and culturally appropriate. Providing this type of information empowers clients and helps them make informed healthcare decisions with their physicians and healthcare team.



CLINICAL TRIAL DATABASE

Awareness of and connection to clinical trials: 1 program, 5 advocacy groups

There are a number of clinical trials focused on MBC patients under way, yet many patients are unaware of where to get information about these research programs. The goal is to increase trial engagement, increase patient awareness, provide easier access to clinical trials, and increase trial participation by all groups of patients, including populations underrepresented in clinical trials.



MEDICATION ASSISTANCE

Medication Assistance: 1 program

Medication for MBC, including pain therapeutics, may be difficult to access at community-based pharmacies. Some treatment options are relatively rare, so may not be in regular stock. MBC patients can access one-stop medication. Quicker access to medication improves adherence to treatment plans and decreases anxiety and financial stress.



PATIENT NAVIGATION SUPPORT

Patient Navigation Support: 4 programs

MBC Patients need help dealing with the fragmented healthcare system, as the labyrinth of screening and diagnostics becomes more complex. MBC-specific navigation empowers clients to make informed decisions about their healthcare.

23 LOCATIONS

serving metastatic patients across the country



23 FUNDED PROGRAMS

a brief overview

FOOD INSECURITY AND NUTRITION FOR PEOPLE LIVING WITH MBC



Memorial Sloan Kettering Cancer Center

Memorial Sloan-Kettering Cancer Center

The FOOD project is designed to assist medically underserved women with MBC in New York City. Access Facilitators obtain referrals from community organizations, conduct an intake needs assessment survey, screen clients in their preferred language for food insecurity, identify specific food needs, enroll clients in the medically tailored food pantry, provide clients with food vouchers and accompanying nutrition counseling, and connect them with relevant psychosocial support services.



God's Love We Deliver

The Nutritional Care for MBC Patients program operated by God's Love We Deliver in New York City prepares and delivers up to 21 meals per week to the homes of MBC clients and their families. Outreach materials are available in English, Spanish, Chinese, Haitian Creole, and Russian at community events throughout the city. Meals are prepared by a dietician according to the individual client's needs and restrictions.

COMPLEMENTARY AND INTEGRATIVE MEDICINE (CIM) FOR PEOPLE LIVING WITH MBC



CHARLOTTE MAXWELL CLINIC
INTEGRATIVE CANCER CARE

Charlotte Maxwell Clinic (CMC)

Based in Oakland, CA, Charlotte Maxwell Clinic (CMC) helps low-income clients understand how integrative medicine works with standard cancer treatments including chemotherapy and radiation. CMC case managers work with individual clients and pay attention to language, culture, health literacy, fears, fatalism, and other factors that interfere with clarity in decision making. For women seeking only medical care or only complementary treatments, CMC helps them understand the benefits of both.



You Can Thrive Foundation

Based in New York City, You Can Thrive focuses on home services and offerings of holistic services for home-bound clients with MBC and those in hospice care. The program allows clients to continue access to long-term care even after they have completed months in the program.



PSYCHOSOCIAL SUPPORT

Cancer Resource Center of the Desert

Cancer Resource Center of the Desert has created a biopsychosocial care framework for MBC clients and their families/caregivers to address the social, psychological, emotional, and functional aspects of living with MBC. The program, which is culturally and linguistically targeted to assist Latina women living in the rural, US-Mexico border region of Imperial County, CA, provides bi-weekly support groups led by trained social workers for MBC clients and their families/caregivers and bi-weekly one-on-one sessions with clients and their families/caregivers to help design a plan of care and provide them with practical and legal information.



City of Hope

The program implemented by City of Hope (Duarte, CA) is designed to assist MBC clients and their partners by providing an audio recording of the first physician visit and consultation with a social worker to improve support, education, and understanding of the audio recording.



Denver Health and Hospital Foundation

Based in Denver, CO, the Denver Health and Hospital Foundation is assessing the effects of psychosocial intervention and social worker support on QOL, depression, treatment adherence, and patient outcomes in ethnically diverse, medically underserved women with MBC.



Gilda's Club of Northern New Jersey

With facilities in Hackensack and Newark, Gilda's Club of Northern New Jersey provides a comprehensive program designed for women living with MBC that includes individual counseling, a fitness program, and educational workshops.



H. Lee Moffitt Cancer Center and Research Institute Hospital Inc.
Based in Tampa, FL, H. Lee Moffitt Cancer Center and Research Institute Hospital Inc. has implemented a local MBC support group, a web-based group for remote clients, teletalks for local and remote clients, peer-to-peer support and mentoring, and weekend retreats for MBC clients in a wellness and healing setting. Moffitt uses a personalized holistic approach to improve QOL and outcomes, which is achieved through an interdisciplinary team approach.



METAvivor
Based in Annapolis, MD, METAvivor is using their own peer-to-peer support group as a model to expand peer-to-peer support groups for MBC clients across the country. They have identified important topics (e.g., end-of-life planning, access to healthcare, clinical trial information, role of palliative care, ending treatment and hospice, and sexuality) and best practices for initiating and sustaining support groups. Potential new leaders are recruited with nationwide emails, social media, and the METAvivor website.



Sanford Health
Sanford Health provides a support group for women with MBC called FOURward in North Dakota, South Dakota, and Minnesota. Video and teleconferencing are available to reach this rural population. They also provide one-day annual retreats for women with breast cancer. Services provided include education on topics focused on the mind-body connection, a quarterly newsletter, a healing arts program to provide therapeutic art at the bedside, and nutrition counseling.



SHARE Self-Help for Women with Breast or Ovarian Cancer Inc.
Based in New York City, SHARE provides eleven telephone-based support group sessions for those living with metastatic breast cancer each month. One of these monthly sessions is for women 45 and under and two are for Spanish speakers. In addition, SHARE has an in-person support group that meets twice monthly in our office. SHARE'S national telephone helpline provides multilingual peer support for women living with MBC. Callers to the helpline can speak with someone with a similar subtype of metastatic disease or treatment protocol. SHARE also distributes bilingual postcards with information about its metastatic services through an outreach program to medically underserved communities that reaches 22,000 people annually, and maintains a 900-page resource guide to assist those living with metastatic disease obtain the services and support they need.

EDUCATION/INFORMATION SUPPORT



Breastcancer.org
Based in Ardmore, PA, Breastcancer.org provides My Breast Navigator, which delivers customized information about topics that are specifically related to MBC including diagnosis, treatment options, finding clinical trials, managing fears, etc. in the form of research news articles, core content, podcasts, and blog posts. This information will improve the role the client plays in conjunction with his or her health team to make decisions about care, thus improving QOL and outcomes.



Living Beyond Breast Cancer
Based in Bala Cynwyd, PA, Living Beyond Breast Cancer has established the Hear My Voice program to address the psychosocial and educational needs of women living with MBC of all ages, backgrounds, and geographic regions of the country via a peer outreach program that provides services and information about new treatments and clinical trials.



West Cancer Center
Based in Memphis, TN, the West Cancer Center has developed a program specifically for clients with MBC called The Patient Companion for Metastatic Breast Cancer Patients that includes an introductory educational program provided by physicians and social support team members, online support groups led by nurses and social workers, and a Patient Companion Library on their website (previously only available in print) that provides MBC-specific information. Clients with MBC are identified through the Congregational Health Network, a covenantal partnership with 600 faith congregations. Women in need are identified by partnerships between hospital navigators and congregation liaisons to connect medically underserved women with MBC to the services provided by this program.



Patient Advocate Foundation
Based in Hampton, VA, Patient Advocate Foundation provides The Managed Care Answer Guide, which is focused on insurance education for clients for self-management by providing educational bulletins for newly insured or uninsured clients. The program seeks out underserved women via the National Hispanic/Latino Outreach Program and the National African-American Outreach Program.



Young Survival Coalition

Young Survival Coalition, based in New York City, has updated its 138-page guide called *Metastatic Navigator: A Young Woman’s Guide to Living with Metastatic Breast Cancer* with the goal of increasing a young woman’s (<40 years old) understanding of living with MBC. The updates to the Guide include user-friendly information about MBC and specifically address emerging treatment options and research results, methods of effective communication with healthcare teams, insurance, financial assistance, ways to improve QOL, end-of-life planning, and various tools to help women stay organized. The guide is now available in an electronic version and in other languages, and additional electronic resources are also available.

METASTATIC CLINICAL TRIALS SEARCH



BreastCancerTrials.org (BCT) – Quantum Leap Healthcare Collaborative (QLHCC)

Based in San Francisco, CA, BCT provides a mini-form on the website of five breast cancer advocacy groups so that patients can search for MBC clinical trials. The output from a trial search is a user-friendly description of the trial that includes the purpose, patient population, study plan, and contact information. By placing the mini-form on breast cancer advocacy groups that reach different subpopulations of patients with MBC, BCT hopes to increase awareness and consideration of participation in clinical trials, especially in medically underserved minority women.

ASSISTANCE IN ACCESSING MEDICATION



HarborPath

Based in Charlotte, NC, HarborPath has designed and implemented a program to provide free medication to low-income, uninsured eligible MBC clients. Through the HarborPath portal, staff at cancer centers will be able to apply on behalf of clients for free medications from multiple manufacturers. This program is a streamlined process that utilizes a single patient portal to access all necessary drugs and is based on a successful model to provide HIV/AIDS medications.



NAVIGATION SUPPORT

Central Suffolk Hospital and Peconic Bay Medical Center

Serving the Long Island, NY, community, Central Suffolk Hospital and Peconic Bay Medical Center have implemented the “The Taking Care of You” Metastatic Breast Cancer Patient Navigation program, which is an expansion of an existing program for breast cancer patients that now focuses on serving the unique needs of MBC patients, especially those with language- and insurance-related barriers. These navigation services are culturally appropriate and bilingual to serve the large number of Hispanics and seasonal agricultural workers in the Long Island area. Bilingual navigation tailored to MBC includes guidance by a dedicated navigator to traverse the medical system and connects the patients to community resources (legal, transportation, home assistance, etc.), palliative care, clinical trials, and support groups. The program integrates families and religious/cultural beliefs that impact clients’ healthcare decisions.



Shanti Project Inc.

Based in San Francisco, CA, Shanti Project provides Care Navigation for low-income and underserved women with MBC that includes patient advocacy, translation services, coordination with medical care teams, emergency resource and care coordination, weekly in-home emotional support, resource referral application assistance (financial and meal assistance, counseling), taxi vouchers, and appointment accompaniment, which are expected to increase treatment adherence and QOL. Clients can participate in multilingual Health, Wellness & Survivorship classes and workshops with topics that include nutrition workshops, art therapy classes, mind-body healing, weekly massage, reiki, and yoga.



The Breast Cancer Resource Centers (BCRC) of Texas Inc.

Based in Austin, TX, BCRC provides the Metastatic Patient Navigation Program to provide long-term support to those with MBC. They have identified and addressed gaps in information (through an MBC-tailored Breast Cancer Companion and live seminars), financial assistance, and transportation for women with MBC living in rural areas.



Yale-New Haven Hospital

Located in New Haven, CT, Yale-New Haven Hospital operates Bridging the Care Continuum for Underserved Women with Metastatic Breast Cancer. This program provides patient navigation specifically to low-income, ethnically diverse minority women with MBC residing in the New Haven area.

