

Patient Navigation in Cancer Care 2.0
Guiding patients to quality outcomes™

Metastatic Breast Cancer Pathways

A Resource Guide for the Navigator



TM

ACKNOWLEDGMENT

Pfizer would like to acknowledge the efforts and dedication of the Metastatic Breast Cancer Steering Committee members who dedicated their knowledge, time, and efforts to enhance the care of patients with cancer through the development of the Metastatic Breast Cancer Resource Guide for Navigators.

Lillie D. Shockney, RN, BS, MAS, ONN-CG

University Distinguished Service Professor of Breast Cancer
Professor of Surgery
Johns Hopkins University School of Medicine
Co-Developer of Work Stride: Managing Cancer at Work
Co-Founder and Program Director, AONN+
Baltimore, MD

Susan Brown, MS, RN

Senior Director
Education & Patient Support
Susan G. Komen
Dallas, TX

Marianne Gandee, MA

Director of Development and Strategic Alliances
Association of Community Cancer Centers (ACCC)
Rockville, MD

Sharon Gentry, RN, MSN, CBCN, ONN-CG

Chair, AONN+ Advisory Committee
Breast Nurse Navigator
Novant Health
Derrick L. Davis Cancer Center
Winston-Salem, NC

Danelle Johnston, MSN, RN, ONN-CG, OCN

Chief Nursing Officer
Senior Director of Strategic Planning and Initiatives
The Lynx Group/AONN+
Austin, TX

Barbara R. McHale, RN, BS, OCN, CBCN, ONN-CG

Retired Multisite Navigator
Hildegard Medicus Cancer Center/St. Mary's/
Samaritan Hospital, St. Peter's Health Partners
Troy, NY

Shirley Mertz

Chair
Metastatic Breast Cancer Alliance
President
Metastatic Breast Cancer Network
Chicago, IL



ACADEMY OF ONCOLOGY NURSE & PATIENT NAVIGATORS: MISSION AND VISION

The mission of the Academy of Oncology Nurse & Patient Navigators (AONN+) is to advance the role of patient navigation in cancer care and survivorship care planning by providing a network for collaboration and development of best practices for the improvement of patient access to care, evidence-based cancer treatment, and quality of life during and after cancer treatment. Cancer survivorship begins at the time of cancer diagnosis. One-on-one patient navigation should occur simultaneously with diagnosis and be proactive in minimizing the impact treatment can have on quality of life. In addition, navigation should encompass community outreach to raise awareness targeted toward prevention and early diagnosis, and must encompass short-term survivorship care, including transitioning survivors efficiently and effectively under the care of their community providers.

The vision of AONN+ is to increase the role of and access to skilled and experienced oncology nurse and patient navigators so that all patients with cancer may benefit from their guidance, insight, and personal advocacy.



The endorsement mark certifies that the information presented in educational seminars, publications, or other resources is reliable and credible.

PFIZER ONCOLOGY: OUR COMMITMENT

Pfizer Oncology is a committed partner in the cancer care community, dedicated to humanity's quest for longer, healthier, happier lives. Our goal is to improve the life of every patient with cancer and positively impact all who deal with this disease. One way we demonstrate our commitment to this goal is through our support of the patient navigation movement occurring throughout the United States.

Ask your Pfizer Oncology Account Manager about *Patient Navigation in Cancer Care 2.0* to support your commitment to making a difference in the lives of patients and in shaping the future of cancer care.

Additional information regarding this program can be found at www.patientnavigation.com.



TABLE OF CONTENTS

| | |
|---|----|
| I. Introduction | 5 |
| II. Treatment of Metastatic Breast Cancer | 13 |
| III. Communication During Treatment | 25 |
| IV. Metastatic Breast Cancer Myths and Facts | 29 |
| V. Navigation in the Context of Metastatic Breast Cancer | 31 |
| VI. Navigation Core Competencies Specific to Metastatic Breast Cancer | 33 |
| VII. Barriers to Care Along the Pathways | 35 |
| VIII. Distress Specific to Metastatic Breast Cancer | 37 |
| IX. Putting It All Together: Continuum of Care for Patients with Metastatic Breast Cancer | 41 |
| X. End-of-Life Care | 45 |
| XI. Developing a Metastatic Breast Cancer Navigation Program | 51 |
| XII. Professional Development in the Metastatic Breast Cancer Space | 53 |
| XIII. Metastatic Breast Cancer Best Practices | 55 |
| XIV. Resources for Metastatic Breast Cancer | 57 |
| Glossary of Key Terms | 61 |

I. INTRODUCTION

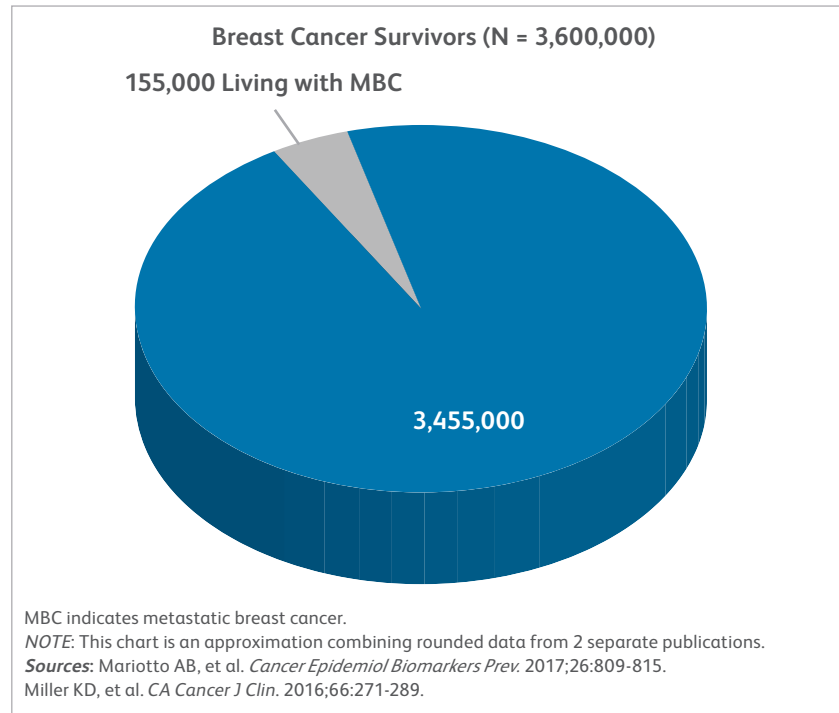
Breast cancer therapy has become more specialized as new treatment methods and genomic subtypes have been discovered. The role of the navigator has become an integral part of the delivery of patient-centered care. Identification and elimination of barriers to diagnosis and treatment, patient education, psychosocial support, coordination of care, advocating for patients, and promotion of survivorship and end-of-life care are all needed to achieve the delivery of multidisciplinary, patient-centered care.

When breast cancer metastasizes, the complexity of care increases and providing optimal support to these patients requires specific attention. Metastatic breast cancer (MBC) is a challenging diagnosis on all levels—physically, psychosocially, and spiritually. For the patient with MBC, a navigator provides essential support to meet the challenges this diagnosis brings. The quality of support in MBC depends on the depth of a navigator’s knowledge of the disease—such knowledge is the goal of this publication.

This toolkit includes:

- An overview of MBC
- Facts about prognosis, treatment pathways, and side effects
- A model of navigation for MBC
- Goals of treatment/care
- Communication within the multidisciplinary team
- Responsibilities of the patient
- Methods for overcoming barriers to care
- Clinical trials
- Distress specific to patients with MBC
- Continuum of care and end-of-life issues
- Resources for you, your patients, and their family/caregivers.

FIGURE 1. Estimated MBC Survivorship as a Proportion of All Current Breast Cancer Survivors



Facts and Figures

As of 2017, approximately 155,000 women in the United States were living with MBC.¹ This is a small proportion of the over 3.5 million female breast cancer survivors who are alive as of 2016 (**Figure 1**).^{1,2} It is also fewer than the 268,670 new cases of invasive breast cancer estimated to be diagnosed in women (266,120) and men (2550) in 2018, along with approximately 63,000 new cases of in situ breast lesions in women.³

From 2005 to 2014—the most recent 10 years for which data are available—invasive breast cancer incidence rates were stable in white women and increased by 0.4% per year in black women.³ This trend has resulted in the convergence of rates in these 2 groups.⁴ Among black women with

breast cancer, the 5-year relative survival rate is 83%, compared with 92% for white women.⁴ The racial disparity in survival reflects later stage at diagnosis and poorer stage-specific survival in black women, as well as higher rates of more aggressive, triple-negative breast cancer.⁴ Another reason is that Asian/Pacific, American Indian/Alaskan, Hispanic, and black women more frequently receive an initial breast cancer diagnosis when their disease is already metastatic compared with women in other groups⁵ (**Table 1**). A finding of MBC carries a poor prognosis, with only 27% of patients surviving for 5 years after diagnosis.^{4,7}

TABLE 1. Diagnosis of Invasive Breast Cancer in Women by Stage and Racial/Ethnic Group (SEER US data, 2005-2014)

| | Stages I-III | | Stage IV | Unstaged |
|--------------------------------------|---|--|--|-----------------|
| | Localized disease ^a (% of patients) | Regional disease ^b (% of patients) | Distant metastasis ^c (% of patients) | (% of patients) |
| White female | 63.8 | 28.8 | 5.3 | 2.0 |
| Black female | 54.4 | 34.7 | 8.6 | 2.3 |
| Asian/Pacific Islander female | 64.0 | 29.5 | 4.7 | 1.8 |
| American Indian/Alaska Native female | 59.1 | 32.4 | 6.3 | 2.2 |
| Hispanic female | 56.9 | 35.2 | 5.7 | 2.1 |

^aCancer confined to the breast.

^bSpread of cancer to nodes near the breast.

^cSpread of cancer to bone, lung, liver, brain, or other tissues and organs away from the breast.

SEER indicates Surveillance, Epidemiology, and End Results Program (National Cancer Institute).

Source: National Cancer Institute/Surveillance, Epidemiology, and End Results Program. <https://seer.cancer.gov/faststats/selections.php>.

Male Breast Cancer

A man diagnosed with breast cancer is rare, accounting for less than 1% of breast cancer cases in the United States.⁴ However, since 1975, the incidence rate has increased slightly, from 1.0 case per 100,000 men during the period from 1975 to 1979 to 1.3 cases per 100,000 men during the period from 2010 to 2014. Men are more likely than women to be diagnosed with advanced-stage breast cancer, which likely reflects decreased awareness and delayed detection, because screening mammography is not recommended for men because of the rarity of the disease. Similar to female breast cancer, the incidence of male breast cancer increases with age. The death rate for male breast cancer has decreased slightly, from 0.4 per 100,000 from 1975 to 1979 to 0.3 per 100,000 from 2011 to 2015, which can be attributed to improvements in treatment. Due to the infrequency of male breast cancer, much less is known about the disease compared with female breast cancer. Risk factors include radiation exposure, *BRCA1/2* gene mutations, Klinefelter syndrome, testicular disorders, family history of breast or ovarian cancer, diabetes, gynecomastia (enlarged breasts), and obesity.⁴

Breast Cancer

Breast cancer is a disease in which cells in the breast grow out of control. Various types of breast cancer exist, with the type depending on which cells in the breast turn into cancer. A breast is made up of 3 main parts—lobules, ducts, and connective tissue—and breast cancer can begin in any one of these parts. The lobules are the glands that produce milk. The ducts are tubes that carry milk to the nipple. The connective tissue, which consists of fibrous and fatty tissue, surrounds and holds everything together. Most breast cancers begin in the ducts or lobules.