FOOD INSECURITY & NUTRITION



CATEGORY ONE: FOOD INSECURITY AND NUTRITION FOR PEOPLE LIVING WITH MBC

Theme Overview

Proper nutrition helps MBC patients maintain a healthy weight, cope with the side effects of treatment, and improve their overall health. That said, the treatment for MBC can cause nausea, weight loss, loss of appetite, and fatigue, which negatively affect a patient's ability to prepare meals and maintain healthy eating habits. Inadequate nutrition is associated with reduced healing, immunosuppression, risk of infection, and decreased QOL (Gany et al., 2013). More than half of medically underserved patients with MBC experience food insecurity—the uncertainty about the availability of adequate amounts of nutritious food. In some cultures, multigenerational households may feed the elderly and children first, leaving whatever is left over for those in between—potentially a breast cancer patient.

For men and women living in food deserts, or areas where grocery stores and farmers' markets are few and far between, purchasing produce or other healthy food may not be possible. Being physically able to leave one's home to go shopping or feeling well enough to prepare a meal might not be realistic, given the often debilitating effect of cancer therapies. Asking patients to fit in yet another appointment at a food pantry on top of higher-priority clinical visits is often too much.

Many medically underserved patients work for an hourly wage with no paid time off for treatment. This drastic reduction in income, coupled with the need to spend money on transportation to appointments and to buy more expensive food due to their cancer treatment-related diet, contributes to food insecurity. Although food pantries are available in many areas of the country, they are limited.

MBC GRANTEE SOLUTIONS

Providing adequate nutrition in chronically ill patients decreases healthcare costs, length of hospital stay, and the number of hospital readmissions (Gurvey et al., 2013). Two funded programs are addressing the problem of food insecurity in underserved patients with MBC in New York City.

Memorial Sloan Kettering (MSK) Cancer Center’s Food to Overcome Outcomes Disparities (FOOD) project assists medically underserved women with MBC in New York City. The average age among enrolled MBC patients was 54. Forty-three percent were high school graduates. All but one patient was insured, and of those insured, 47% were covered by Emergency Medicaid. The majority of patients (83%) reported being unemployed at the time of enrollment in the FOOD program. Average household size was 3.5. For those patients who reported both household income and household size, nearly half (47%) lived below the household poverty line.

The program’s “Access Facilitators” conduct outreach to potential clients as they wait to see a provider at the clinic. During this outreach, the Access Facilitator conducts an intake needs assessment survey in a preferred language to identify specific food needs and screen for food insecurity. The Access Facilitator then provides referrals to community organizations, enrolls clients in the clinic’s medically-tailored food pantry, provides food vouchers and nutrition counseling, and connects patients with relevant psychosocial support services. **The program distributes bags of healthy, shelf-stable food each week—the**

equivalent of 9 meals per patient—and also includes NYC Health Bucks, which can be exchanged for produce at local farmers’ markets.

The program also trained additional staff and interns to screen and identify food insecure MBC patients, link them with external emergency food resources, provide printed nutrition education materials, and tailor pantry bags. By ensuring that more are aware of patient’s nutrition needs, this effort helped to fill gaps at clinics where making referrals to a nutritionist is a challenge, or where there is no outpatient nutritionist onsite.

Among MBC clients (30 females, mostly minorities) enrolled in FOOD, MSK observed increases in food security and patient-reported improvements in quality of life. Only one client stopped treatment before completion.

A patient from the Dominican Republic was diagnosed with metastatic breast cancer. Her young eight-year-old son was at home, living with distant relatives. She was in New York alone, without any money. A friend provided a place to stay, but did not offer financial or nutritional support. On her first visit to the pantry (Lincoln Hospital), she was given a large bag of food, some of which she ate immediately. When she told the FOOD staff member that she was planning to walk home, the staff member provided MetroCards for transportation. The patient has been coming to the pantry every week since, and is extremely grateful that she no longer goes hungry or worries about how to get home. She has been given oral chemotherapy and will soon return to her son.

God’s Love We Deliver (GLWD) in New York City operates a weekly meal service, Nutritional Care for MBC Patients, that provides up to 21 meals per week (up from 10 meals per week) to underserved MBC clients in New York City and surrounding areas. Clients include immigrants and others with limited English proficiency. The organization partners with clinical, community-based, and social service agencies to identify clients when they are discharged from hospitals and treatment centers. At the time of program enrollment, registered dietitians assess nutritional needs of breast cancer clients. Patients with MBC are immediately assigned to receive seven meals per week and then assessed for a possible need to receive 14 or 21 meals per week. Meals are cooked, frozen or chilled, and home delivered to patients, senior caregivers and children of the client.

Over the course of the project, God’s Love We Deliver cooked and home delivered >17,000 meals to 66 clients, 14 children, and one senior caregiver. Eligible patients receive their meals the day after enrollment, providing immediate relief from food insecurity.

Of God’s Love We Deliver’s current MBC clients, 41% are black, 23% are Latino, 20% are white, and 5% are Asian/Pacific Islander; 81% live below the poverty line. Individuals that are 65 years old or older are the largest MBC client demographic, comprising 39% of GLWD’s metastatic breast cancer population, reflecting a largely senior client population overall (63% of GLWD’s total client population are 60 years old or older).

In their recent client survey of those living with cancer, GLWD found that:

- 91% of clients report that getting food helps them live more independently;
- 75% report that the meal program makes their medical treatments easier to tolerate;
- 89% report that the food received helps them to eat more nutritiously;
- 84% report that receiving food from GLWD has reduced their stress about not having enough to eat.





CHALLENGES TO OVERCOMING FOOD INSECURITY

Grantees identified a number of challenges to tackling food insecurity. First, clinical grantees sought better ways to find and connect with MBC patients. Those in medical settings determined that searchable clinical data could help locate MBC patients to target outreach to screen for their needs. Through the use of medical records, nutritionists, providers and Access Facilitators could cross-reference treatments with comorbidities and medications. Grantees also grappled with the amount of foodstuffs to provide clients to ensure food safety, particularly with perishable items.

Other challenges included reliable access to nutritionists, especially in outpatient settings. Grantees emphasized the importance of cultural competent nutrition counseling, particularly given the strong role that food plays in many cultures.

Addressing Food Insecurity: Grantee Best Practices

Over the course of the programs, a few best practices were identified to address food insecurity for MBC patients. Partners found that an MBC patient's nutritional needs should be assessed to determine what type of food they need to best complement their treatment—this could range from small portions to bland food to soft food.

Because food security and the need for support is pervasive among MBC patients, it is important to integrate nutrition counseling into all MBC client assessments as a regular part of their care. This is especially important for MBC patients, as treatment regimens often change over time, resulting in a need for frequent reassessment of one's nutritional needs.

Within programs to combat food insecurity, patients should receive foodstuff immediately, concurrent with nutrition counseling. Finally, co-located food bank services or direct meal delivery to the home are critical to help MBC patients overcome barriers to getting to a food bank, like access to reliable transportation.

Given that MBC patients have a number of unmet needs, nutrition being one of them, grantees found that strong partnerships with clinical and community-based organizations are critical to ensure appropriate and timely referrals.

Food insecurity can be addressed in underserved MBC clients through co-located food bank and clinical services programs, home delivery of prepared meals, and frequent nutrition counseling.

Nutrition regimens for MBC patients should be tailored to the individual client's dietary guidelines, personal and cultural preferences. Targeted referral can be accomplished by employing various outreach programs and databases to screen for MBC clients who may be eligible for these services. In addition, multilingual follow-up and sustained partnerships with multiple groups are essential for adherence to nutrition as a key component of a patient's treatment. Grantees indicated that their future goals for reducing food insecurity include expanding access to outpatients, providing customized nutrition curricula, and enhancing the searchability of medical records and electronic databases to more readily identify potential clients.

COMPLEMENTARY MEDICINE & PALLIATIVE CARE



CATEGORY TWO: COMPLEMENTARY AND INTEGRATIVE MEDICINE (CIM) FOR PEOPLE LIVING WITH MBC

Theme Overview

Medical treatments for MBC (e.g., targeted therapies, chemotherapy, surgery, radiation treatments) cause a variety of side effects, which in some cases can be eased by the use of CIM. When a patient does not feel well as a result of often aggressive clinical therapy, she is more likely to deviate from her care plan. The use of CIM practices allow women to experience a better QOL during their care. CIM can allow patients to better tolerate and continue with their clinical treatment (Greenlee et al., 2014).

Oftentimes, patients from medically underserved communities do not have access to information about CIM and its importance within their treatment regimens. Access to and education about CIM is often limited for underserved women with MBC. In addition, both provider and patient attitudes about CIM vary widely.

Examples of CIM modalities include:

CIM modalities	Areas addressed by these modalities <i>*Talk to your doctor about starting any of these modalities</i>
Acupuncture	<ul style="list-style-type: none"> • Reduce pain • Lessen fatigue and nausea
Massage therapy	<ul style="list-style-type: none"> • Reduce pain • Reduce stress
Herbs and tinctures	<ul style="list-style-type: none"> • Alleviate pain from mouth sores • Increase appetite
Yoga and exercise	<ul style="list-style-type: none"> • Improve range of motion • Improve overall health • Reduce anxiety and stress

MBC GRANTEE SOLUTIONS

Underserved MBC patients can greatly benefit from education and opportunities for CIM as part of their care. Two funded programs are providing holistic care, centered around CIM, to their clients:

Charlotte Maxwell Clinic (CMC) is the only health center to provide CIM services at no charge to low-income women with MBC in the San Francisco Bay area. CMC works with patients before, during and after treatment to integrate CIM modalities throughout their care regimen. CMC serves women 21-80 years old, 25% are African American, 24% are Asians, 24% are Hispanic/Latinas, and 25% are white; 40% of CMC's clients speak little or no English. Throughout their program, the CMC worked with 550 MBC patients, caregivers and family members to provide CIM.

To ensure that CIM therapies are truly integrated, CMC works closely with each client's oncologist and provides social services, education, advocacy, and referrals to help patients get all of the support they need. CMC seeks to empower a client by teaching her that she is entitled to high quality care. CMC staff works with each client to ease fears, address misunderstandings about clinical treatments, and explain how CIM can make conventional cancer care more tolerable. Messages are delivered in a clear, compassionate, culturally and spiritually appropriate manner, with constant feedback from clients. CMC pays careful attention to barriers of health literacy, fatalism, and other factors that prevent clear decision making, and within that framework, respects all decisions made by clients.

CMC works with women living with the physical, economic and social burdens of cancer. The path for healing for each is as unique as a fingerprint. And that is the strength of integrative medicine combined with compassionate social services.

The Charlotte Maxwell Clinic has a client who has reached a milestone of 9 years of living with MBC. While she has been in treatment for extended periods of time, she has fared very well with the integrated treatment plan that optimizes acupuncture, therapeutic massage, and herbal formulas with her chemotherapy regimens. Her brain lesions are small and have been stable for some years. She experiences less anxiety now when her screening exams come due. She gets fewer treatments now that she is stable, but she will always be eligible for community acupuncture and for her periodic appointments for reassessment.

You Can Thrive (YCT) Foundation, based in New York City, provides palliative CIM care and end-of-life support to MBC patients at home or in retreat settings. Grounded in the belief that mind-body palliative care services for MBC patients is essential, not optional, YCT focuses on improving QOL for low-income MBC patients with deteriorating physical health (10% <40 years old, 53% 40-60 years old, 37% >60 years old).