Breast cancer can spread outside the breast through blood vessels and lymph vessels. When breast cancer spreads to other parts of the body, it is said to have metastasized.⁸

Subtypes

The 5 main intrinsic or molecular subtypes of breast cancer are based on the genes a cancer expresses⁹:

- **Luminal A** breast cancer is hormone receptor (HR)-positive (estrogen receptor [ER]- and/or progesterone receptor [PR]-positive), HER2-negative, and has low levels of the protein Ki-67, which helps control how fast cancer cells grow. Luminal A cancers are low-grade, tend to grow slowly, and have the best prognosis
- **Luminal B** breast cancer is HR-positive (ER- and/or PR-positive), and either HER2-positive or HER2-negative, with high levels of Ki-67. Luminal B cancers generally grow slightly faster than luminal A cancers, and their prognosis is slightly worse
- **Triple-negative/basal-like** breast cancer is HR-negative (ER- and PR-negative) and HER2-negative. This type of cancer is more common in women with *BRCA1* gene mutations. Researchers are not sure why, but this type of cancer also is more common among younger and African American women
- **HER2-enriched** breast cancer is HR-negative (ER- and PR-negative) and HER2-positive. HER2-enriched cancers tend to grow faster than luminal cancers and can have a worse prognosis, but they are often successfully treated with targeted therapies aimed at the HER2 protein

MBC Fast Facts, based on US data^{1,4,7,10,11}

- MBC – The spread of breast cancer cells to tissues outside the breast
- ~155,000 – Number of women in the United States living with MBC in 2017
- 27% – Proportion of patients who survive 5 years if MBC is found at initial diagnosis

- **Normal-like** breast cancer is similar to luminal A disease: HR-positive (ER- and/or PR-positive), HER2-negative, and has low levels of the protein Ki-67. However, although normal-like breast cancer has a good prognosis, its prognosis is slightly worse than that of luminal A cancer.

Metastatic Breast Cancer Defined

When breast cancer is staged, it is based on the cancer's characteristics, such as the size of the tumor itself and whether any lymph nodes contain cancer along with whether it has hormone receptors or HER2 receptors. The stage of cancer helps determine the prognosis and best treatment, as well as whether certain clinical trials are an option. Stage is a measure of the severity and risk of the cancer—the higher the stage, the greater the risk that the cancer will spread.

Stage IV breast cancer is defined as an invasive cancer that has spread beyond the breast and

nearby lymph nodes to other organs of the body, such as the lungs, distant lymph nodes, skin, bones, liver, or brain.^{10,11} Cancer may be stage IV at first diagnosis, called *de novo*, or it can be a recurrence of a previous breast cancer that has spread to other parts of the body. The stage indicates the extent of the cancer in the body. Metastasis refers to the spread of the cancer.¹⁰

Because metastatic disease can arise when the cancer that has been treated progresses or recurs, up to 30% of patients initially diagnosed with stage I to III breast cancer will ultimately progress to stage IV.¹² The extent and characteristics of MBC are determined via computed tomography (CT) scan and other imaging and biopsy of the tumor.¹³

Understanding Metastatic Breast Cancer

The risk for MBC is determined primarily by 3 factors¹⁴⁻¹⁸:

- Location, size, and invasiveness of the primary tumor
- Breast cancer subtypes, which are distinguished by the tumor's hormonal features and genomics—the profile of genetic mutations in the cells of the tumor
- The patient's menopausal status.

FIGURE 2. Breast and Adjacent Lymph Nodes

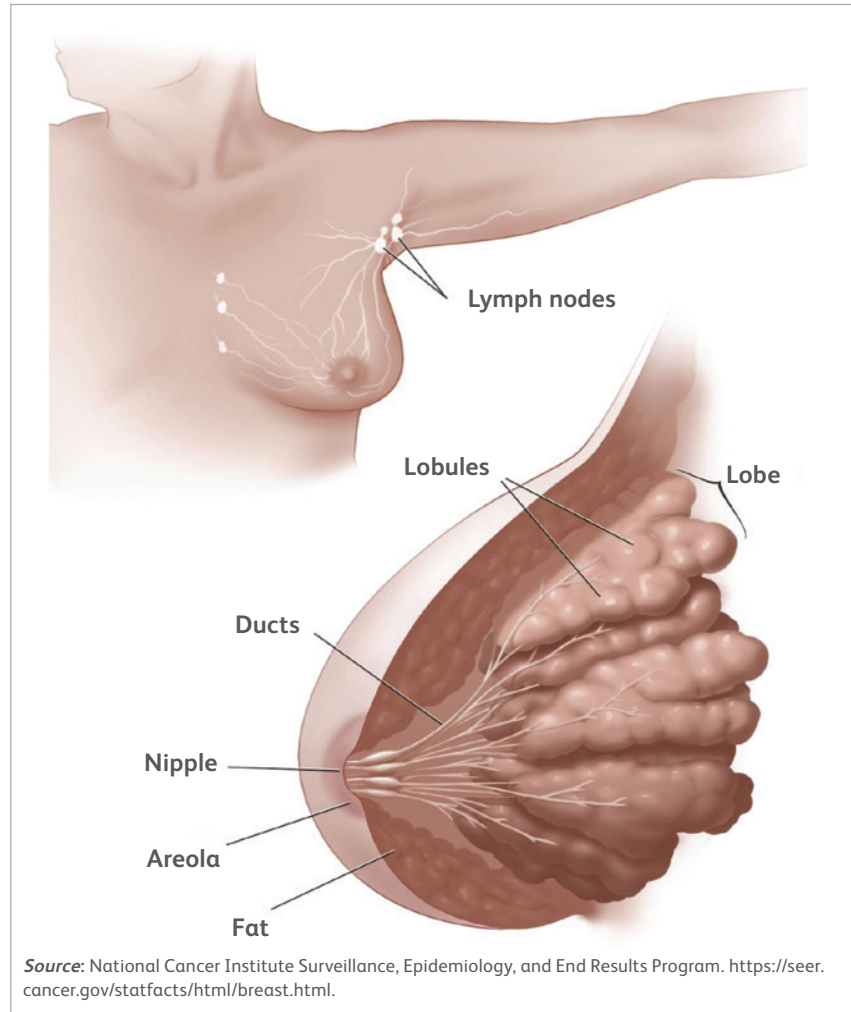
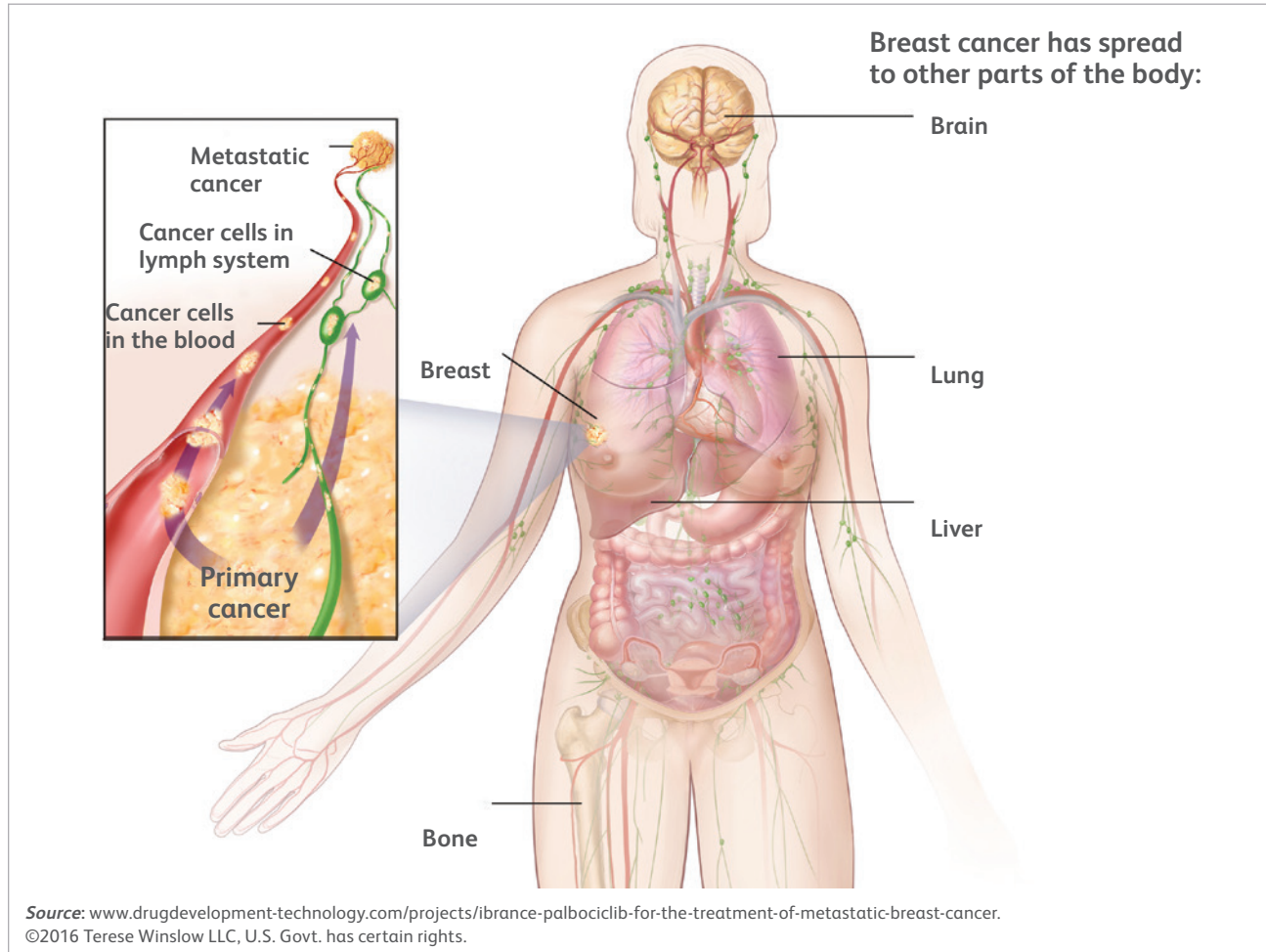


FIGURE 3. Stage IV Breast Cancer with Common Sites of Metastases



Location, Size, and Invasiveness of Primary Tumor

The primary breast tumor may invade the breast tissue (invasive breast cancer), or may be a small gathering of abnormal cells in the duct (ductal carcinoma in situ) or lobule (lobular carcinoma in situ) of the breast¹⁸ (Figure 2¹⁵).

In a patient without distant metastasis at diagnosis, the larger and more invasive the primary tumor, the greater the risk for cancer recurrence, which may include MBC; the presence of affected lymph nodes also increases risk.¹⁶

Evidence suggests that invasive breast cancer of the duct, or invasive ductal carcinoma (IDC), may have a better prognosis than invasive breast cancer of the lobule, or invasive lobular carcinoma (ILC).¹⁵ IDC and ILC appear to have different patterns of metastasis. Although rates of metastasis to bone appear comparable for the 2 locations, IDC may have greater lung, liver, and distant lymph-node metastases, whereas ILC has greater ovarian and gastrointestinal metastases¹⁵ (Figure 3). Stage IV ILC is also known to metastasize to the uterus, ovaries, intestines, stomach, and the adrenal glands.

Subtypes and Staging

Research has identified intrinsic breast cancer subtypes defined by hormonal and molecular features, and in some cases, how rapidly the number of tumor cells is increasing (proliferation rate). The subtypes exhibit

TABLE 2. Intrinsic Breast Cancer Subtypes and MBC

| Subtype ^a | Features of subtype | 15-year rate of distant MBC relapse, % | Time from finding of metastases to death, yrs |
|-----------------------------|--|--|---|
| Luminal A | ER+ and/or PR+ and HER2-; Ki-67 <14% | 27.8 | 2.2 |
| Luminal B | ER+ and/or PR+ and HER2-; Ki-67 ≥14% | 42.9 | 1.6 |
| Luminal/HER2+ | ER+ and/or PR+ and HER2+ | 47.9 | 1.3 |
| HER2-enriched | ER-, PR-, and HER2+ | 51.4 | 0.7 |
| Triple-negative, basal-like | ER-, PR- and HER2- and EGFR+ and/or CK5/6+ | 43.1 | 0.5 |
| Triple-negative, nonbasal | ER-, PR-, HER2-; EGFR-, CK5/6- | 35.1 | 0.9 |

^aThis study defined 6 subtypes; often, 4 or 5 subtypes are defined. The 5-subtype version is: luminal A; luminal B; HER2-enriched, basal-like (usually, triple-negative); and normal-like (similar to luminal A). The 4-subtype version is: luminal A, luminal B, HER2-enriched, and triple-negative.