YCT works with community-based organizations to provide support groups and information about MBC, in-person and online. **Outreach workers conduct weekly visits with clients that have been found to improve primary and secondary symptoms, reduce interference with activities, and aid overall patient well-being.** As part of their program, YCT hosted an intensive seaside retreat for 10 women living with MBC that included CIM modalities like yoga, meditation, art, healthy food and peer support, which resulted in patient-reported improvements in QOL

compared to their traditional model of weekly interactions. For women with more advanced disease where participation in a retreat is not possible, YCT provides hands-on palliative services delivered in the home or bedside to patients receiving long-term care and those in home hospice through partnerships with hospitals throughout the city. Overall, YCT's MBC clients expressed a relief in symptoms and also a greater overall happiness and peace.

“Through YCT, I have been given the gifts of nutritional counseling, emotional freedom technique (tapping), acupuncture, healthy living, meditation and other workshops, all of which have been beneficial to lowering my stress, anxiety, reducing pain, and I believe contributing to my overall healing.”

*—Testimonial from Marilyn
YCT MBC client*



CHALLENGES TO INTEGRATING CIM INTO CLINICAL CARE

Grantees acknowledged a number of challenges to making CIM programs a regular part of the standard of breast cancer care. On both the patient and provider side, there is a lack of knowledge about the benefits of CIM as part of cancer care. Many oncologists believe that CIM interferes with clinical treatment plans, and do not discuss these options with patients during visits. In some cases, attempting to provide CIM services in a hospital setting is met with confusion by administrators.

Patients are not aware of options for care, including CIM, thus do not inquire further with their physicians. Oftentimes, CIM services are not co-located nor streamlined with clinical treatment schedules, creating barriers to accessing these modalities of care. Additionally, for many patients, CIM is not covered by insurance, which presents financial barriers to obtaining these services.

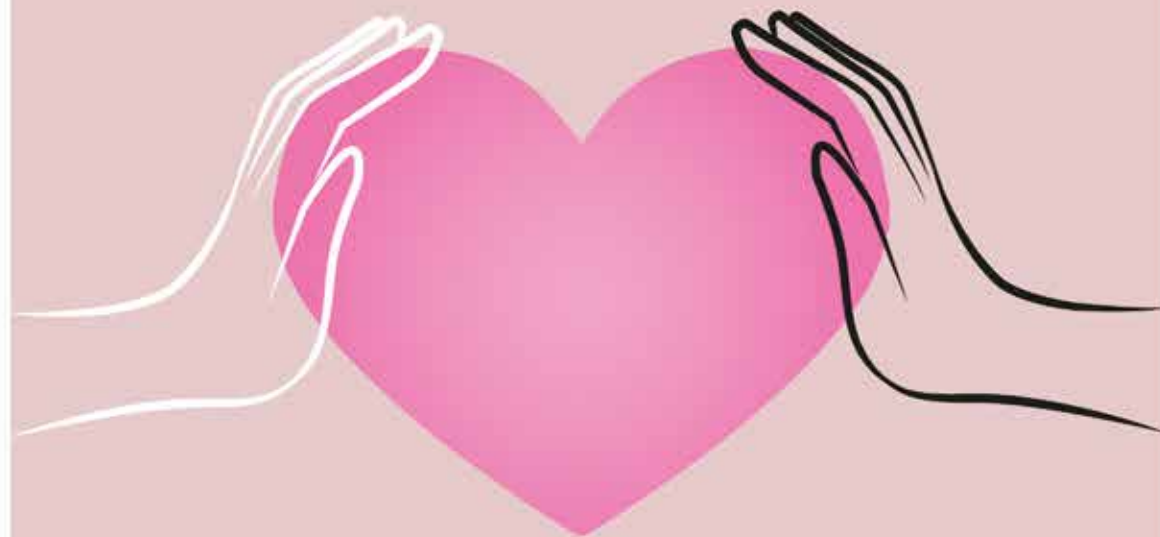
Moving Towards CIM as a Part of Comprehensive Care: Grantee Best Practices

Palliative care, including CIM, should be an available option as one component of a holistic care plan discussed with a provider upon an MBC diagnosis. Considering the rigor of their clinical treatment, options to relieve pain, reduce stress and increase appetite are critical to support patients and to ensure that they are strongly adherent to their care plans. Grantees found that working closely with providers is essential to integrate CIM into treatment. The co-located CIM services—or at the very least referrals—are important to help minimize the barriers patients face in receiving multiple types of care. Partnerships between medical providers and community-based organizations are essential to ease the transitions between clinical care and CIM—especially at the point in time when medical treatments are no longer effective.

In underserved communities, awareness of the spectrum of CIM options may be limited. Community outreach, education and information sharing are critical to ensure that women are aware of the resources available to them in their communities.



PSYCHOSOCIAL SUPPORT



CATEGORY THREE: PSYCHOSOCIAL SUPPORT

Theme Overview

Stress-related psychosocial factors are associated with poor survival in cancer patients overall (Chida et al., 2008). Patients with anxiety and depression demonstrate lowered adherence to medical treatment (Bender et al., 2014). A randomized clinical trial of early-stage breast cancer patients (Stage IIA, IIB, IIIA, or IIIB) showed that intervention to reduce psychological stress resulted in a reduced risk of cancer recurrence and death (Andersen et al., 2008).

However, patients with MBC have a different set of realities, needs, and concerns than those with earlier-stage disease. They often feel left out of or unwelcome in programs focused on early-stage breast cancer and survivorship (<http://advancedbc.org/node/26>), and often feel that their MBC-specific needs are not met. Cancer support groups can offer relief from isolation, societal stigma and rejection and provide a unique sense of community and unconditional understanding (Ussher et al., 2006). Unfortunately, few support groups exist that specifically meet the needs of patients with MBC.

Poverty, language barriers, and cultural practices also contribute to the growing disconnect between a patients' psychosocial needs and ability to access services. A patient's diagnosis may be confusing to their family members; even though an MBC patient may not look sick, family members may be uncomfortable with the diagnosis. Additionally, relating to one's partner during a time of illness presents major challenges.

A late-stage diagnosis may be especially stressful for patients and their families, give that there is no cure for MBC. This distraught may be exacerbated by psychosocial barriers, including lack of education and limited health literacy, limited income, finite understanding of English and inadequate insurance. These challenges may disrupt a family's functioning, particularly if the patient is a primary provider or caregiver within the household. An underserved MBC patient may not fully understand their diagnosis or treatment plan, may be unfamiliar with the cancer healthcare system, and may not understand their insurance coverage.

Physically weaker patients, particularly those who reside in rural areas and have limited income, may experience challenges to seeking care and psychosocial support outside the home. Furthermore, research indicates that African American and Hispanic women report greater need for psychosocial support (Moadel et al., 2007). Culturally-focused peer-to-peer support groups—either in person or via technology—build the foundation for spiritually and linguistically appropriate discussions and opportunities for relationship-building among those living with MBC (Ashing-Giwa et al., 2012). However, many of the vital psychosocial services needed to improve MBC patient QOL are not covered by insurance and are provided by community-based organizations that are oftentimes working with limited resources.

MBC Grantee Solutions

Many of the MBC Grants Program partners developed innovative approaches to addressing the barriers that patients face when seeking psychosocial support, including: support groups (both in person and virtual), engagement for couples and families working through an MBC diagnosis, depression screening and engagement with social workers. Seven programs provided psychosocial support for women living with MBC, their families and communities:

The Cancer Resource Center of the Desert (CRCDD), based in El Centro, CA (110 miles east of San Diego and 60 miles west of Yuma, Arizona, along the California-Mexico border), provides support to the rural underserved population in the area. Within its program, all 14 clients with MBC are female, many of whom are first-generation immigrants.

CRCDD provides culturally and linguistically appropriate social support groups, as well as practical and legal advice for MBC clients and their families and caregivers. Groups meet bi-weekly and are led by trained social workers. Based on previous programs designed for Stage I – III clients, **CRCDD found that their support groups decrease anxiety, depression, and fatigue, while improving overall QOL.** Beyond the peer-to-peer support groups, one-on-one counseling increases communication between the client and healthcare provider and provides financial assistance, information about clinical trials, and referrals to services beyond those provided by CRCDD—the organization takes a whole person approach in an effort to establish trust between patient and navigator. For clients, the program increases understanding of MBC, helps with insurance challenges, and empowers the client by allowing her to take control of her healthcare decisions.

Many participants found the most important part of the program to be the individual support received from their peers and by their social worker, emphasizing the fact that they are not alone.

“We learned the importance of support groups for MBC patients, a place where they can express themselves freely, support one another, brainstorm, and educate one another. The interaction between those women is amazingly supportive, compassionate, and helpful. Support group is where we saw the most growth with patients...While some were in denial, angry, fully accepting, and others somewhere in-between, our continued support and coaching helped them make forward progress.”

—Staff member, Cancer Resource Center of the Desert

City of Hope, based in Duarte, CA, supports MBC patients and their partners to make informed decisions about options for treatment and care. The organization initiated the Supporting Metastatic Breast Cancer Patients and Partners Program that supports 44 MBC clients and their partners as couples coping with MBC. A large part of coping with an MBC diagnosis involves both members of the couple having a clear understanding of the patient’s medical status and treatment plan. The program relies on the use of technology, specifically audio recordings, so that couples are aligned about treatment and care plans, and can continually reference discussions with their provider.

The first step in this program is providing each newly diagnosed MBC client with an inexpensive MP3 audio recording of the initial visit with her doctor. Because this first visit is usually overwhelming, the ability to replay the visit and extract additional information is very important for making informed decisions about treatment and care. City of Hope medical or social work staff members are available to answer follow-up questions after listening to the recording. The second step in the program is referral to a social worker who leads the Couples Coping with Cancer Together Program (offered in English now and Spanish in future years), which is also audio recorded and aims to teach couples how to support each other, provide tailored education, refer them to other resources, and reinforce the use of the audio recording from the physician visit. The couples will be asked to attend a focus group to assess the usefulness of the physician visit recording.

The goals of the City of Hope program are for MBC clients and their partners to become more engaged, informed, and supported when managing a cancer diagnosis and treatment. Although the program is open to all women with MBC, special emphasis is placed on assisting underserved patients such as low-income women, elderly women, or those with limited English skills (approximately 38% of the total MBC population at City of Hope). Throughout the program, 44 women and 39 partners have been screened for this program. The team saw that 34% of patients had income between \$40,000-\$100,000 and 41% of patients had income greater than \$100,000. In addition, 65% of patients and 62% of partners had a college degree or advanced education.

Patients reported that they were most grateful to have a resource that was tailored to their needs and immediate access to care if there was a problem or questions. Care coordination made patients feel as if they were in good hands.

EXAMPLE OF THE CITY OF HOPE TOOL IN ACTION: ALICE AND BILL

Alice is 58 and has been married to Bill for 24 years. They recently received custody of their three grandchildren (10-year-old twins and a sibling close in age), which in itself was a stressful and complicated process. Bill works as a manager at local plant and has a demanding, stressful job that often requires long work hours. Alice is a home-maker caring for the children and her husband, and she has always prided herself on her role. In the initial couple's session where the importance of communication was discussed, Bill verbalized fears related to Alice's ability to comply with medical recommendations given 1) the amount of work she did around the house, 2) her lack of communication with Bill about this, and 3) the fact that she had serious complications that required hospitalization. Bill told Alice that he often spends time at work worrying about her, making it emotionally difficult to manage work responsibilities.

They attended a Couples Group and shared the following story with others. Alice had been fatigued and was having a difficult day, unable to do as much as she wanted to around the home. She was also frightened about the next step in her surgical plan. She was starting to comprehend what a diagnosis of metastasis means and was experiencing fears of her own mortality. Alice tried to tell Bill this. He was supportive but told her not to worry so much and then went to work. Alice became angry, thinking that Bill did not hear or really care about her and began to ignore his regularly scheduled phone calls all day, causing him to become even more worried. He left work early and found Alice at home crying and angry. As he held her, Alice was able to tell Bill that when he just reassures her, it makes her feel alone and isolated and that it seems he is not listening to her. Bill then talked about how he feels powerless to relieve her suffering. He also talked about his Hispanic culture and how men are supposed to be strong and take care of their family and that he felt he could not do this for Alice. Because he felt inadequate, he had not really wanted to talk about how Alice was scared. Alice then told him that it makes her feel safe when he just holds her and listens—that he doesn't have to fix things. This was a powerful reminder to the group of their common experiences.

The Denver Health and Hospital Foundation in Denver, CO implemented a program designed to provide support to ethnically diverse, underserved women with MBC in the greater Denver area that may be experiencing depression or severe psychological distress. Prospective clients are identified by their oncologist and referred into the program. This pilot is based on an intervention that was studied in adjuvant breast cancer patients (Andersen et al., 2008) and is expected to improve QOL and survival, decrease depression, improve adherence to medical treatments, and improve tolerance of symptoms and side effects.

One element of the intervention is a monthly group meeting for MBC patients that aims to address the high levels of stress caused by the oftentimes overwhelming barriers to care. **During these meetings, patients receive a myriad of interventions to reduce stress, including: muscle relaxation, problem solving techniques to address fatigue and depression, strategies to identify supportive family members and friends, practices to assert one's medical and psychological needs to family and care teams, and guidance on diet, symptom management, treatment adherence, and maintenance of daily activities.** Simultaneously, a social worker helps clients individually to address barriers to adherence to medical treatment, including: child care concerns, loss of income, and the need for public food assistance, unemployment benefits, transportation, palliative care, end-of-life care, and additional patient and family counseling.

Gilda's Club of Northern New Jersey (GCNNJ), located in both Hackensack and Newark, seeks to bridge the gap between medical and psychological care. GCNNJ provides a comprehensive program for people living with MBC that includes:

- Individual counseling that takes place in the hospital to remove barriers to access by underserved patients;
- Weekly 1-hour fitness program customized for cancer patients that is designed to improve range of motion, posture, balance, strength, and emotional well-being; and
- Monthly educational series that addresses topics such as pre-treatment information and post-treatment coping strategies for patients with MBC.

Improved emotional health and physical ability are measured at enrollment and 6 and 12 months later through surveys of patients, healthcare partners, and facilitators.

The program aims to decrease stress, increase self-awareness, and improve levels of fitness. Approximately 40 women and their caregivers are participating, half of which are medically underserved. In Hackensack, about half of program participants are white, with a nearly equal split of African Americans and Hispanics, and a smaller proportion of Asian patients. In Newark, 73% of those served are African American, 9% are Hispanic, and 18% are white.





H. Lee Moffitt Cancer Center and Research Institute Hospital Inc., based in Tampa, FL, has begun a program called Metastatic Breast Cancer Identify, Amplify and Unify Support that seeks to reduce fear and anxiety in a safe, comfortable environment or remotely through the use of technology. The personalized, holistic approach has been developed with input from clients at every step, is customized for MBC, and is improving QOL and outcomes in women with MBC. This new, support group centered program is designed specifically for MBC clients and is based on a similar, highly successful program for women with gynecological cancer. The program includes targeted, proactive outreach to actively identify possible participants from underserved communities in the area and provide financial assistance to help remove barriers to attendance. In addition, MBC client and caregiver support groups, an event for MBC families with school-age children, tele-talks, and peer-to-peer support have been implemented as part of the program.

Given geographic isolation in rural areas of Florida, many of the program's participants were reassured just to know that there were others in the area also living with MBC.

The program recently hosted a retreat that was attended by 18 women with MBC. The retreat involved a cooking demo, yoga, makeovers, and performance art. The retreat allowed time for sharing and peer-support among a group of people who understand each other's situation. Another retreat is in the planning stages specifically for Latina women that will incorporate their specific cultural preferences, including ongoing family engagement through treatment and care.

Collectively, these programs aim to build a network of MBC patients and provide opportunities for them to share their experiences and receive support from others in similar situations. Over the course of the program, 60 clients were served.

METAvisor Research and Support Inc., based in Annapolis, MD, is working to establish peer-to-peer support groups that meet the unique needs of MBC patients. MBC patients often feel unwelcome in support groups designed for earlier-stage patients, given concerns that are unique and often not met by these groups. **Peer groups specifically for MBC patients provide a safe space without the need for explanation, offer a relaxing environment, and allow clients to feel less isolated and alone.** Members and their families will often assist each other with transportation, meals, emotional support, and respite for their partners and families in times of need. Although gatherings are not topic specific, they offer the opportunity for individual participants to bring up and discuss important issues such as access to healthcare, clinical trial information, role of palliative care, ending treatment and hospice, and sexuality. Some groups may wish to occasionally bring in guest speakers to discuss these topics. METAvisor specifically targets African Americans and Hispanics, younger patients and men with MBC, and those living in rural areas.

Sanford Health's network encompasses facilities in 126 communities across the United States, primarily in the remote areas of North Dakota, South Dakota, and Minnesota. Sanford's psycho-oncology and cancer survivorship departments have now established three process-based support groups for skill building and development of the mind-body connection (located in Fargo, ND, Sioux Falls, SD, and Bemidji, MN) for women with MBC called FOURward. **The rural setting presents a major obstacle for patients to access services, thus telephone and video conferencing are being used to better serve this population.**

In October 2015, Sanford Health held three 2-day breast cancer retreats. Topics discussed included connections with local resources, use of technology in cancer care, mindfulness for managing symptoms and fear, medical updates and research, helping loved ones deal with cancer, and self-advocacy. MBC-specific breakout groups and presentations were part of these retreats. The clients served are mostly in their 60s, but ages range from the 20s to the 90s. Over half are eligible for Medicare, Medicaid, or other government assistance. Most are either white or Native American. Goals include increasing the number of clients served, the number of process groups, and expansion of retreats.

Patients stated that having a safe space to share their fears and concerns was the most important part of this program. Given the very rural nature of the area served by FOURward, recruitment and virtual community building are top priorities for the program.

The youngest member of the FOURward group was a 24-year-old patient. At first, the facilitator of the group was hesitant to have such a young woman attend the group due to the intensity of the topics that are discussed there and one patient being close to death at the time when this patient was going to join. However, the patient benefited very much from coming to the group. She once stated: "What we talk about is really, really, really hard, but it isn't anything I don't already think about. It is nice to know that other people think about things that go on in my brain and to talk about them."

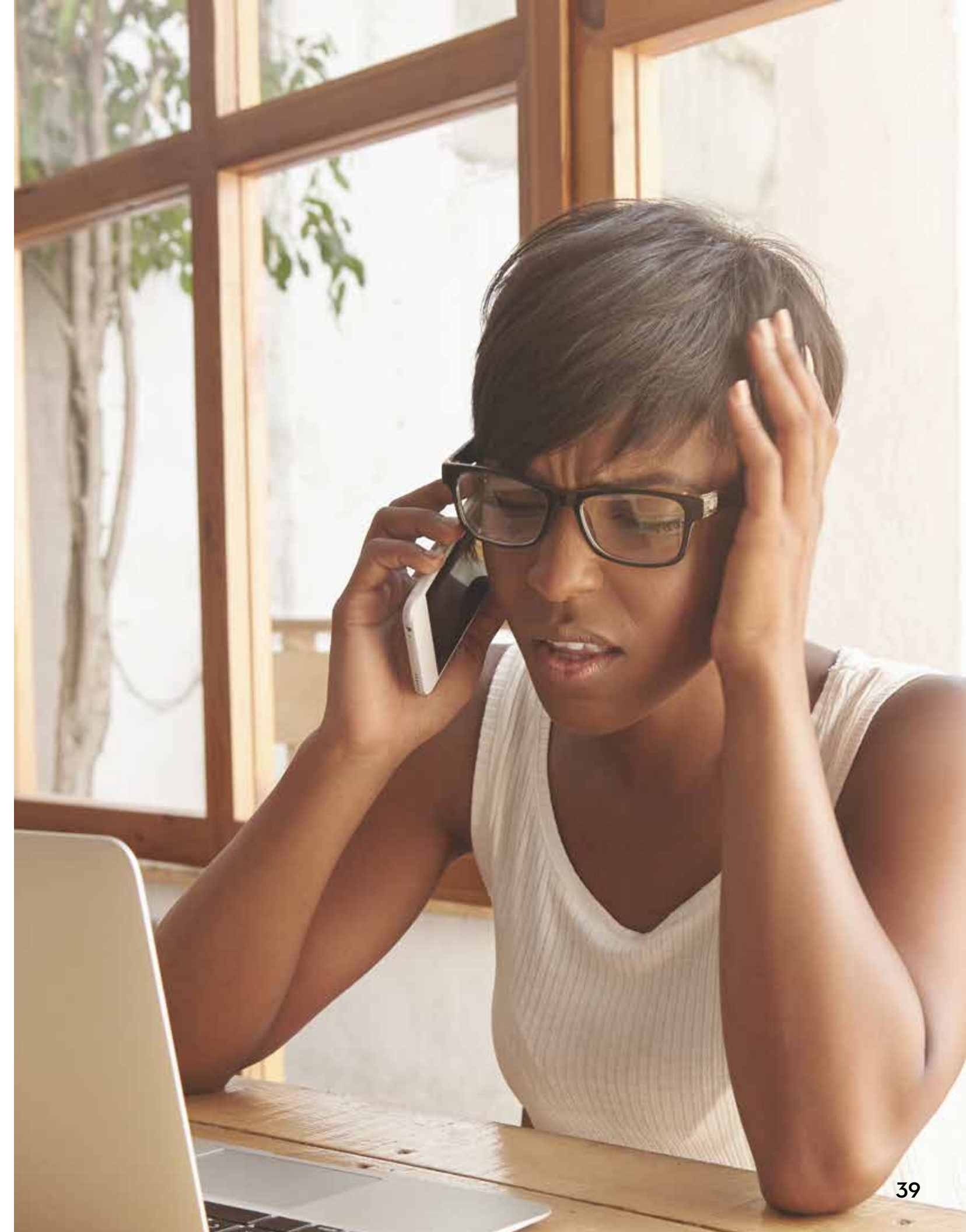
SHARE (Self-Help for Women with Breast or Ovarian Cancer Inc.) based in New York City, has a history of offering telephone support groups for women with MBC. These groups are more accessible than in-person groups to women who may be physically weak, have limited financial resources for travel, or who live in rural areas. Building on this experience, SHARE is now offering two additional groups: one for younger women (under 45 years), initiated by the Young Survival Coalition, and the other for Spanish-speaking MBC patients. The groups are led by a professional social worker and an MBC peer. SHARE conducts outreach via “metastatic slim jims,” postcards describing the support groups and services available from the organization. Spanish language “metastatic slim jims,” were printed for the first time, and 4,200 have been distributed throughout the five boroughs of New York City via various LatinaSHARE initiatives such as support groups, Survivor Patient Navigator services at New York City cancer clinics, as well as community centers, senior centers, and cultural organizations that are part of SHARE’s ongoing Ambassador outreach program.