Study design: Analysis of archival tissue samples in patients with early-stage breast cancer diagnosed between 1986 and 1992 (N = 3726 eligible patient samples). CK5/6 indicates cytokeratin 5/6; EGFR, epidermal growth factor receptor; ER, estrogen receptor, HER2, human epidermal growth factor receptor 2; MBC, metastatic breast cancer; PR, progesterone receptor.

Sources: American Cancer Society. *Breast Cancer Facts & Figures 2017-2018*. Atlanta, GA: American Cancer Society; 2017; Breastcancer.org. www.breastcancer.org/symptoms/types/molecular-subtypes; Kennecke H, et al. *J Clin Oncol*. 2010;28:3271-3277; Parker JS, et al. *J Clin Oncol*. 2009;27:1160-1167.

notable differences in incidence of distant metastasis and survival after relapse¹⁶ (Table 2).^{4,9,16,19}

For all subtypes except triple-negative basal-like, bone is the most common metastatic site for MBC.¹⁶ Compared with luminal A tumors, which are the least aggressive subtype¹⁶:

- Luminal/HER2+ and HER2-enriched tumors had a significantly higher rate of brain, liver, and lung metastases
- Triple-negative, basal-like tumors had a higher rate of brain, lung, and distant nodal metastases but a significantly lower rate of liver and bone metastases. Triple-negative nonbasal tumors demonstrated a similar pattern, except the liver metastases rate was not lower.

The breast cancer subtype so strongly predicts the course of breast cancer that it has now been incorporated into the 2018 updated staging system developed by the American Joint Committee on Cancer (AJCC). In addition to the invasiveness of the primary tumor (spread outside the breast) and the degree of abnormal appearance of the cancer cells, stage of breast cancer depends on ER/PR and HER2 status—the hormonal and molecular features of breast cancer subtypes and size of the tumor.¹⁴ In stage IV breast cancer, the tumor can be any size and has spread to other organs, such as the lungs, brain, liver, distant lymph nodes, or chest wall (any T [size and invasiveness of tumor], any N [nearby lymph node involvement], M1 [metastasis to distant organs]).²⁰ The higher staging for the triple-negative primary tumor reflects the greater risk shown for this subtype. Complete details on staging are available on the AJCC website (<https://cancerstaging.org>).

The clinical navigator's role is to discuss the potential goals of therapy with patients with MBC and encourage them to talk with their healthcare provider about goals of treatment and whether it is considered curative. In addition, the navigator should ask patients with MBC about the life goals that are most important to them.



Menopausal Status

Menopausal status contributes to decision-making for intervention and treatment. The premenopausal and perimenopausal patient with MBC can be clinically challenging. Breast cancer tends to be more aggressive in these younger patients, and there is a higher frequency of ER-/PR-negative disease (ie, higher-risk subtypes).²¹ These

patients also tend to be diagnosed later in the disease process, when their cancer is more advanced.²¹ Delays in diagnosis may be attributed to several factors, including younger women's tendency not to think a lump or mass is breast cancer, instead assuming it is a harmless cyst or other growth. Doctors also may dismiss breast lumps in young women as cysts. In pre- or perimenopausal women with tumors responsive to estrogen, ovarian ablation, or removal of the ovaries' ability to produce estrogen, may be used. This may involve surgery to remove the ovaries, radiation, or chemical control of the ability of the ovaries to produce estrogen. Whether a woman has gone through menopause is important for some breast cancer treatments. For example, women with HR-positive breast cancers are treated with hormone therapy (eg, Tamoxifen or aromatase inhibitors).²² Tamoxifen can be used to treat pre- and postmenopausal women. Aromatase inhibitors are only used to treat postmenopausal women, and are not an option for premenopausal women (unless ovarian suppression is also part of treatment).

Evaluation of the Patient with Metastatic Breast Cancer

Detecting MBC

At the time of initial stage IV diagnosis or at first cancer recurrence after treatment, MBC is detected by the following¹³:

- History and physical examination
- Laboratory results
 - Complete blood count (hemoglobin, hematocrit, white blood cells, platelets)
 - Comprehensive metabolic panel of blood tests, including liver function tests and alkaline phosphatase
- Tumor pathology
 - Biopsy of a metastatic lesion (to assess tumor grade [degree of cellular abnormality]; proliferative behavior, measured, for example, by Ki-67 testing)
 - Determination of metastatic tumor ER/PR and HER2 status on metastatic site
 - Confirmation by biopsy that the cancer cells are in fact breast cancer cells
- Tumor biology
 - Based on the results of the tumor histology and biomarkers, genetic counseling should be recommended if the patient is at high risk for hereditary breast cancer

“One of the most important things that I can do when I am taking care of a patient is to find out what their life goals are because I want to keep them on track for those life goals. There is a tendency often times for us to be treating the pathology—the patient is more than her pathology. She has a life, a family, a career, and she has what she hopes to be a future after this diagnosis and treatment is completed. So, I consider myself to be a key person for her in educating the rest of the multidisciplinary oncology team so they know more about this individual. And for patients with metastatic breast cancer, they too have life goals. Some may still be achievable while others, more far reaching into the future, may need to be achieved in alternative ways with my support.”

Lillie Shockney, RN, BS, MAS, ONN-CG, AONN+ Co-Founder and Program Director



- Imaging
 - Chest diagnostic CT scan with contrast
 - Abdominal and pelvic diagnostic CT with contrast or magnetic resonance imaging (MRI) with contrast
 - Brain MRI if there are central nervous system symptoms (eg, seizure)
 - Spine MRI if there is back pain or symptoms of cord compression
 - Bone scan or sodium fluoride positron emission tomography/CT
 - X-rays of symptomatic bones and long and weight-bearing bones that are abnormal on bone scan.

Monitoring Metastatic Breast Cancer

The National Comprehensive Cancer Network recommends using objective criteria for response/stability/progression when monitoring for metastatic disease. The most accurate assessments of disease activity typically occur when previously abnormal studies are repeated on a serial and regular basis. Generally, the same method of assessment should be used over time (eg, an abnormality found on a chest CT should generally be monitored with repeat chest CT).²³

Hormonal and Genomic Evaluation

Histology Evaluation

To help determine breast cancer subtype and to plan for treatment, the tumor cells must be tested for the presence of hormone receptors (ER/PR) and for HER2.¹³ This is true of both early-stage and metastatic breast cancer.

Genomic Evaluation

If a patient is at high risk for hereditary breast cancer (carrying gene mutations that increase risk), genetic testing of tumor cells and counseling may be warranted.¹³ Testing without formal counseling is discouraged.¹³ Testing may be done for multiple mutations in patients at risk for hereditary breast cancer to assess the overall breast cancer risk and the potential prognosis if cancer should occur. Mutations assessed by testing may include *BRCA1/2*, *ATM*, *PALB2*, and *PTEN*, among others.²⁴

Goals of Treatment

As no cure currently exists for MBC, the goals of treatment are disease control and palliation to preserve quality of life. The metastatic site will have to be biopsied as part of the workup to confirm tumor histology and biomarker status, because this can change after having been previously treated. Traditionally, the goal of treating MBC has been to prolong survival and enhance quality of life. Treatment has not been considered curative, and this remains the case. The length of time someone lives with metastatic disease is dependent on the treatments available and the effectiveness of those treatments. Some patients live only for a few years while others live for more than a decade.

References: 1. Mariotto AB, Etzioni R, Hurlbert M, Penberthy L, Mayer M. Estimation of the number of women living with metastatic breast cancer in the United States. *Cancer Epidemiol Biomarkers Prev*. 2017;26:809-815. 2. Miller KD, Siegel RL, Lin CC, et al. Cancer treatment and survivorship statistics, 2016. *CA Cancer J Clin*. 2016;66:271-289. 3. American Cancer Society. *Cancer Facts & Figures 2018*. Atlanta, GA: American Cancer Society; 2018. 4. American Cancer Society. *Breast Cancer Facts & Figures 2017-2018*. Atlanta, GA: American Cancer Society; 2017. 5. Susan B Komen. Breast Cancer Statistics. <https://www5.komen.org/BreastCancer/Statistics.html#Race-ethnicity-and-breast-cancer-rates>. Accessed September 11, 2018. 6. National Cancer Institute/Surveillance, Epidemiology, and End Results Program. Fast stats—stage distribution SEER summary (stage 2000) by race and sex, female breast, all ages, 2005-2014. <https://seer.cancer.gov/faststats/selections.php>. Accessed November 15, 2017. 7. Howlader N, Noone AM, Krapcho M, et al. SEER cancer statistics review, 1975-2014. Bethesda, MD: National Cancer Institute. https://seer.cancer.gov/csr/1975_2014. Accessed November 10, 2017. 8. Centers for Disease Control and Prevention. www.cdc.gov/cancer/breast/basic_info/what-is-breast-cancer.htm. Accessed September 2, 2018. 9. Breastcancer.org. Molecular subtypes of breast cancer. www.breastcancer.org/symptoms/types/molecular-subtypes. Accessed September 2, 2018. 10. National Cancer Institute. What is metastatic cancer? www.cancer.gov/types/metastatic-cancer#what. Accessed November 10, 2017. 11. National Comprehensive Cancer Network. NCCN Quick Guide™. Stage IV Breast Cancer. v1. 2015. www.nccn.org/patients/pdf/guidelines/quick_guide/nccn_quick_guide-breast_stage_iv.pdf. Accessed November 10, 2017. 12. Redig AJ, McAllister SS. Breast cancer as a systemic disease: a view of metastasis. *J Intern Med*. 2013;274:113-126. 13. National Comprehensive Cancer Network. *NCCN Clinical Practice Guidelines in Oncology*. Breast Cancer. v3. 2017. www.nccn.org/professionals/physician_gls/pdf/breast.pdf. Accessed November 12, 2017. 14. NCI Breast Cancer-Health Professional version. <https://www.cancer.gov/types/breast/hp/breast-treatment-pdq>. 15. Mathew A, Rajagopal PS, Villgran V, et al. Distinct pattern of metastases in patients with invasive lobular carcinoma of the breast. *Geburtshilfe Frauenheilkd*. 2017;77:660-666. 16. Kennecke H, Yerushalmi R, Woods R, et al. Metastatic behavior of breast cancer subtypes. *J Clin Oncol*. 2010;28:3271-3277. 17. Rugo HS, Rumble RB, Macrae E, et al. Endocrine therapy for hormone receptor–positive metastatic breast cancer: American Society of Clinical Oncology Guideline. *J Clin Oncol*. 2016;34:3069-3103. 18. National Cancer Institute Surveillance, Epidemiology, and End Results Program. Cancer stat facts: female breast cancer. <https://seer.cancer.gov/statfacts/html/breast.html>. Accessed November 10, 2017. 19. Parker JS, Mullins M, Cheang MC, et al. Supervised risk predictor of breast cancer based on intrinsic subtypes. *J Clin Oncol*. 2009;27:1160-1167. 20. Cancer.Net. Breast cancer: Stages. April 2017. www.cancer.net/cancer-types/breast-cancer/stages. Accessed September 21, 2018. 21. Ademuyiwa FO, Cyr A, Ivanovich J, Thomas MA. Managing breast cancer in younger women: challenges and solutions. *Breast Cancer (Dove Med Press)*. 2016;8:1-12. 22. Susan G. Komen. Hormone therapies. Updated May 2, 2018. www5.komen.org/BreastCancer/HormoneTherapies.html. Accessed September 21, 2018. 23. National Comprehensive Cancer Network. *NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®)*. Breast Cancer. NCCN Evidence blocks™. v1. 2018—April 23, 2018. www.nccn.org/professionals/physician_gls/pdf/breast_blocks.pdf. Accessed September 20, 2018. 24. National Comprehensive Cancer Network. Genetic/Familial High-Risk Assessment: Breast and Ovarian. v1. 2018. www.nccn.org/professionals/physician_gls/pdf/genetics_screening.pdf. Accessed November 12, 2017.

II. TREATMENT OF METASTATIC BREAST CANCER

Treatment: General Principles

In metastatic breast cancer (MBC), treatment has 2 goals¹:

- Control of disease—to extend life
- Palliation of disease—to relieve symptoms and suffering and to enhance quality of life.