Furthermore, in collaboration with Living Beyond Breast Cancer and the Metastatic Breast Cancer Network, **SHARE has expanded operation of a national telephone helpline that identifies peer matches for MBC callers and finds linguistic matches for Spanish and other language callers.** The helpline has now been expanded to include the medically underserved cities of Boston, Dallas, Denver, and Memphis, which the 2014 Racial Disparity in Breast Cancer Mortality Study, a national study published by Sinai Urban Health Institute

and Avon Foundation for Women, identified as among the top U.S. cities with the largest disparities in breast cancer mortality for African American women (Hunt et al., 2014). Taken together, these programs allow SHARE to serve more medically underserved women, including African Americans, Latinas, and women in rural areas, both in the New York City area and across the US.

Diane first called the SHARE helpline in December 2012. She had been diagnosed with early stage breast cancer and had 5 positive lymph nodes. She was terrified that she would die and leave her two children. In that first month, Diane called the helpline 10 times. About a year later, Diane was diagnosed with metastatic breast cancer. From the date of diagnosis in December 2013 until her death in October 2015, Diane had 115 calls to and from the helpline.

Diane’s story shows how women who reach out to SHARE are able to receive ongoing and evolving support that is individualized and personal. Women like Diane are able to rely on SHARE’s support services over the course of many years from an early stage diagnosis through the last months of metastatic disease.



Challenges to Providing Psychosocial Support for MBC Patients and their Families

These innovative psychosocial support programs engaged MBC patients where they are located—especially important, given that many are physically weak, live in remote areas without immediate access to services, and face other barriers to seeking these services in addition to their clinical treatment. Grantees had varying experiences identifying MBC patients through traditional referral systems; some had difficulty finding these patients, while others were overwhelmed by the sheer number of individuals seeking support. For community-based organizations not part of the medical system, integration of psychosocial services into treatment plans has been difficult—further provider referrals are needed to ensure that patients are aware of their options for this essential holistic care and support.

Grantees indicated that many of the patients that greatly need psychosocial support face denial, depression, and other psychological obstacles that prevent them from seeking these types of services to improve their overall health. Fatalism about an MBC diagnosis can prevent patients from seeking psychosocial services that they may really need.

Language barriers present major challenges for MBC patients, as many supportive services are provided in English only. One grantee stated that for these complex patients, “We don’t have English-to-English down yet,” emphasizing the urgent need for improving the basic delivery of psychosocial services.

Peer-to-peer groups also reported challenges with members or group facilitators being too ill to participate or ultimately dying from MBC. This very real challenge further underlines the difficult nature of MBC.

Grantees also found it difficult at times to actively engage caregivers, as many were in denial about their partner’s disease and did not know how to provide support.

Providing Psychosocial Support: Grantee Best Practices

Grantees emphasized that psychosocial support for clients with MBC is essential not optional. MBC patients have unique needs that require culturally, linguistically, and disease-stage appropriate support in one-on-one and in peer settings. Being able to connect with others in the same situation is invaluable. These programs recommended that psychosocial support for MBC patients be included as part of the standard of care, requiring provider training and awareness to ensure timely referrals.

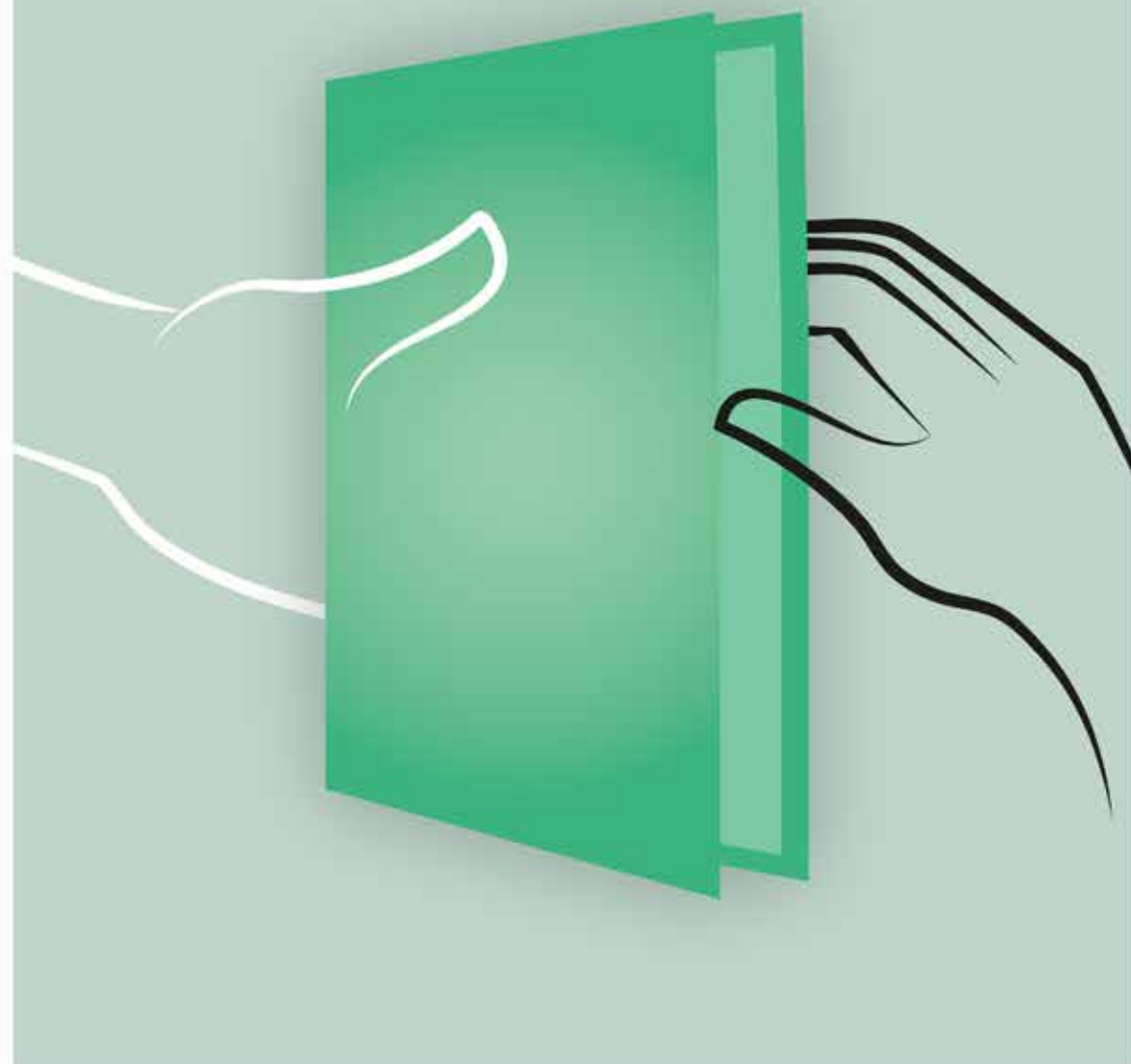
Grantees shared success with use of technology to provide resources to patients and providers. Best practices include training providers online, which can be less costly and time consuming. Use of phone or video technology allows support groups to accommodate patients living in rural areas and those with limited ability to travel. Patients and families need to have access to the proper equipment in order to access information via technology. Programs also found in-person, intensive retreats to be empowering for patients as they move through their treatment and care.

Finally, engagement of the whole family is vital to further adherence to care plans. Partners, children, caregivers, and other members of the family and community should be invited into safe spaces to learn how they can best support their loved one with MBC, as well as each other as part of the overarching MBC community. For MBC patients who are single or do not have immediate family in the area, ongoing peer-to-peer support critical. Finally, grantees emphasized the use of self-paced, flexible modules, as patients and their families move through a diagnosis, treatment and care at a varied pace.

Further learnings include the need to address dying in cancer care to decrease the isolation experienced by MBC patients. This insight is also essential for facilitating a shift in provider’s perspective and comfort as they work with patients who are going through the dying process. This may mean that at times throughout the course of MBC, non-clinical intervention is the best choice for a patient. Increased provider understanding of the MBC patients’ journey has the potential to improve the patient-physician relationship and remove the feeling of abandonment that some MBC patients experience as they progress through their care.



EDUCATION & INFORMATION



CATEGORY FOUR: EDUCATION AND INFORMATION SUPPORT

Theme Overview

A MBC diagnosis can be overwhelming and confusing for patients and their families. A vast amount of continually updated medical information about the early stages of breast cancer is available, but there is a dearth of patient-focused materials for those with MBC.

When MBC patients and their caregivers are informed about the disease, they are able to play a greater role in shared decision-making with their healthcare providers. This results in a more empowered patient who has more control over their QOL. Education and information should be tailored to patients with MBC and should be user friendly, culturally and linguistically appropriate, and readily accessible.

MBC Grantee Solutions

Breastcancer.org, based in Ardmore, PA, provides reliable, accessible, complete, compassionate, and current information about breast cancer. **Recognizing that the journey of each person with MBC is unique, Breastcancer.org developed My Breast Navigator, a program that provides personalized medical and practical support information that is relevant to an individual based on their diagnostic and treatment profile.** As part of the MBC Grants Program, My Breast Navigator expanded to deliver additional personalized information about topics specifically related to MBC including diagnosis, treatment options, clinical trials, managing fears, and more. Content delivery includes research news articles, long-form medical and practical content, podcasts, and blog posts. This program empowers the user and provides knowledge, increases confidence and prepares the user to ask his or her doctor questions. This improved the role the patient plays in conjunction with his or her healthcare team to make decisions about care.

Information from My Breast Navigator requires minimal health literacy and is culturally appropriate, while tailored to both patients and caregivers. Approximately one-third of users are considered medically underserved. The content provided is now responsive for all mobile devices, which is important because underserved populations including young people, Latinos, and African Americans are more likely to have mobile internet access via a cell phone (<http://www.pewinternet.org/fact-sheets/health-fact-sheet/>) compared to other devices.

Living Beyond Breast Cancer in Bala Cynwyd, PA established the Hear My Voice program to address psychosocial and educational needs of women living with MBC across the country. **This digital peer outreach program provides services, information about new treatments and clinical trials, and a related public education outreach campaign.** Thirty-one outreach volunteers with MBC across the country were trained—35% reported household incomes below 250% of the federal poverty line, six are African American, two are Asian or Pacific Islander, and 23 are white. Four volunteers live in rural communities. Volunteers led outreach projects to reach other MBC patients and their families on topics including: personal or organizational outreach, media and social media outreach, and scientific outreach and education.

Hear My Voice also included a social media campaign on September 21, 2015 with the goals of reducing the isolation of people with MBC and to increase public knowledge by developing blogs, short videos, and social media content. During the campaign, Hear My Voice was featured on a radio program in Philadelphia, PA that reaches an audience of many low-income, African American women. Throughout the interview, the team discussed disparities in the MBC population, connected listeners to the Hear My Voice site, and tweeted messages about Beyond the Breast, a campaign aimed at informing the public about the experience of living with MBC.

Participants found the connection to one another and the education they received from the LBBC staff about metastatic breast cancer to be most helpful. They appreciated learning about the resources and organizations serving those with MBC, and expressed deep gratitude for investing time and education in them as the MBC patient population is often overlooked.

“My own voice became so much stronger when it was part of a larger group. In the past year, I found and defined what my personal metastatic advocacy voice is. I have more knowledge and wisdom. I am gaining perspective and gaining wisdom from the other voices...I learned so much and got hope and encouragement. I really appreciate that.”

—Lesley, Hear My Voice Program Participant



The West Cancer Center (a partnership of Methodist Healthcare, West Clinic, and the University of Tennessee) in Memphis, TN, developed a program specifically for clients with MBC called The Patient Companion for Metastatic Breast Cancer Patients. This compilation of resources provides patients with an introductory education from physicians and social support team members, online support groups led by nurses and social workers, and a Patient Companion Library that provides MBC-specific information. The program aims to increase awareness of available services, decrease stress, and increase the geographic reach of services for MBC clients. The program reaches medically underserved women in the Memphis area: approximately 51% African American and 53% of the target population having an annual household income less than \$50,000.

One woman diagnosed with metastatic breast cancer had delayed seeking treatment because she faced many barriers to care; she was uninsured, unemployed, and had very little income. Through the patient navigator program, she was connected with a navigator who worked with the physician staff, chaplain, and educator to provide information on the importance of her treatment, the funding that was available to help her, as well as what breast cancer really was. She didn't understand why she should get treatment when she had no money to pay for it. The team worked with the patient to ensure that she was compliant with her treatment. Unfortunately she succumbed to the disease, but she had received 6 chemotherapy treatments and was undergoing radiation therapy.

Memphis has the highest disparity in breast cancer mortality rates between African American and white women (Hunt et al., 2014; Metropolitan Chicago Breast Cancer Task Force and Avon Breast Cancer Crusade; http://www.uthsc.edu/CHEER/documents/CHEER_Breast_Health_Summit_Program.pdf), and thus, the need for education in this population is high. **Individuals with MBC are identified in the clinic by patient navigators and through the Congregational Health Network, a covenantal partnership with 600 faith congregations.** Partnerships between hospital navigators and congregation liaisons function to connect these women with MBC to the services provided by the West Cancer Center and referrals to outside services.

Patient Advocate Foundation Inc., based in Hampton, VA, works to ease financial burdens by assisting clients with insurance issues, which can be overwhelming for the client and family. Up to 40% of MBC patients survive up to 5 years post-diagnosis,¹ allowing the disease for a time to be managed as a chronic condition. **Patients with MBC may face difficulty staying both employed and insured, and face increased financial burden as treatment is prolonged. Sustained access to financial resources, especially insurance, is critical for MBC patients and their families, and allows continued access to care.**

1. <http://www.webmd.com/breast-cancer/features/metastatic-breast-cancer-chronic-condition>

The Patient Advocate Foundation developed The Metastatic Breast Cancer Guide, which focuses on an overview of insurance for newly insured or uninsured clients. These tools empower patients to address insurance issues on their own, with any needed support from the Patient Advocate Foundation. The campaign includes the newly revised Managed Care Answer Guide, written in plain language and focused on: insurance eligibility and enrollment; understanding and navigating plan provisions; and explanations of payment methods, benefits, and appeals processes.

The MBC Guide also includes information on cancer-related employment concerns; access to medication, medical devices, clinical trials, etc.; special considerations for caregivers of MBC patients; support networks for both MBC clients and their families; treatment options; decision-

making support; and other topics. The MBC Guide is available in both English and Spanish and was initially introduced in North Carolina, South Carolina, and DC, regions with high breast cancer incidence and mortality rates, but has since been disseminated nationally. Over the course of the project, Patient Advocate Foundation has assisted 897 women with advanced breast cancer (Stage III or IV).

Over the course of the project, 51% of patients reached were Caucasian, 27% were African American and 14% were Hispanic/Latina. Almost a third of patients served (31.0%) reported being unemployed, 21.4% of patients were still actively employed, and more than a third of patients (37.0%) met the guidelines to be deemed disabled by social security administration. Retired women made up the remaining 13.3% of patients.



PATIENT ADVOCATE FOUNDATION

A 60-year-old Hispanic woman who lives in Texas was referred to PAF by another national non-profit organization. She had been diagnosed with stage IV breast cancer in 2002, and experienced metastasis to the bone in 2009. She lives alone on \$1,078 a month from social security disability payments. She was struggling to afford her co-payments for her medications as well as her doctor's visits. The PAF case manager was able to assist the patient with enrolling into a co-pay assistance program, as well as identifying a national transportation program that offered financial assistance for trips to her provider's office which was 80 miles round trip. The patient was able to apply for three additional support funds to help offset expenses, allowing her to continue treatment. The case manager provided the Metastatic Breast Cancer Guide and the Coverage Access Guide to the patient to help educate and inform about other disease specific healthcare tips that can reduce barriers in the future.

Young Survival Coalition (YSC), based in New York, NY, works with women <40 years old with MBC. This population faces unique concerns including impact of breast cancer on their romantic/sexual relationships, adoption and fertility, speaking to young children about MBC, career development and future earning potential, insurance concerns, not knowing how to connect to other young women, and a lack of awareness of their needs in the medical community. YSC updated its 138-page guide called *Metastatic Navigator: A Young Woman's Guide to Living with Metastatic Breast Cancer* with the goal of increasing a young woman's understanding of managing MBC. Updates to the electronically available guide include: user-friendly information about MBC; emerging treatment options and research results; methods of effective communication with healthcare teams; insurance; financial assistance; ways to improve QOL; end-of-life planning such as living wills, powers of attorney, hospice, guardianship considerations, and legacy projects; and various tools to help busy women stay organized.

YSC serves approximately 3,500 young women with MBC, all of whom are considered underserved because they are a minority of patients with breast cancer and little research focuses on this group.

Challenges to Providing Education and Information to MBC Patients

MBC patients and their families are in need of further resources and materials to help them understand this difficult disease. Grantees found that they needed to make information as accessible as possible—all education needs to be lay-friendly, assuming low levels of health literacy and in a number of languages. Programs found that MBC patients use various types of technology and may not have access to certain types of devices. For instance, one grantee found that women were more likely to seek information on smart phones because they did not have internet service in their homes.

Grantees struggled to obtain feedback on content from program participants, particularly as it relates to the information provided by other providers as part of a multi-faceted treatment plan. Finally, partners shared the overwhelming demand for their programs, as the population of MBC patients increases.

Sharing Education and Information on MBC: Grantee Best Practices

Information and education provided to people with MBC and their family members should be: focused on late-stage disease, based on input from patients, rooted in evidence, accurate, current, reasonably concise, easy to understand,

accessible, sensitive, personalized, and linguistically, spiritually, and culturally appropriate. Given the variety of ways MBC patients may access information, education materials should be available electronically and optimized for mobile devices when possible, as well as in print. Grantees found that clients in need of education and information can be identified while receiving treatment in clinical settings, as well as through social media, minority-specific outreach programs, and faith organizations. Currently, 87% of American adults use the internet (<http://www.pewinternet.org/fact-sheets/health-fact-sheet/>), and Latinos and African Americans are likely to access the internet with a cell phone (<http://www.pewinternet.org/fact-sheets/health-fact-sheet/>). For users who receive information electronically, grantees recommend that users keep their profiles up to date to allow delivery of timely, appropriate content. However, grantees said to know your population—some patients prefer community-based, in-person communications and may not have readily available internet access to get messages through online platforms.

Grantees found that MBC patients are eager to define action items, particularly for advocacy around MBC. Women with MBC are often interested in reaching out to the public about this disease and sharing their experiences and stories, creating a network of people with MBC and raising the visibility of MBC issues.



CLINICAL TRIAL DATABASE



CATEGORY FIVE: METASTATIC CLINICAL TRIALS SEARCH

Grantees reported that patient access to MBC-specific clinical trials is an important, yet unmet, need. Clinical trials present an important opportunity to create improvements in MBC treatment options, yet fewer than 5% of adult cancer patients enroll in trials (Doroshov, 2013).

Throughout the course of treatment and care, providers may not readily share information about clinical trials, and MBC patients may not consider engaging in their own clinical trial search. Participation in clinical trials is inconsistent across the population of MBC patients. Young women tend to join trials more often than older women. African Americans and Latinas enroll in trials less frequently than white women (Murthy et al., 2004). Given that tumor biology and breast cancer outcomes may vary by race, it is important to ensure that all MBC patients have complete and accurate information about clinical trials (Carey et al., 2006). Furthermore, MBC patients interested in clinical trials should have the opportunity to ask questions about participation with those they trust, oftentimes peers or members of their community.

“Every advance in breast cancer care has been the result of a clinical trial. As trial participants, patients gain access to new and innovative therapies while at the same time helping to improve care for the whole community.”

—Elly Cohen Ph.D.
Program Director,
Breastcancertrials.org

MBC Grantee Solutions

BreastCancerTrials.org (BCT) obtains and curates trial details from ClinicalTrials.gov and the NIH’s National Cancer Institute Physician Data Query (NCI PDQ), presents the information in an easy-to-understand format, and matches patients with trials. Patients submit a detailed profile including: breast cancer stage, biomarkers, sites of disease, age, gender, and menopause status.

To increase access to information about clinical trials, BCT partnered with five trusted advocacy organizations (Metastatic Breast Cancer Network, Young Survival Coalition, Triple Step Toward the Cure, Breastcancer.org, and Living Beyond Breast Cancer) that already reach underserved MBC patients through their online platforms. BCT embedded a form on each site that requests information about a woman’s health and background, then provides lists of possible clinical trials that she might be interested in investigating further.

The output from the trial search is a user-friendly description of the trial that includes the purpose of the research, patient population being studied, study plan, participant requirements, and contact information. To further increase awareness of enrollment opportunities, BCT hosts a webinar to assist advocacy groups with their clinical trials page, installs the mini-forms, repackages BCT educational content, and trains staff about clinical trials.