These 2 goals overlap in the care of metastatic or advanced cancer, including MBC. They overlap because the choice of treatment to control MBC must factor in the patient’s quality of life and personal preference based on values and lifestyle.

Currently, palliative care and quality-of-life considerations are being integrated into the treatment to tie together these 2 goals.

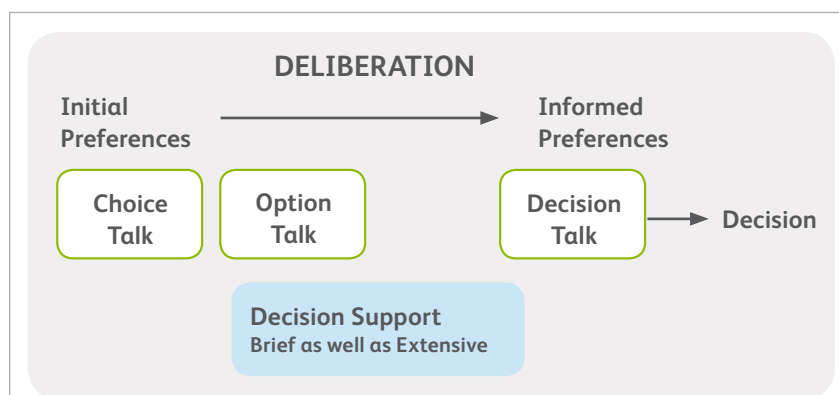
The old model—anticancer treatment to control disease, followed by palliation only at the end of life—is being replaced. The new model recognizes that palliative care should be provided alongside active oncologic therapy.^{2,3} In the setting of advanced cancer, data show that when palliative care accompanies active anticancer treatment, not only does quality of life improve—survival time increases, too.²

Treatment for MBC cannot provide a cure. For this reason, minimizing the toxicity of treatments is an important consideration.¹

Shared Decision-Making

Shared decision-making is defined as “an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences.”⁴ It is recommended that, at the start of treatment for MBC, the healthcare team and the patient discuss the need to share in the processes of

FIGURE 1. A Shared Decision-Making Model



Key to the figure

| | |
|-----------------------------|---|
| Deliberation | A process where patients become aware of choice, understand their options, and have the time and support to consider what matters most to them: may require more than 1 clinical contact not necessarily face-to-face and may include the use of decision support and discussions with others |
| Choice talk | Conveys awareness that a choice exists – initiated by either a patient or a clinician. This may occur before the clinical encounter |
| Option talk | Patients are informed about treatment options in more detail |
| Decision talk | Patients are supported to explore what matters most to them, having become informed |
| Decision support | Decision support as designed in 2 formats: 1) brief enough to be used by clinician and patient together and 2) more extensive, designed to be used by patients either before or after clinical encounters (paper, DVD, web) |
| Initial preferences | Awareness of options leads to the development of initial preferences, based on existing knowledge. The goal is to arrive at informed preferences |
| Informed preferences | Personal preferences based on what matters most to patients, predicated on an understanding of the most relevant benefits and harms |

Source: Elwyn G, et al. *J Gen Intern Med.* 2012;27:1361-1367.

care.¹ In shared decision-making, everyone works toward agreement; the healthcare team alone does not dictate the treatment plan (**Figure 1**).⁴

This model has 3 steps⁴:

- Introducing choice
- Describing options, often by integrating the use of patient decision support
- Helping patients explore preferences and make decisions.

When assisting patients with treatment decisions, the clinical navigator can utilize the following model⁴:

- Observe patient's verbal and nonverbal reactions and help to justify the patient's choice
- Review information patient has been given
- Check patient's knowledge
- Explore and focus on patient's preferences to help in decision-making
- Summarize options and provide patient with decision support to help in making informed decisions.

Treatment Plan

Treatment for MBC begins with a comprehensive, patient-centered treatment plan. The multidisciplinary team reviews the findings from the physical examination, biopsy of the metastatic tumor, computed tomography (CT) scans, x-rays and other imaging, and laboratory tests.

For patients whose MBC is a cancer recurrence, it is vitally important that the team uses information from tests conducted at the recurrence and does not rely on the results of tests conducted at the time of initial diagnosis. Otherwise, the treatment plan could be inaccurate.⁵

For example, in some cases, the metastatic tumor will have a different profile of hormonal and genomic features, such as estrogen receptor (ER) status or human epidermal growth factor receptor 2 (HER2) status, than the primary breast tumor.⁵ Because hormonal and genomic features can affect the choice of treatment, basing the metastatic treatment plan on biopsy results from the primary tumor runs the risk of selecting an ineffective treatment. Therefore, a new biopsy with hormonal genomic analysis is needed at the time of metastasis.⁵

The clinical navigator can utilize the shared decision-making model when assisting patients with treatment decisions.⁴

Valuable questions for the navigator to ask are:

1. How much do you know about your breast cancer?
2. How much do you want to know about your breast cancer?
3. What are you hoping for?
4. What are you most worried about?
5. Tell me 3 things that bring you joy (or brought you joy before you became sicker).

The answers to these questions will change over time too, so they need to be asked often and consistently with the rest of the treatment team being aware of the responses.



The patient-centered treatment plan summarizes⁶:

- All key medical information about the patient—including overall health status, symptoms, physical changes, biopsy results (with hormonal and genomic features), results of CT scan and other imaging tests, and laboratory test results
- Quality-of-life and psychosocial assessment—including patient’s limitations, concerns, preferences and advance directives, financial stresses, and family and relationship status
- Specific treatment objectives for the patient
- Individualized treatment to control MBC with anticancer drugs/radiation/surgery, including projected efficacy and potential toxicities
- Individualized palliative care plan to relieve symptoms and suffering, and enhance quality of life.

Overview of Treatment Types

When discussing treatment modalities used in MBC, it can entail more than 1 therapy. Current treatment protocols can utilize systemic anticancer therapies, surgery, and radiation. The oncology team may also decide to use a combination of treatments (**Table 1**).^{1,7-9} In some cases, patients with MBC can go from receiving multiple drug therapies (taxanes and platinums) to one drug therapy at a time. This can imply to the patient that the team is not being “aggressive.” Current research being done on MBC has provided new recommendations for treatment based on hormonal and targeted therapies. The clinical navigator needs to be current regarding the latest recommended treatment modalities so they can further educate their patients with MBC.

Surgery

Tumor Surgery

Sometimes a patient with stage IV MBC may be a candidate for surgical removal of the primary breast tumor. Evidence does not fully support this approach as a way to extend a patient’s life and more research is needed.¹ Surgery can also be performed to clear metastatic disease from various sites. Examples of these surgeries are removal of brain metastasis and tumor obstruction of the bowel or urinary tract.¹

Rehabilitative Surgery

Surgeons also help to palliate MBC—managing pain and supporting function with various procedures. Orthopedic surgery can stabilize a fractured leg with rods and pins or alleviate back pain attributed to vertebral fracture and spinal cord compression.¹ Fluid around the lung or heart caused by MBC can be drained surgically.¹ Wounds from metastasis to the skin and soft tissue can be surgically cleaned and closed.¹

Radiation Therapy

Radiation therapy is used to shrink tumors, control pain, and support function.¹ For example, external beam radiation can be used to reduce a bowel obstruction caused by a tumor.^{1,10} Radioisotopes (eg, strontium-89 chloride, samarium-153 lexidronam), when injected, travel preferentially into the bone, where they shrink metastatic sites to control pain.^{9,10}

Clinical navigators must discuss with patients the way MBC is treated. The discussion should involve both single and combination therapies the team chooses during the course of treatment.



TABLE 1. Treatment of Metastatic Breast Cancer at a Glance

| Treatment type | Examples of specific treatments | Mode of action | Typical MBC patient ^{a,b} |
|-------------------------|---|--|--|
| Surgery | <ul style="list-style-type: none"> • Total mastectomy to remove open or painful breast tissue • Surgery to remove cancer in the spine, brain, or lung • Surgical repair/stabilization of bones or bone fractures • Surgery to remove fluid from the chest that can occur in lung metastasis | | Patient who needs surgery to control disease/reduce symptoms, and is also healthy and strong enough to undergo the procedure |
| Radiation | <ul style="list-style-type: none"> • External beam (from outside the body) radiation to bone, brain, spine, breast/chest wall • Strontium-89 chloride, samarium-153 lexidronam internal radiation (inside the body); injected for relief of bone pain | Damages DNA to kill cells | Patients with metastatic sites that can benefit from radiation to relieve symptoms, enhance quality of life |
| Hormone therapies | <ul style="list-style-type: none"> • Aromatase inhibitors • Selective ER modulators/antagonists • Ovarian-suppressing hormones and drugs | Block/suppress hormones that stimulate growth in some breast cancer tumors | Patient with ER+/PR+ tumor cells found in biopsy |
| Targeted therapies | <ul style="list-style-type: none"> • HER2-targeted agents • HER2/tyrosine kinase inhibitors • CDK4/6 inhibitors • mTOR inhibitors • PARP inhibitors • Biosimilars | Identify and attack cancer cells that have specific genomic features | <p>If the drug's genomic target only occurs in some patients:</p> <ul style="list-style-type: none"> • Patients whose tumor cells have that genomic target <p>If the drug's genomic target occurs in most breast cancers:</p> <ul style="list-style-type: none"> • Potentially, any breast cancers |
| Chemotherapies | <ul style="list-style-type: none"> • Taxanes • Anthracyclines • Platinum drugs | Kill cells or stop cells from dividing (also called cytotoxic drugs) | Patients with any MBC type, as a single drug or in combination with other drugs |
| Bone-specific therapies | <ul style="list-style-type: none"> • Bisphosphonates • Anti-RANKL antibodies | Control bone disease, bone degradation, and pain | Patient with bone metastasis |

^aSometimes patients enrolled in clinical trials may be treated with drugs that they would not typically be given.

^bSometimes radiation and surgery are used together (eg, neurosurgery to remove metastatic disease from part of the brain, followed by radiation to the brain).

CDK indicates cyclin-dependent kinase; ER, estrogen receptor; HER2, human epidermal growth factor receptor 2; MBC, metastatic breast cancer; mTOR, mechanistic target of rapamycin; PARP, poly (ADP [adenosine diphosphate]-ribose) polymerase; PR, progesterone receptor.

Sources: National Comprehensive Cancer Network. *NCCN Clinical Practice Guidelines in Oncology: Breast Cancer*. v3. 2017. www.nccn.org/professionals/physician_gls/pdf/breast.pdf; National Cancer Institute. www.cancer.gov/types/breast/breast-hormone-therapy-fact-sheet; National Cancer Institute. www.cancer.gov/types/breast/patient/breast-treatment-pdq#section/_222; National Cancer Institute. www.cancer.gov/about-cancer/treatment/types/radiation-therapy/radiation-fact-sheet.

Systemic Drug Therapies

Hormone Therapies

Hormone therapies are used to treat MBC in patients whose tumors are hormone sensitive—that is, the tumor cells have hormone receptors (HRs). These are identified as ERs and progesterone receptors. In cancers

such as these, the hormones estrogen and progesterone—produced in the ovaries and other tissues—stimulate tumor growth. Therefore, blocking or suppressing the hormones slows or stops the growth of the tumor. Women whose tumors do not have HRs do not generally benefit from hormone therapies.⁷

Specific classes of hormone therapy include⁷:

- Aromatase inhibitors—drugs that block the production of estrogen by blocking an enzyme (aromatase) that the body uses to make estrogen
- Selective estrogen receptor modulators—drugs that prevent estrogen from binding to its receptor
- Estrogen antagonists—drugs that prevent estrogen from binding to its receptor, but also can destroy the receptor.

Another type of treatment for hormone-sensitive MBC is suppression of the ovaries' function, called ovarian ablation, which can be done via drugs and hormones that directly suppress the ovaries' ability to make hormones, or through surgical removal of the ovaries.⁷

Hormone therapies are used to treat patients whose tumors have hormone receptors. These hormones are estrogen and progesterone. Patients whose tumors do not have these receptors do not benefit from hormone therapies.