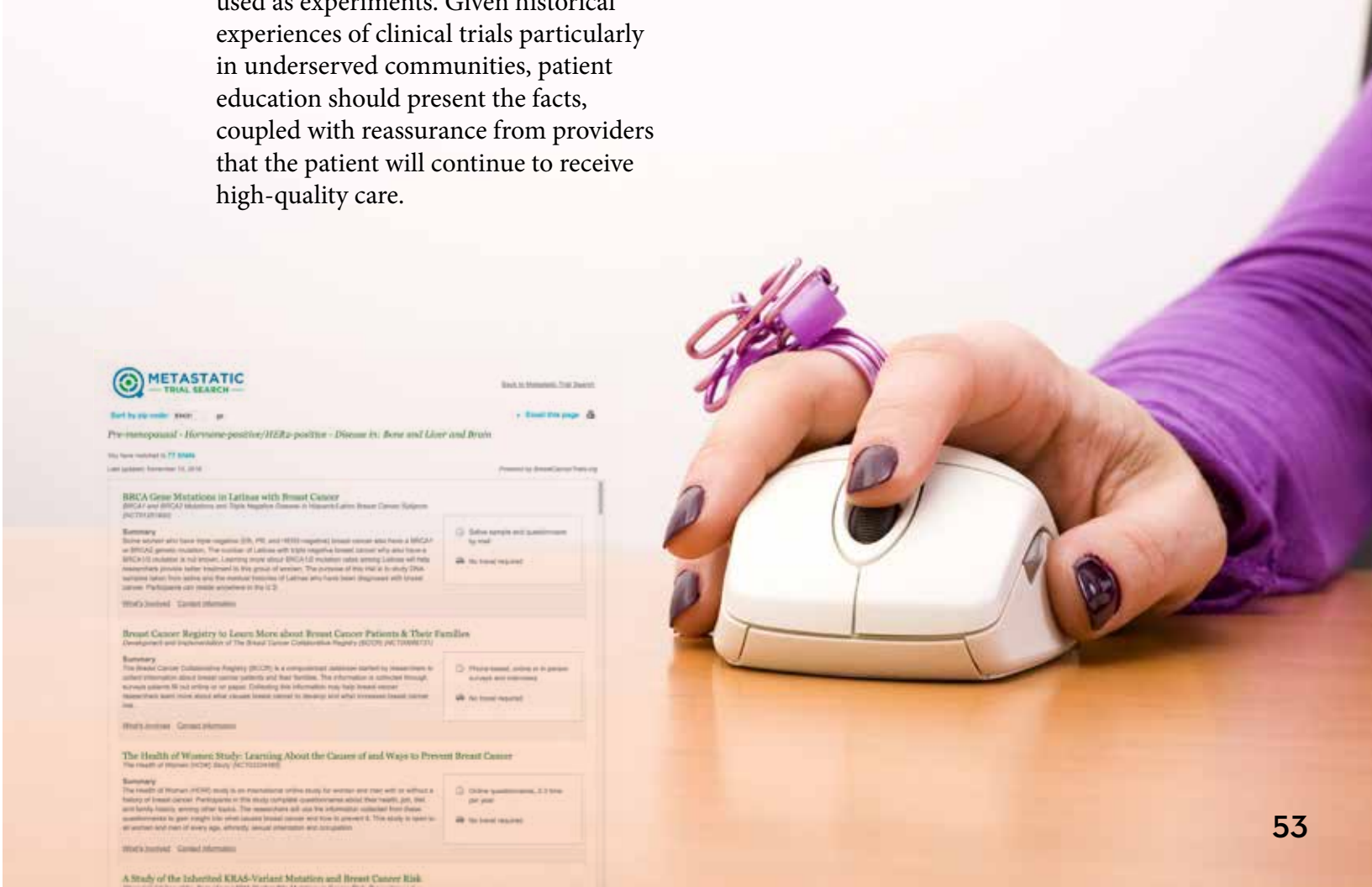
Through this project, BCT and its advocacy partners want to spark conversation about MBC clinical trials and encourage consideration of clinical trials among all patients and providers.

Challenges to Increasing Linkages to Clinical Trials

BCT encountered a few challenges as it increased its reach to MBC patients. The team faced difficulties integrating platforms on advocacy partner websites; interoperability issues must be addressed to ensure that the form can live on a variety of websites. From the outset, sustainable partnerships and training specifically for advocacy organizations are needed so that communities are hearing about the clinical trial resource from individuals that they trust. Finally, BCT learned that they need to provide guidance to advocacy partners to address patient concerns and perceptions of clinical trials and create a safe space for those living with MBC to consider their options. Some MBC clients have felt pressure to participate in a clinical trial and have felt like they were being used as experiments. Given historical experiences of clinical trials particularly in underserved communities, patient education should present the facts, coupled with reassurance from providers that the patient will continue to receive high-quality care.

Increasing Access to Clinical Trials: Grantee Best Practices

As BCT plans to expand their clinical trial matching program, they will continue to work with advocacy partners who can encourage participation within the communities they serve. The program underlined the importance of working with stakeholders across the continuum of care from providers to those in the community. One area where BCT plans to further their work is with providers as they engage in culturally sensitive, historically aware conversations with patients about the benefits of participation. They also plan to engage other online networks where patients may go for information and support.



MEDICATION ASSISTANCE



CATEGORY SIX: MEDICATION ASSISTANCE

Theme Overview

Treatment for MBC requires many types of medications from chemotherapy to medication designed to mitigate the side effects of clinical care regimens. Many medications are very expensive and difficult to obtain at a community-based pharmacy. Although assistance is available to help defray drug costs, often multiple applications for assistance—even one for each medication—must be completed. This can be especially difficult for underserved patients who lack English skills or guidance on how to complete such paperwork. Delays or inability to obtain medications can lead to fragmented care, poor adherence to treatment plans, lower QOL for patients and families, and higher mortality rates.



MBC Grantee Solutions

HarborPath, based in Charlotte, NC, is developing a web-based portal to distribute necessary, non-generic, oral medications to treat MBC to low-income, underinsured MBC patients at no cost. Based on a previous effort that provided free medication to those living with HIV/AIDS, HarborPath is partnering with pharmaceutical companies to receive donations of their medications, which they can then provide to patients. Mirroring the experience of the HIV/AIDS patient portal, HarborPath will aim to fill and ship patient orders within 48 hours, as compared to the typical 2-6 weeks required for traditional prescription assistance.

HarborPath envisions the development of partnerships with community-based healthcare facilities that work with

underserved patients, and plans to help them access the portal and apply for medication assistance on their patients' behalf. Upon release, the portal will serve women living in Southern states. Given the importance of this service for those living in remote areas, it is envisioned that the portal may eventually serve many around the country.

Challenges to Increasing Access to Medication

Though this portal is based on the existing model that HarborPath used to distribute medication to HIV/AIDS patients, the team has found that each disease has its own unique challenges. Since many MBC-specific treatments are continually changing, a variety of industry and academic partnerships are essential to make new drugs available at no cost as soon as they are ready for

patient use. Given that MBC patients are in regular need of new line drugs as their disease progresses, HarborPath must ensure that a supply chain is built for a multitude of medications. The team has had great success getting oral therapies to patients, but has faced difficulties getting intravenously administered drugs to patients.

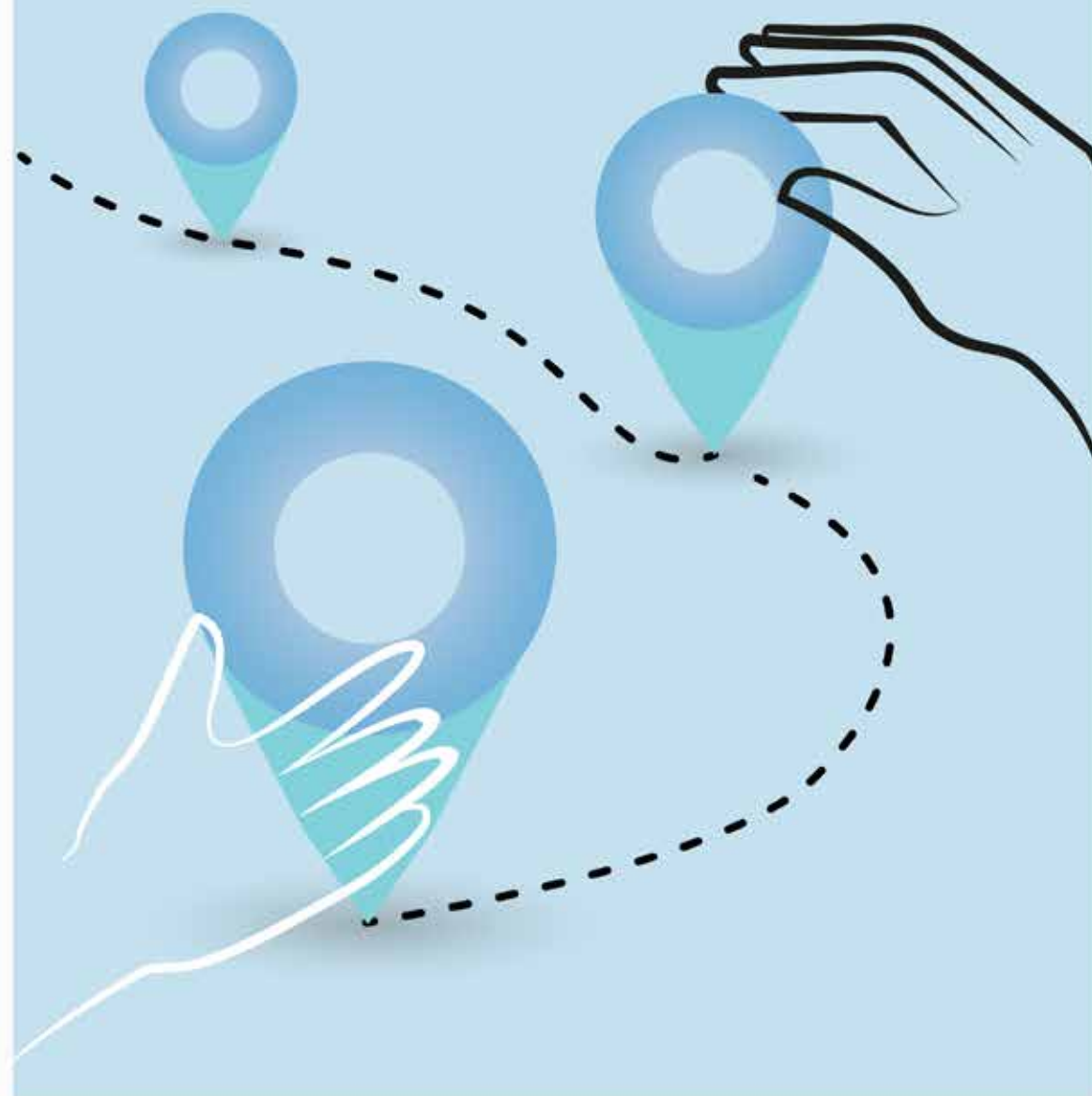
Currently, the portal can be used in a limited geographic catchment, but additional capacity is needed to distribute medication to as many individuals as possible. Grantee indicated the challenges that some patients face as their personal safety is compromised by those who desire to steal medication for private

sales on the black market. This is a major concern for patients who should feel safe obtaining needed treatment.

Increasing Access to Medication: Grantee Best Practices

Building on its previous best practices for distributing medication at no cost to HIV/AIDS patients, HarborPath is testing the model in other areas including cancer care. Strong partnerships across the continuum of care are vital to ensure that patients and providers are aware of the service. Some medications are more suited towards mail-order model, and further focusing on a full mix of available therapies is next for HarborPath.

PATIENT NAVIGATION SUPPORT



CATEGORY SEVEN: PATIENT NAVIGATION SUPPORT

Theme Introduction

Conceptualized by Dr Harold Freeman in the 1990's at Harlem Hospital in New York City, patient navigation was developed to support cancer patients as they maneuver through the complex maze of cancer screening, diagnostics, and treatment (Freeman et al., 1995). Initially, patient navigators focused primarily on early detection, by conducting outreach in underserved communities to raise awareness of breast and colon cancer screenings. Upon recruitment to a screening, patient navigators would monitor results and follow up with patients who required additional screenings and subsequent appointments.

Shortly thereafter, navigators expanded their work across the continuum of care by helping newly diagnosed patients through the acute phase of treatment and into survivorship (Shockney, 2015). For MBC patients, navigation includes linkage to palliative care options and services specific to end-of-life care.