For postmenopausal women with MBC who are HR-positive, drug therapy without ovarian ablation is recommended. For premenopausal women, drug therapy should be combined with ovarian ablation.¹¹

Targeted Therapies

Targeted therapies attack a specific cellular process involved in the growth or proliferation of tumor cells. Depending on molecular profile of the primary cancers in MBC, these drugs may be used for patients with MBC whose cancers are HR+/HER2+, HR+/HER2-, HR-/HER2+, HR-/HER2-, BRCA1/2+. The multiple targeted therapies used in MBC include^{7,8,12,13}:

- HER2-targeted agents, including anti-HER2 antibodies and HER2 conjugates that deliver cell-specific chemotherapy. These agents control the growth of tumor cells that have the type 2 receptor for the protein human epidermal growth factor. These drugs are primarily used in women with HER2+ MBC
- Tyrosine kinase inhibitors (TKIs), which target a pathway that, when blocked, may help to inhibit the growth of the tumor cells. These drugs are primarily used in women with HER2+ MBC
- Cyclin-dependent kinase (CDK)4/6 inhibitors are a class of drugs that target enzymes called CDK4 and CDK6. These enzymes are important in cell division. CDK4/6 inhibitors are designed to interrupt the growth of cancer cells. These drugs are primarily used in women with HR+/HER2- MBC
- Mechanistic target of rapamycin (mTOR) inhibitors suppress the mTOR, a protein that can stop hormone therapy from working. These drugs are primarily used in women with HR+/HER2- MBC
- Biosimilars are versions of a biologic agent that are very similar to the reference FDA-approved product, and do not have clinically meaningful differences from that approved product

Navigators render a great service when they open the lines of communication among the patient, family, and healthcare team to maintain an ongoing conversation about adverse effects.¹⁴



TABLE 2. Clinical Trials: Issues and Barriers That Confront Patients with MBC

| Type | Issues/barriers |
|--|---|
| Low enrollment | <ul style="list-style-type: none"> • 20% of all US patients with cancer are eligible for a clinical trial • Only 3% to 5% actually participate • Minority, rural, and elderly patients have especially low enrollment |
| Lack of understanding | <ul style="list-style-type: none"> • Patients and caregivers may be unsure about the process of trial enrollment and participation |
| Lack of effective decision-making | <ul style="list-style-type: none"> • Patients and caregivers may lack the ability to make an informed decision and give ongoing consent to a trial due to: <ul style="list-style-type: none"> — Literacy — Language barrier — Unrelieved distress — Lack of time — Lack of capacity (attributed to psychosocial/physical barriers such as lack of transportation or pain) — Misconceptions about the nature of trials |
| Financial/cost issues | <ul style="list-style-type: none"> • Patients have unanswered concerns about coverage for “usual care” costs apart from treatment and testing that is specific to the trial • Financial problems and their effects (lack of support network, food insecurity, etc), which raise fears of unexpected costs of participation |
| Healthcare team deficits in knowledge/time | <ul style="list-style-type: none"> • Busy professionals may not be up to date on available trials • Potential reasons include: <ul style="list-style-type: none"> — Lack of knowledge of the portfolio of trials available to patients — Time constraints for enrolling and managing the patient on a trial — Negative perceptions of clinical trials |

Sources: Cartmell KB, et al. *Contemp Clin Trials Commun.* 2016;3:86-93; Fouad MN, et al. *J Oncol Pract.* 2016;12:556-563; Oncology Nursing Society. 2016 *Oncology Clinical Trials Nurse Competencies.* www.ons.org/sites/default/files/OCTN_Competencies_FINAL.PDF; Sutter Health/Palo Alto Medical Foundation. www.pamf.org/cancercaare/trials/cost.html.

- Poly (ADP [adenosine diphosphate]-ribose) polymerase (PARP) inhibitors are drugs that block the PARP enzyme, which is important in cancer cell survival. These drugs are primarily used in women with *BRCA1/2+ MBC*

Chemotherapies

Chemotherapies are drugs that are toxic to cells, or cytotoxic. Many of these are drugs that have been used in cancer for decades.^{8,12} Chemotherapy is used in MBC that is HR-negative or has not responded to

Navigators can prepare the patient and family for ways to recognize these side effects, as well as provide methods to diminish or even prevent them from happening.¹⁴



hormone therapy.⁸ Various classes of drugs can be used to treat MBC. These classes include, but are not limited to, taxanes, anthracyclines, and platinum drugs (**Table 1**).

Bone-Specific Therapies

Drugs and antibodies that build bone may help patients with cancer-related bone metastasis.⁸ These agents are used to control pain and decrease the risk for bone fractures.¹⁴

Combining Systemic Therapies

To individualize treatment, the healthcare team may choose to offer the patient with MBC a combination of systemic therapies. The types of combinations are numerous—hormone therapy may be combined with targeted therapy, chemotherapy with HER2-targeted treatments, multiple chemotherapy drugs may be used together, and chemotherapy and/or targeted therapies are used concurrently with radiation therapy.

TABLE 3. Navigator Skills for Supporting Patients in Clinical Trial Participation

| Class of skill | Navigators' skills/activities |
|-------------------------------------|---|
| Trial identification and enrollment | <ul style="list-style-type: none"> • Develop awareness of trials in MBC through fact-finding and discussion with healthcare team members • Focus on educating and supporting patients on clinical trials, rather than pushing for enrollment • Provide population-appropriate peer support that encourages participation of racial/ethnic minorities and other underserved groups |
| Informed consent | <ul style="list-style-type: none"> • Present the trial option in a neutral way—do not “sell” the trial • View informed consent as a process • Emphasize patient’s right to decline/drop out • Identify and discuss with patient and caregiver any impediments to informed consent and decision-making • Learn the cancer center’s policies and procedures regarding informed consent • Offer support to patients who are considering withdrawing consent after initially consenting to participate; discuss reconsenting |
| Shared decision-making | <ul style="list-style-type: none"> • Facilitate ongoing patient education • Be aware of ethical issues and standards for clinical trials • Encourage patients to report concerns to healthcare team |
| Logistics | <ul style="list-style-type: none"> • Help the patient address issues that interfere with ongoing trial participation: <ul style="list-style-type: none"> — Coverage issues – Example: Work with patient, healthcare team, and cancer center financial staff to learn what the trial pays, what insurance pays, and which costs the patient pays — Transportation/lodging issues – Example: Help patient secure transportation or hotel — Distress/psychosocial issues – Examples: Involve social worker; connect patient with community resources that provide food, social interaction, housing • Literacy/language/cognitive issues – Examples: Identify translators; make reminder calls to patients for testing and treatment/postvisit calls |
| Communication | <ul style="list-style-type: none"> • Maintain open, regular communication among patient/caregiver/healthcare team • Reach out to healthcare team to obtain status updates on patients in trials^a • Encourage patients to communicate with the healthcare team regarding: <ul style="list-style-type: none"> — Adverse effects of treatment — Problems following the treatment/testing plan of the study — Problems remembering to take oral medication |

^aWithin the parameters of HIPAA and the cancer center’s ethical standards for clinical trials.

MBC indicates metastatic breast cancer; HIPAA, Health Insurance Portability and Accountability Act.

Sources: Cartmell KB, et al. *Contemp Clin Trials Commun*. 2016;3:86-93; Fouad MN, et al. *J Oncol Pract*. 2016;12:556-563; Oncology Nursing Society. *2016 Oncology Clinical Trials Nurse Competencies*. www.ons.org/sites/default/files/OCTN_Competencies_FINAL.PDF; Sutter Health/Palo Alto Medical Foundation. www.pamf.org/cancercaare/trials/cost.html.

Different combinations may be tried at different junctures along the treatment pathway—for example, when MBC progresses following a period of time when it was controlled.¹

Clinical Trials

Patients with MBC are often candidates for participation in clinical trials of investigational treatments. As of September 2018, the National Library of Medicine’s site, ClinicalTrials.gov, lists more than 1300 clinical trials in MBC.¹⁵ Some of the drug classes under investigation include:

- Newer TKIs and CDK4/6 inhibitors
- Immunotherapy—therapy targeted to increase the body’s immune response to cancer cells
- PARP inhibitors
- Biosimilars.

TABLE 4. Common Terminology Criteria for Adverse Events Grades for Adverse Effects of Cancer Therapies, v.4.03

| Grade 1 | Grade 2 | Grade 3 | Grade 4 |
|---|---|--|--|
| Mild; asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated | Moderate; minimal, local, or noninvasive intervention indicated; limiting age-appropriate instrumental activities of daily living | Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of hospitalization indicated; disabling; limiting self-care activities of daily living | Life-threatening consequences; urgent intervention indicated |

NOTE: Grade 5, not shown, is death from an adverse event.

SOURCE: National Cancer Institute. Common Terminology Criteria for Adverse Events (CTCAE). v4.03, 2010.

Trial participation is beneficial for patients with MBC, as it gives them access to clinically advanced care delivered with meticulous attention to detail.¹⁷ However, navigating patients through the process of enrollment and participation in a clinical trial can be difficult. In a survey conducted by the Academy of Oncology Nurse & Patient Navigators, which was specific to MBC, navigators said awareness of clinical trials and connecting patients with appropriate trials are among the major challenges they face.¹⁸ Nurse navigators can start a search for MBC trials on ClinicalTrials.gov, and use the website's various filters to narrow down results to a particular area.¹⁵ Also, metastatictrialssearch.org is another patient-friendly search engine for clinical trials.¹⁶

Despite the multitude of clinical trials that are underway at any given time, patients with metastatic disease face issues and barriers that can prevent them from participating in these studies (**Table 2**).^{117,19-21} Navigators can help patients to overcome these barriers and facilitate their participation (**Table 3**).^{17,19-21}

Palliation with Systemic Therapies


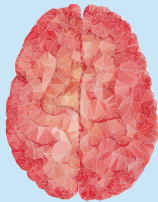
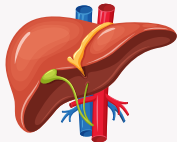
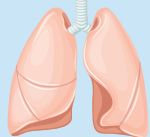
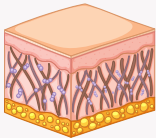
Systemic therapy can be used to palliate specific symptoms in MBC by reducing the burden of the tumor on the body. For instance, chemotherapy or hormonal therapy may be administered to reduce the pain of bone metastasis; if a tumor's growth is causing bowel obstruction, chemotherapy may help clear the obstruction.¹⁰ Conversely, at times, systemic therapy is a hindrance to palliation, rather than a help. Systemic therapy may cause side effects that compromise patients' comfort as well as potentially provide a negative impact on survival time and psychosocial status.^{2,10,22,23}

Addressing Adverse Side Effects of Systemic Therapy

The many types of systemic therapy for MBC come with a vast array of side effects related to these treatments. Some examples are:

- Cardiac/circulatory: bradycardia, tachycardia, fatigue, decrease in cardiac function, QTc prolongation
- Central nervous system: nerve damage (neuropathy), vertigo, brain fog ("chemo brain")
- Endocrine: hot flashes, menopause
- Gastrointestinal: nausea and vomiting, constipation, anorexia, mouth sores (stomatitis)
- Hematologic: neutropenia, leukopenia, anemia, thrombocytopenia
- Integumentary/exocrine: skin rashes, hair loss, discolored and cracked nails, eye problems, etc
- Lymphatic/immune system: lymphedema, infection secondary to neutropenia, myelosuppression
- Muscular: myalgia, arthralgia
- Renal: decreased urinary output, hypercalcemia, swollen hands and feet
- Respiratory: dyspnea, cough.

TABLE 5. Symptoms of Metastatic Breast Cancer Specific to Sites of Metastasis

| Site | Symptoms |
|---|---|
| BONE  | Severe, progressive pain Swelling Bone fractures Spinal cord compression Loss of mobility High levels of calcium in the blood (hypercalcemia), which can adversely affect many other organs |
| BRAIN  | Persistent, progressively worsening headache or intracranial pressure Vision disturbances Seizures Palsy-like symptoms Vomiting or nausea Behavioral changes or personality changes Vertigo Weakness/difficulty ambulating without help Cognitive dysfunction Memory problems/confusion Speech impairment |
| LIVER  | Jaundice Itchy skin/rash Abdominal pain/appetite loss/nausea and vomiting Ascites (abdominal swelling caused by fluid accumulation) Dark-colored urine |
| LUNG  | Chronic, dry cough Dyspnea (perception of impaired breathing, including chest tightness, air hunger, suffocation, the sensation of breathlessness, and increased effort to breathe) Positional shortness of breath Chest pain Hemoptysis (coughing up blood) |
| SKIN  | Wounds, swelling, or rashes that appear on the breast skin, chest, upper arm, abdomen, or back Skin lesions/nodules Scalp lesions Skin infection, draining or bleeding wounds, pain |

Patients require counseling and monitoring for these effects, and must be encouraged to report any troubling symptoms that are possibly related to the use of a drug. When a patient reports an adverse effect, an oncology nurse or other team member will assess the effect. Each institution may have its own guidelines on managing side effects; therefore, it is important to follow the individual guidelines of the center where one works. The Putting Evidence into Practice resources, found on the Oncology Nursing Society website, can be very helpful for navigators to learn more about interventions for specific adverse effects.²⁴

An important factor in the assessment of adverse effects is grading them on a scale of 1 to 4 according to the Common Terminology Criteria for Adverse Events (**Table 4**).²⁶ Grading is essential, because the decision to lower the dose, interrupt, or discontinue a drug is often based on the grade, or severity, of the adverse effect.²⁶

Symptoms of Metastatic Breast Cancer

MBC is not a silent disease—the spread of the cancer announces itself in symptoms. Disease-related symptoms are evaluated separately from the adverse effects that result from cancer treatment. When cancer metastasizes to distant organs, patients may experience symptoms and complications specific to the organs involved (**Table 5**).²⁷⁻³¹

NOTE: This table does not provide an exhaustive list of symptoms.

Sources: Irvin W Jr, et al. *Oncologist*. 2011;16:1203-1214; Tsao MN. *Ann Palliat Med*. 2015;4:225-232; Oltean D, et al. *Tumori*. 2009;95:697-701; Ramakrishna N, et al. *J Clin Oncol*. 2014;32:2100-2108; National Breast Cancer Foundation. www.nationalbreastcancer.org/metastatic-breast-cancer.

In addition to organ-specific symptoms, general symptoms of advancing cancer include^{27,32}:

- Fatigue
- Depression
- Insomnia
- Pain
- Poor appetite/weight loss—a syndrome called cancer cachexia.

The physical, psychosocial, and spiritual comfort of palliation should be part of care for all patients with advanced cancer.

Lymphedema

A common symptom among patients with MBC is lymphedema, which frequently occurs as a result of surgery and can also be related to the disease. Lymphedema is a chronic condition caused by a disruption or damage to the normal drainage pattern in the lymph nodes. It most often causes swelling of the arm, but it can also affect the breast, chest, and sometimes even the legs. Lymphedema is caused by an abnormal buildup of excess fluid. Removing the axillary lymph nodes increases the risk for developing lymphedema. That risk continues for the rest of the patient's life.³¹

Palliation/Relieving Symptoms of MBC

One of the goals of anticancer therapy in MBC is symptom reduction. Diminishing the size and extent of metastasis helps to alleviate symptoms (see Treatment of Metastatic Breast Cancer, page 13). In addition to these therapies, clinicians have many forms of symptom management—called palliation—to offer patients. Palliation was once a term associated with end-of-life care, but that is no longer the case. Major oncology organizations now emphasize that the physical, psychosocial, and spiritual comfort of palliation should be part of care for all patients with advanced cancer.^{2,3,33} This recommendation is supported by clinical evidence from multiple studies.²

Palliation Guidelines

In 2017, the American Society of Clinical Oncology (ASCO) convened members of the ASCO Ad Hoc Palliative Care Expert Panel to develop a guideline update. The resulting publication, "Integration of Palliative Care Into Standard Oncology Care," states that patients with advanced cancer, such as MBC, should receive dedicated, interdisciplinary palliative care early on, while receiving treatment for their cancer.³ Essential components of palliative care include³:

- Rapport-/relationship-building with patients and caregivers
- Symptom, distress, and functional management—for example, pain, shortness of breath (dyspnea), fatigue, sleep disturbance, mood disorder, nausea, or constipation
- Exploration of understanding and education about disease and prognosis
- Clarification of treatment goals
- Assessment and support of coping skills
- Assistance with medical decision-making (discussion of healthcare proxies and advance directives)
- Coordination with other care providers
- Provision of referrals to other care providers, as needed.

Relieving Symptoms

A variety of medications are prescribed to help manage the numerous symptoms experienced by patients with MBC. The following are some common methods used to treat these symptoms:

Medication

- Opioid and nonopioid analgesic medications can relieve bone and other types of pain
- Adjuvant pain medications, including antidepressants and anticonvulsants, manage pain arising from nerve damage or sensitization (neuropathic pain)²⁷
- Mood disorders and insomnia can be treated with antidepressant medication, anti-anxiety medication, and prescription sleep aids²⁷
- Medications for control of nausea and vomiting²⁷
- Other specific symptoms may be managed with medication at the clinician's recommendation
- Nerve blocks.^{10,27}

Radiation Therapy

Therapeutic radiation may be given by an external beam or by injecting radioactive isotopes into the body. Radiation may relieve multiple symptoms. For example, bone pain may respond to localized radiation.²⁷ In brain metastasis, radiation therapy may be part of a multimodal strategy to reduce disease and, in doing so, manage symptoms.³⁰

Surgery

Palliative surgery relieves a range of symptoms in MBC, such as skin wounds and pain.¹ Surgical care of fractures and of metastasis in the brain, liver, or chest wall may also be recommended for some patients.³⁴

Integrative Care

Patients may also find relief of pain, distress, and fatigue through integrative therapies. Interventions include, but are not limited to^{10,22,35}:

- Massage (cancer massage—by someone certified in cancer massage)
- Acupuncture
- Mindfulness practice
- Relaxation
- Yoga (gentle yoga)
- Cognitive behavioral therapy
- Reiki
- Counseling.

References: 1. National Comprehensive Cancer Network. *NCCN Clinical Practice Guidelines in Oncology. Breast cancer.* v3. 2017. www.nccn.org/professionals/physician_gls/pdf/breast.pdf. Accessed November 12, 2017. 2. Smith TJ, Temin S, Alesi ER, et al. American Society of Clinical Oncology provisional clinical opinion: the integration of palliative care into standard oncology care. *J Clin Oncol.* 2012;30:880-887. 3. Ferrell BR, Temel JS, Temin S, et al. Integration of palliative care into standard oncology care: American Society of Clinical Oncology Clinical Practice Guideline update. *J Clin Oncol.* 2017;35:96-112. 4. Elwyn G, Frosch D, Thomson R, et al. Shared decision making: a model for clinical practice. *J Gen Intern Med.* 2012;27:1361-1367. 5. Krøigård AB, Larsen MJ, Thomassen M, Kruse TA. Molecular concordance between primary breast cancer and matched metastases. *Breast J.* 2016;22:420-430. 6. Balogh EP, Ganz PA, Murphy SB, Nass SJ, Ferrell BR, Stovall E. Patient-centered cancer treatment planning: improving the quality of oncology care. Summary of an Institute of Medicine workshop. *Oncologist.* 2011;16:1800-1805. 7. National Cancer Institute. Hormone therapy for breast cancer. www.cancer.gov/types/breast/breast-hormone-therapy-fact-sheet. Accessed November 24, 2017. 8. National Cancer Institute. Breast cancer treatment (PDQ®)—patient version. www.cancer.gov/types/breast/patient/breast-treatment-pdq#section/_222. Accessed November 10, 2017. 9. National Cancer Institute. Radiation therapy to treat cancer. Updated July 19, 2017. www.cancer.gov/about-cancer/treatment/types/radiation-therapy/radiation-fact-sheet. Accessed November 24, 2017. 10. National Comprehensive Cancer Network. *NCCN Clinical Practice Guidelines in Oncology. Adult cancer pain.* v2. 2017. www.nccn.org/professionals/physician_gls/pdf/pain.pdf. Accessed November 27, 2017. 11. Rugo HS, Rumble RB, Macrae E, et al. Endocrine therapy for hormone receptor-positive metastatic breast cancer: American Society of Clinical Oncology guideline. *J Clin Oncol.* 2016;34:3069-3103. 12. National Comprehensive Cancer Network. *NCCN Guidelines for Patients. Breast cancer, metastatic.* v2. 2017. <http://nccn.org/patients>. Accessed November 24, 2017. 13. Susan G. Komen. Emerging areas in metastatic breast cancer treatment. Updated August 31, 2018. www5.komen.org/BreastCancer/EmergingMetastaticBreastCancer.html. Accessed September 22, 2018. 14. Burhansstipanov L, Shockney LD. The role of the navigator during a patient's cancer treatment. In: Shockney LD (ed). *Team-Based Oncology Care: The Pivotal Role of Oncology Navigation.* Chapter 8. Cham, Switzerland: Springer International; 2018:149-176. 15. National Cancer Institute. Cancer pain. Updated September 18, 2018. www.cancer.gov/about-cancer/treatment/side-effects/pain/pain-pdq#iink/_230. Accessed November 26, 2017. 16. ClinicalTrials.gov. Search of metastatic breast cancer. <https://clinicaltrials.gov/ct2/results?cond=metastatic+breast+cancer&term=&cntry1=&state1=&Search=Search>. Accessed September 3, 2018. 17. Cartmell KB, Bonilha HS, Matson T, et al. Patient participation in cancer clinical trials: a pilot test of lay navigation. *Contemp Clin Trials Commun.* 2016;3:86-93. 18. AONN+ Metastatic Survey Data. Data on file. Cranbury, NJ: Academy of Oncology Nurse & Patient Navigators (AONN+). 2017. 19. Metastatic Breast Cancer Trials Search. www.breastcancertrials.org. Accessed October 22, 2018. 20. Fouad MN, Acemgil A, Bae S, et al. Patient navigation as a model to increase participation of African Americans in cancer clinical trials. *J Oncol Pract.* 2016;12:556-563. 21. Oncology Nursing Society. 2016 *Oncology Clinical Trials Nurse Competencies.* www.ons.org/sites/default/files/OCTN_Competencies_FINAL.PDF. Accessed November 24, 2017. 22. Sutter Health/Palo Alto Medical Foundation. The cost of clinical trials. www.pamf.org/cancer-care/trials/cost.html. Accessed November 28, 2017. 23. National Comprehensive Cancer Network. *NCCN Clinical Practice Guidelines in Oncology. Cancer-related fatigue.* v2. 2017. www.nccn.org/professionals/physician_gls/pdf/fatigue.pdf. Accessed November 27, 2017. 24. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med.* 2010;363:733-742. 25. Oncology Nursing Society. PEP rating system overview. www.ons.org/practice-resources/pep. Accessed September 2018. 26. National Cancer Institute. Common Terminology Criteria for Adverse Events (CTCAE). v4.03. 2010. 27. Irvin W Jr, Muss HB, Mayer D. Symptom management in metastatic breast cancer. *Oncologist.* 2011;16:1203-1214. 28. Tsao MN. Brain metastases: advances over the decades. *Ann Palliat Med.* 2015;4:225-232. 29. Oltean D, Dicu T, Eniu D. Brain metastases secondary to breast cancer: symptoms, prognosis and evolution. *Tumori.* 2009;95:697-701. 30. Ramakrishna N, Temin S, Chandralapaty S, et al. Recommendations on disease management for patients with advanced human epidermal growth factor receptor 2-positive breast cancer and brain metastases: American Society of Clinical Oncology Clinical Practice Guideline. *J Clin Oncol.* 2014;32:2100-2108. 31. National Breast Cancer Foundation. Metastatic breast cancer. 2016. www.nationalbreastcancer.org/metastatic-breast-cancer. Accessed November 17, 2017. 32. Blum D, Omrin A, Baracos VE, et al. Cancer cachexia: a systematic literature review of items and domains associated with involuntary weight loss in cancer. *Crit Rev Oncol Hematol.* 2011;80:114-144. 33. National Comprehensive Cancer Network. *NCCN Clinical Practice Guidelines in Oncology. Palliative care.* v2. 2017. www.nccn.org/professionals/physician_gls/pdf/palliative.pdf. Accessed November 27, 2017. 34. Cardoso F, Costa A, Senkus E, et al. 3rd ESO-ESMO international consensus guidelines for advanced breast cancer (ABC 3). *Ann Oncol.* 2017;28:16-33. 35. National Comprehensive Cancer Network. *NCCN Clinical Practice Guidelines in Oncology. Distress management.* v2. 2017. www.nccn.org/professionals/physician_gls/pdf/distress.pdf. Accessed November 27, 2017.