MBC patients require support for a terminal illness that presents differently over the course of treatment, meaning that navigators must connect patients to a continual cycle of treatments, scans, and change of treatment plans from the time of diagnosis until end-of-life. This cycle is often referred to as "Scan, Treat, Repeat" (Metastatic Breast Cancer Network). Navigation is particularly needed for MBC patients in underserved communities who may also need social support beyond the clinic walls.

MBC Grantee Solutions

Four grantees furthered the patient navigation model to address the unique needs that MBC patients face as they move through the fragmented healthcare system:

“A woman was screened and eventually diagnosed with MBC through the cancer services program 4 years ago. She never responded to our in-reach efforts at the beginning of this project. One day, she comes in to renew the insurance we helped her secure. After talking to us about the new MBC project, she reveals that her husband was recently hurt on the job and could no longer work. They were struggling to live off his disability.

We were able to connect her with a variety of resources, like HEAP (Home Energy Assistance Program). Ultimately, she received financial assistance to pay for her rent and utilities. We learned that even after working with people for years, you may not know their whole story. We learned that many people won't volunteer critical information. You have to ask the right questions. For example, instead of “Are you able to feed yourself?” we need to ask first “Do you have food at home?”

—Staff, Central Suffolk Hospital



Central Suffolk Hospital and Peconic Bay Medical Center on Long Island, NY implemented the The Taking Care of You initiative, which expands an existing program for breast cancer patients to include clients with MBC, specifically those with language- and insurance-related barriers. Of the clients served, 95% are considered medically underserved. The program provides bilingual services to serve the large number of Spanish-speakers in the area.

Bilingual navigators specifically focus on helping underserved MBC clients seek palliative care, including pain management and psychosocial support, as patients are not always aware that these services exist. **In consideration of cultural preferences, navigators open program services to families, as oftentimes shared decision making is vital to moving a client's care plan forward.**

The program includes assistance in traversing the medical system through clinician engagement to ensure that treatment plans are well understood by the patient. The program provides referrals to community resources (eg, legal aid, home-based assistance), clinical trials, and support groups (one-on-one and group based). To further support patients in the geographic area, Central Suffolk Hospital partnered with the Breast Cancer Coalition to provide patient transportation.

Shanti Project Inc., based in San Francisco, CA, provides holistic, client-centered Care Navigation for underserved women with MBC. Care Navigation includes: patient advocacy, translation services, linkage to medical care teams at hospitals and clinics, emergency resource coordination, application assistance for community resources and referrals to assistance organizations (e.g., financial support, food, housing, counseling), taxi vouchers, appointment accompaniment, and weekly in-home visits.

Care Navigators support clients as they complete paperwork, schedule follow-up services, communicate with providers, access educational materials, keep medical appointments, and receive emotional support. High-intensity, one-on-one navigation services have been provided to 42 MBC clients; 90% live at or below 200% of the FPL, 36% percent of our MBC clients are unstably or marginally housed. Most receive their health insurance from Medical or Medicare (66%).

Additionally, care navigators work with clients reaching the end-of-life and support their families to make home or hospice visits and funeral arrangements. During and after treatment, clients can participate in Health, Wellness & Survivorship classes and workshops. Topics include nutrition workshops (in Cantonese, Spanish, and English), art therapy classes, mind-body healing, weekly massage, reiki, and yoga. Over the course of the project, all MBC patients received Care Navigation services in their preferred language.

Juana was referred to Shanti by SF General Hospital in 2009 when she was 32 and her children were 15 years old and 8 months. She is a single mom who lives in a basement apartment in San Francisco. Spanish is Juana's first language, but she also speaks some English and is an undocumented immigrant. She was matched with a Care Navigator named Millie. Initially, she had Lumpectomy surgery and went through chemotherapy, radiation, and hormonal treatment for 5 years.

Her Care Navigator helped her access financial assistance, alternative care, a support group for Latinas, taxi vouchers, and grocery support. Millie also attended medical appointments and provided emotional support. With this support, Juana was able to attend to her health and support her young children.

In October 2015, Juana called her Care Navigator crying—she now had metastatic breast cancer Stage IV. Her cancer had spread to her liver, spine, spleen, hips, and lungs. She is now receiving her medical care at UCSF.

Immediately, her Care Navigator renewed her referrals for financial, food, and transportation support. She provided her with taxi vouchers. She visited Juana at home and accompanied her to her doctor appointments and tests. At the doctor appointments, Millie helped Juana prepare questions regarding her concerns about her treatments. She also facilitated conversations between Juana and her doctor. She provided her with emotional support and talked with her about her feelings.

While accompanying her to one of her CAT scan appointments, Millie noticed Juana was having a lot of physical symptoms. The appointment took 4 hours and Juana had not eaten. When they were finished with the appointment, they shared a meal. Juana talked freely about her life including her concerns about who will care for her children after she dies. She thanked Millie for the all the time she spent with her.

The Breast Cancer Resource Centers (BCRC) of Texas Inc., based in Austin, Texas developed a Metastatic Patient Navigation Program to provide long-term support to those with MBC. The program provides one-on-one consultations wherever and by whatever means the client feels most comfortable, identifies barriers to care, and refers clients to supportive resources. BCRC navigators are familiar with each client's situation and act as a constant throughout a patient's treatment and care. **Navigators provide integrative therapies and conduct support groups, specifically designed for MBC clients to learn to advocate for themselves.**

In response to client requests, BCRC created the Breast Cancer Companion, featuring MBC-specific information. Moving forward, experts will provide additional information to enhance the companion. Additionally, BCRC provides assistance to address two other gaps: financial and transportation barriers.

Of the 152 women with metastatic disease served by the program, 68% were White, 16% Latina, 5% Black, 5% Asian, 26% live below 200% FPL, 70% are younger than 65 years of age, 3% are uninsured and 17% are enrolled in health access programs for low-income populations.

Over the course of the project, 136 clients expressed psycho-social issues (a total of 544 instances). Of these women, 126 were able to confront all of their psycho-social issues (95%).

Beth is single and cares for her elderly father. Her navigator is the first person she calls for reassurance. For example, Beth has a specific prescription schedule. One day she realized she was off of the schedule by a day. It was a weekend, so she called her patient navigator in a panic. Her navigator was able to calm her anxiety until Beth was able to contact the doctor when their office opened. At Beth's request, her patient navigator attends doctor's appointments with her to take notes and "be a second pair of ears." Because it is hard to take in all of the information she receives at these appointments, Beth uses her navigator's notes to help her process the information at a later time. Her navigator provided her with a copy of the Metastatic Companion to act as a reminder of the information she has learned and to be a resource when Beth encounters new, unfamiliar information. Most importantly, Beth has taken advantage of several step-by-step guides included in the Companion such as how to update your will. Because Beth has a small personal support system, she has leaned on BCRC for companionship, transportation assistance, housecleaning services, and food delivery—all provided through BCRC's As Sisters volunteer program.

Yale-New Haven Hospital in New Haven, CT operates the Bridging the Care Continuum: Underserved Women with Metastatic Breast Cancer program. The program features a medical oncologist and bilingual nurse coordinator who support underserved women as they move through their treatment plans at Yale-New Haven Hospital. Many of the program's clients encounter physical, financial, psychosocial, and language barriers to medical care. Throughout the program, 28 women with MBC were served; 25% were African American, 10.7% Hispanic, 7.2% Asian Pacific Islander and 53.6% Caucasian. There were 32.2% on Medicaid, while 17.8% were Medicare and 50% had private insurance.

In this navigation program, the client's oncologist works closely with a bilingual nurse coordinator to help patients and their families navigate the complex care required and allow them to make informed healthcare decisions consistent with their needs, values, and cultural preferences. **The nurse coordinator serves as a consistent contact for clients and their families, helping the client adhere to their care plan by ensuring coordination across the continuum of care within the hospital and beyond.**

Challenges to Including MBC Clients in Patient Navigation Programs

As stated throughout this paper, grantees emphasized that MBC patients have unique needs that may be more extensive than those patients with earlier stage disease. That said, patient navigation for these clients must provide linkages to a number of services beyond just clinical care, requiring existing navigation programs to create new connections with potential referral sources like palliative care.

A persistent challenge will be to help providers re-conceptualize MBC as a chronic condition versus a terminal illness, to bolster the understanding that clients indeed need services beyond medical care and emotional support. For patients who are not receiving care at a comprehensive cancer center, providers and navigators must work together to ensure that MBC patients are receiving support through community-based organizations and that they have the needed information to provide an MBC patient services.

MBC clients also have a number of practical needs that are amplified given their often intensive and fluctuating treatment plans. Patient navigators must think creatively to support MBC patients with transportation, child care, financial services and other challenges that might prevent them from getting to care. Volunteer ride-sharing services, gas cards, and other mechanisms are possible options to get patients the care they need.

Patient Navigation: Grantee Best Practices

Navigators are the trusted face of an MBC patient's care. They can help a client get the care they need and often act as a translator between medical and social services. MBC patients may experience physical limitations, and navigators can conduct home visits that ensure that patients are receiving high-quality care during a difficult time. Grantees reported that care navigation services have alleviated fears, anxieties, and isolation in MBC clients nearing the end-of-life.

Similar to support groups, grantees said that using navigators that have had breast cancer are important for building a supportive community, and may also be more attuned to client needs. Peer guidance helps MBC patients through the complex medical treatments associated with MBC and empowers clients to make informed decisions about their care. Navigation should be linguistically and spiritually appropriate, and proactive, sensitive, and holistic. Each client should be seen as a unique individual and should be asked what she wants. Proactive navigation—reaching out to clients regarding anticipated needs before those they arise—can help patients feel at ease as they move through the course of this difficult disease.





CONCLUDING REMARKS

Patients with MBC often feel isolated and ignored by the overall breast cancer community. These patients have specific needs that are different from those with earlier-stage disease. These needs are often not met by general breast cancer programs and change as the disease progresses. The initiatives funded by the Avon-Pfizer MBC Grants Program are working to collectively address the specific needs of medically underserved MBC patients. To reiterate, needs that are particularly unique to MBC patients compared to those with earlier-stage disease include: end-of-life issues, palliative care, pain management, legal support, education to promote awareness by the public, information specific to their disease stage, and many others. Important considerations include access to nutritious food, medications, complementary and integrative medicine, psychosocial support, navigation, clinical trials, and information.

The initiatives funded by the MBC Grants Program are addressing these issues with engaging and innovative approaches. Enthusiastic plans for future collaborations among these funded groups will improve implementation of these and related programs, improve QOL and patient outcomes, and empower all clients with MBC.

Important gaps in assisting medically underserved clients with MBC remain. Each client's cancer journey is his or her own, and the heterogeneity of those with MBC presents challenges that remain to be addressed patient by patient. Clients may not volunteer for information about food insecurity, personal safety, and

other issues, thus a proactive approach is required to determine client needs. Clinical care and community-based services need to form sustainable partnerships to ensure that patients are receiving support beyond their medical treatment.

Medical care addresses the cancer but does not provide patients with the tools to heal. The non-medical interventions funded by the MBC Grants Program are essential and should be available outside the hospital setting, be holistic in nature, and based on what the individual client needs and wants. These initiatives are indeed providing people with MBC and their families with a better "today".

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