III. COMMUNICATION DURING TREATMENT

Treatment of metastatic breast cancer (MBC) is often complex, and will continue for the duration of the patient’s life. Navigators play key roles in facilitating communication among the patient, family, and care team. Effective communication is a necessity in patient navigation, as noted in both the *2017 Oncology Nurse Navigator Competencies* issued by the Oncology Nursing Society (ONS) and the *Core Competencies for Non-Clinically Licensed Patient Navigators from The George Washington University (GW) Cancer Institute*.^{1,2}

In its toolkit for MBC, the Association of Community Cancer Centers maps the communication process through diagnosis, treatment, treatment monitoring, treatment failure and retreatment, and end of life

(**Figure 1**).³The map emphasizes how communication applies 6 “support principles” in navigation³:

1. Empower the patient
2. Reframe the conversation (to remove self-blame, negativity)
3. Reduce patient isolation

Communication Competency:

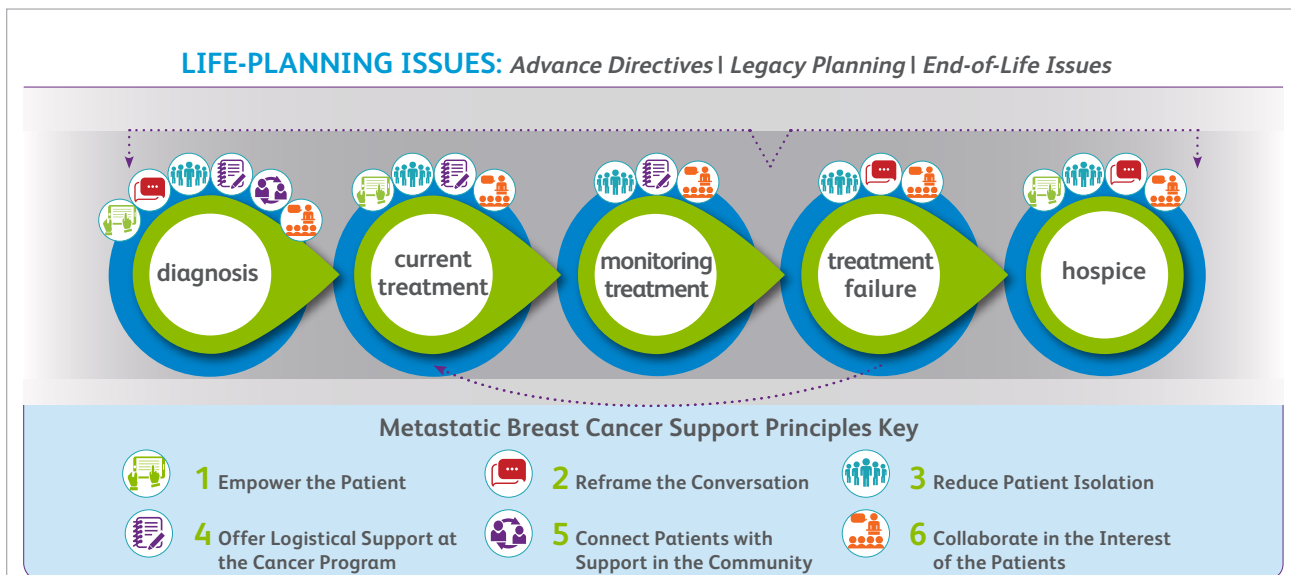
Clinical Navigator

The navigator—“demonstrates interpersonal communication skills that enable exchange of ideas and information effectively with patients, families, and colleagues at all levels. This includes writing, speaking, and listening skills.”¹

Patient Navigator

The navigator will—“demonstrate interpersonal and communication skills that result in the effective exchange of information and collaboration with patients, their families, and health professionals.”²

FIGURE 1. ACCC Communication Process Map for Metastatic Breast Cancer



ACCC indicates Association of Community Cancer Centers.

Source: Association of Community Cancer Centers. www.accc-cancer.org/resources/pdf/MBC_Workbook.pdf.

4. Offer logistical support at the cancer program
5. Connect patients with support in the community
6. Collaborate in the interest of patients.

Healthcare Team Responsibilities

In the care of MBC, many professionals treat and support the patient, including:

- Medical oncologist – Physician who evaluates, treats, and monitors the patient through all phases of MBC
- Radiation oncologist – Physician who administers radiation to treat cancer in localized areas for symptom management
- Surgeon (eg, general surgeon, plastic surgeon, breast surgical oncologist, neurosurgeon) – Physician who conducts surgery to remove tumors or manage symptoms
- Pathologist – Physician who analyzes the characteristics of metastatic tumors, including hormonal and genomic features
- Radiologist – Physician who conducts diagnostic imaging (such as x-rays or computed tomography scans)
- Advanced practitioner – Nurse practitioner or physician assistant, who is highly trained to care for and manage patients with a variety of illnesses; he or she works alongside the physicians and is an integral part of the team
- Clinical navigator – Oncology patient navigator should have knowledge of cancer screening guidelines, diagnostic processes, treatment options, and survivorship, as well as related physical, psychological, and social issues that may confront patients with cancer. Working at the top of his or her licensure, a nurse navigator or social work navigator should have knowledge of the clinical impact of cancer on patients, caregivers, and families, as well as the skills needed to intervene on their behalf (eg, assess functional and psychosocial health and manage symptoms).⁴ For clinically licensed navigators (such as the nurse navigator or social work navigator) within the healthcare system, the focus of evaluation should be clinical outcomes and quality indicators⁴
- Nonclinical patient navigator – Should have general knowledge of health issues, such as cancer and chronic diseases. During the course of their work, they focus their evaluation on the community's needs and health behaviors.⁴ Patient navigators straddle the boundary between the community and the healthcare setting by evaluating barriers to care and health disparities within the community against quality indicators of the healthcare system⁴
- Oncology nurse – Specialist nurse who gives anticancer medication and ensures the continuity of care
- Other medical specialists – Physicians who care for organ- or system-specific symptoms (eg, dermatologists for rashes and skin wounds, neurologists for brain and nervous system symptoms)
- Genetic counselor – Healthcare professional with specialized training in medical genetics and psychological counseling, who works as a patient advocate as well as a genetic resource to physicians⁵
- Palliative care specialist – Physician or others who assist with symptom management through medication/surgery/radiation and psychosocial/spiritual support
- Support professionals – Physical therapists, pulmonary therapists, lymphedema specialists, counselors and psychotherapists, nutritionists, social workers, financial navigators, and others who provide supportive care
- Chaplain – Clergy and counselors who provide spiritual support

Navigators must remember to comply with the privacy provisions in the Health Insurance Portability and Accountability Act when discussing patient information.



- Hospice staff – Supports and prepares patients for end of life once treatment has been agreed upon to be discontinued. Dying with dignity, pain in control, quality of life preserved, elements of experiencing a good peaceful death fulfilled.

Patient Responsibilities

Patients with MBC have their own set of responsibilities. These include:

- Providing the treatment team information about any medications/supplements taken, as well as side effects and symptoms she/he is experiencing so they can be more effectively managed
- Adhering to medications as prescribed and maintaining appointment schedules
- Informing the healthcare team members of her/his goals of care (these will likely change over time)
- Informing the appropriate team members (such as the clinical navigator and medical oncologist) of her/his current significant milestones and future life goals, so they can be incorporated into the treatment planning process and fulfilled while living or in alternative ways after death
- Actively participating in the decision-making about her/his treatment and care options
- Requesting assistance from members of the team if family members are interfering with her/his wishes and goals of care
- Always being honest with the team members how she/he is feeling, what she/he is most worried about, and what she/he needs spiritually, emotionally, and physically.

Adherence to Treatment

Adherence means sticking with all aspects of treatment—keeping appointments for intravenous drug therapy, taking oral medications as prescribed, making routine visits for any testing needed to confirm response to treatment, and so on.

Distress, however, can be a deterrent to adherence for many patients. A patient with MBC who feels physical pain, social isolation, and mental confusion, and as a result, skips doses of oral medication, exemplifies the effect of distress on adherence. Patients with metastatic cancer often experience distress, and it can interfere with their willingness or ability to comply with treatment.⁶ Types of distress that can affect adherence include⁶:

- Fear and concern about the future
- Concerns about illness
- Anger related to lack of control
- Poor sleep and appetite
- Poor concentration
- Preoccupation with thoughts of illness and death
- Concerns with disease or treatment side effects
- Concerns about social role (father, mother, husband, or wife).

There are also times that the patient may not be honest about the side effects or symptoms she/he is

“A navigator’s role is integral in getting to learn about our patients, developing a trusting relationship and ensuring that we are there to assist them through this journey. We need to be able to have an open, shared and trusting communication with patients and families.”

*Cheryl Bellomo, MSN, RN, OCN, ONN-CG,
Oncology Nurse Navigator,
Intermountain Cancer Center*



Navigators play a key role in supporting and encouraging patients to adhere to therapy. Patients may not understand all the information given to them by their oncology providers.¹



experiencing, in fear that the treatment will be discontinued or the dosage reduced. Again, the importance of the patient working with her/his treatment team is key; therefore, honesty is also key or more harm may come to the patient than benefit from the current treatment she/he is receiving.

Clinical navigators can help reiterate medical information in ways that make it more understandable for the patient. They can help the patient understand the purpose of the medications and create a reliable way for the patient to remember to take medications as prescribed.⁷ An increasing number of anticancer medications are given orally. The patient is responsible for taking them at home, on a schedule, unlike injectable medications that require a visit to a treatment center. However, with the convenience of oral medications comes the risk for poor adherence to therapy.

Distress is an especially pronounced risk factor for nonadherence to oral medications, and must be addressed and relieved.⁶ Other specific risk factors for nonadherence to oral medications that are relevant to the patient include⁸:

- Patient factors, such as poor financial resources (eg, as the result of inability to work)
- Psychosocial and cognitive factors, such as verbal memory problems (eg, due to brain metastasis)
- Disease factors, such as longer duration since diagnosis (eg, in patient with MBC as a recurrence) or worse disease severity marker (eg, triple-negative breast cancer).

Reasons for nonadherence span factors related to the patient, disease, treatment, provider, and healthcare system, but all result in poorer clinical outcomes.⁸ Overall, patients with all types of metastatic solid tumors, their caregivers, and healthcare professionals report fairly high levels of adherence to oral medication—more

Patients with metastatic cancer may experience distress, which can interfere with their willingness or ability to adhere to treatment.

than 80% take their medication always or almost always as prescribed. However, 2 factors complicate this scenario. First, assessment of adherence may differ with the different perspectives of patients, caregivers, and the healthcare team. Patients may state that they took the medication when they did

not. Second, approximately 5% to 10% of patients with a metastatic solid tumor fail to adhere to oral anticancer medication.⁹

Two tools the clinical navigator can utilize to improve oral adherence among patients are^{10,11}:

- Medication Nonadherence Risk Tool Assessment: http://adultmeducation.com/downloads/Nonadherence_Risk_TOOL.pdf
- ONS Oral Adherence Toolkit: https://www.ons.org/sites/default/files/ONS_Toolkit_ONLINE.pdf.

References: 1. Oncology Nursing Society. 2017 Oncology Nurse Navigator Core Competencies. www.ons.org/sites/default/files/2017ONNcompetencies.pdf. Accessed November 10, 2017. 2. Pratt-Chapman ML, Willis LA, Masselink L. *Core Competencies for Non-Clinically Licensed Patient Navigators from The George Washington University (GW) Cancer Institute*. Washington, DC: The George Washington University Cancer Institute; 2014. 3. Association of Community Cancer Centers. *Metastatic Breast Cancer: Effective Principles & Practices in Patient Support*. www.accc-cancer.org/resources/pdf/MBC_Workbook.pdf. Accessed November 10, 2017. 4. Willis A, Reed E, Pratt-Chapman M, et al. Development of a framework for patient navigation: delineating roles across navigator types. *J Oncol Navig Surviv*. 2013;4:20-26. 5. Academy of Oncology Nurse & Patient Navigators. Helpful definitions. www.aonnonline.org/education/helpful-definitions. Accessed December 18, 2017. 6. National Comprehensive Cancer Network. *NCCN Clinical Practice Guidelines in Oncology. Distress management*. v2. 2017. www.nccn.org/professionals/physician_gls/pdf/distress.pdf. Accessed November 27, 2017. 7. Burhansstipanov L, Shockney LD. The role of the navigator during a patient's cancer treatment. In: Shockney LD (ed). *Team-Based Oncology Care: The Pivotal Role of Oncology Navigation*. Chapter 8. Cham, Switzerland: Springer International; 2018:149-176. 8. Greer JA, Amoyal N, Nisotel L, et al. A systematic review of adherence to oral antineoplastic therapies. *Oncologist*. 2016;21:354-376. 9. Feiten S, Weide R, Friesenhahn V, et al. Adherence assessment of patients with metastatic solid tumors who are treated in an oncology group practice. *Springerplus*. 2016;5:270. 10. Medication nonadherence risk assessment. http://adultmeducation.com/downloads/Nonadherence_Risk_TOOL.pdf. 11. Oncology Nursing Society. ONS oral adherence toolkit. 2016. https://www.ons.org/sites/default/files/ONS_Toolkit_ONLINE.pdf. Accessed September 16, 2018.

IV. METASTATIC BREAST CANCER MYTHS AND FACTS

Although the level of awareness about early-stage breast cancer is high, knowledge of metastatic breast cancer (MBC) remains low. *Breast Cancer: A Story Half Told, A Focus on Metastatic Disease*¹ is an excellent tool for understanding these issues.

In a survey conducted in 2014, 60% of people reported that they know little to nothing when it comes to MBC. Lack of awareness of MBC is particularly acute among individuals earning less than \$35,000 annually.¹ This lack of knowledge leads to misconceptions about MBC, as shown in **Table 1**.¹⁻⁷

TABLE 1. Myths and Facts

| Myth | Fact |
|---|---|
| “People cause themselves to get MBC by not taking care of their health—not dealing with stress, missing checkups, not having mammograms, etc” | MBC can happen regardless of health habits, self-care, or getting checkups. 30% of women who had early breast cancer will eventually develop MBC. |
| Most people believe breast cancer rates are the same across various ethnic groups | 5-year survival is much lower in certain ethnic groups: <ul style="list-style-type: none"> • African American women are 40% more likely to die than white women • For Hispanic women, breast cancer is the leading cause of cancer death |
| Patients and oncologists talk openly about diagnosis and treatment plans | Patients do not have a high level of engagement during office visits. Patients offer minimal input and ask few questions. <ul style="list-style-type: none"> • 50% of MBC patients believe they have a voice in treatment and 50% see it as the oncologist’s responsibility |
| “Once you have MBC, you don’t have long to live” | People with MBC can live for many years after diagnosis—about a quarter of patients diagnosed with MBC live for 5 years or more. |
| “When people have MBC, they have to withdraw from life because no one understands” | There are ways for patients with MBC to stay connected: <ul style="list-style-type: none"> • Joining in-person and online patient support groups • Seeking help from mental health professionals and social workers • Speaking honestly, sharing openly, and learning together about MBC with loved ones • Remembering that MBC is not shameful and is not a punishment—dealing with negative feelings can prevent a patient from withdrawing socially • Understanding that their need for support and encouragement never ends because they will always be in treatment |
| “You cannot keep working when you have MBC” | 50% of employed individuals with MBC stop working within a year after diagnosis—but 50% do not. MBC is not automatically an end to professional life; 56% of patients with breast cancer and 46% of patients with MBC who were surveyed said they preferred to continue working. In addition, when someone with MBC stops working, there are sources of financial help, including Social Security Disability and the cancer center’s financial assistance team. |
| “If you find breast cancer early, you cannot get metastasis” | MBC may occur as a recurrence after early treatment of breast cancer; 30% of women diagnosed early with breast cancer eventually develop metastatic disease. |
| “The drugs for MBC are a cure for the cancer” | Patients treated with drugs for MBC are not cured but may continue to live with continuous ongoing treatment. |

MBC indicates metastatic breast cancer.

Sources: Pfizer Oncology. www.pfizer.com/files/news/Statement_ofNeed.pdf; Redig AJ, McAllister SS. *J Intern Med*. 2013;274:113-126; Rugo HS, Rumble RB, et al. *J Clin Oncol*. 2016;34:3069-3103; Mayer M, Crawford-Gray K. Metastatic Breast Cancer Alliance. *Changing the Landscape for People Living with Metastatic Breast Cancer*, 2nd ed. New York, NY: Metastatic Breast Cancer Alliance/Avon Foundation for Women; 2014:57-73; Association of Community Cancer Centers. www.accc-cancer.org/resources/pdf/MBC_Workbook.pdf; Weeks JC, et al. *N Engl J Med*. 2012;367:1616-1625; Pfizer Oncology. https://www.pfizer.com/files/news/BC_Abbreviated_Workplace_Report.pdf.

Patients with breast cancer, their friends, and family members—and even some healthcare professionals and navigators—may believe myths about MBC. Learning the facts, debunking the myths, and sharing the truth are important components of navigator communication and education.

Navigators can make a big difference in replacing patients' mistaken beliefs with facts.



References: 1. Pfizer Oncology. *Breast Cancer: A Story Half Told, A Focus on Metastatic Disease*. www.pfizer.com/files/news/Statement_ofNeed.pdf. Accessed December 2, 2017. 2. Redig AJ, McAllister SS. Breast cancer as a systemic disease: a view of metastasis. *J Intern Med*. 2013;274:113-126. 3. Rugo HS, Rumble RB, Macrae E, et al. Endocrine therapy for hormone receptor–positive metastatic breast cancer: American Society of Clinical Oncology guideline. *J Clin Oncol*. 2016;34:3069-3103. 4. Mayer M, Crawford-Gray K. Analysis of quality of life research on living with MBC. In: Metastatic Breast Cancer Alliance. *Changing the Landscape for People Living with Metastatic Breast Cancer—Effective Principles & Practices in Patient Support*. www.accc-cancer.org/resources/pdf/MBC_Workbook.pdf. Accessed November 10, 2017. 5. Association of Community Cancer Centers. *Metastatic Breast Cancer—Effective Principles & Practices in Patient Support*. www.accc-cancer.org/resources/pdf/MBC_Workbook.pdf. Accessed November 10, 2017. 6. Weeks JC, Catalano PJ, Cronin A, et al. Patients' expectations about effects of chemotherapy for advanced cancer. *N Engl J Med*. 2012;367:1616-1625. 7. Pfizer Oncology. Breast Cancer and the Workplace. July 30, 2014. https://www.pfizer.com/files/news/BC_Abbreviated_Workplace_Report.pdf.

V. NAVIGATION IN THE CONTEXT OF METASTATIC BREAST CANCER

Navigators in MBC

A specific evidence-based model of navigation for metastatic breast cancer (MBC) does not exist; therefore, MBC navigators will need to follow the general models of navigation, as outlined in the *Pfizer General Navigation Toolkit*. There are several different navigator roles that may be involved in the support of patients with MBC.

Clinical navigators – These navigators support the patient with MBC from the time of diagnosis through end of life. They have the education and professional experience to help the patient understand the complicated medical terminology and decision-making that is part of their cancer journey. Clinical navigators:

- Must determine the level of distress the patient is experiencing. The Commission on Cancer recommends that all patients with cancer be screened for distress a minimum of 1 time during a pivotal medical visit. Pivotal medical visits that confer the greatest risk for distress, such as recurrence/progression, advanced cancer, and end of life, can be given preference¹
- Should have knowledge of the clinical impact of cancer on patients, caregivers, and families, as well as the skills needed to intervene on their behalf (eg, assess functional and psychosocial health and manage symptoms)²
- Facilitate shared decision-making and empower patients to identify their life goals. The goal of shared decision-making is to afford patients autonomy by offering information and supporting the decision-making process³
- Provide access to timely care, facilitate coordination of care, and ensure that the treatment plan is followed
- Can determine what the patient understands about the diagnosis and plan of care, and review what the patient has been told. Can review recommended treatments with the patient and answer specific questions regarding medications
- Search for appropriate clinical trials and discuss this with the oncologist and the clinical trials coordinator. Education can then be provided on clinical trials that are available to the patient
- Address the importance of palliative care from the beginning of the MBC diagnosis, if not already done
- Obtain from the patient a list of life goals in the short-term and long-term future that carry significance and may be achievable while living or need to be fulfilled in alternative ways on his/her behalf (such as a card and letter for a 10-year-old daughter who will marry one day in the distant future)
- With the palliative care team, can review the elements that must be fulfilled to experience a peaceful death.

A valuable reference tool from the Association of Community Cancer Centers is the 2018 ACCC Financial Advocacy Services Guidelines.⁴

Social work navigators:

- Address practical, family, and emotional barriers that were noted on the National Comprehensive Cancer Network Distress Tool
- Complete a psychosocial assessment and offer interventions as deemed appropriate
- Can address advance care planning and answer questions the patient may have about this topic.

Financial navigators work closely with the patient to discuss:

- Their insurance benefits and out-of-pocket cost obligations
- For patients in need, the resources available to assist them in defraying their out-of-pocket cost burden.⁵

Nonclinical patient navigators assist with^{2,5}:

- Transportation issues
- Recommending resources within the community that can help the patient, such as temporary housing and food banks
- Introduction to support groups for patient and family or caregiver.

Refer to Pfizer General Navigation Toolkit:

Models of Navigation, pages 15-16.

Goals of Navigation, pages 16-17.

Barriers to Care, pages 19-21.

Distress and Psychosocial Needs, pages 23-27.

VI. NAVIGATION CORE COMPETENCIES SPECIFIC TO METASTATIC BREAST CANCER

Navigators must demonstrate competence in oncology, as well as the psychosocial and spiritual aspects of care for patients and families. The National Navigation Roundtable has created 7 nationally recognized domains of competency for navigators.¹ One of the most important core competencies for the metastatic breast cancer (MBC) clinical and nonclinical navigator is patient care coordination. The clinical navigator acts as a liaison among all team members to advocate for patients with MBC to optimize health and wellness by improving access to services.² The nonclinical navigator can assist with evaluating barriers to care and health disparities within the community against quality indicators of the healthcare system. Patients with MBC also need to have a clinical navigator who can assist them in shared decision-making based on their needs, goals, strengths, barriers, solutions, and resources.¹

Educating the patient and family is a key role for the clinical navigator to perform; this education helps patients to more confidently engage in decision-making about treatment. It also helps promote adherence to care.³ Health knowledge is paramount to navigating patients with MBC. Sensitivity and responsiveness to diversity in gender, age, ethnicity, and abilities, respecting confidentiality and ethical principles, are also necessary when managing patients with MBC.

“In today’s fragmented healthcare system, patients need to know they can turn to a trained navigator to guide them through their cancer journey. Navigators should be educated to deliver patient-centered care, and core competencies are essential to driving the framework for training and professional standards.”

Monica Dean, Director, American Cancer Society National Navigation Roundtable



Refer to Pfizer General Navigation Toolkit:

Navigation Core Competencies, pages 11-12

Navigators must create and maintain positive interpersonal interactions that lead to trust and collaboration among the patient, family, caregivers, and the entire healthcare team.¹



References: 1. American Cancer Society National Navigation Roundtable Training & Certification Working Group. Navigator Core Competencies. 2018. www.navigationroundtable.org. 2. Strusowski T. Navigation and survivorship 101. Presented at: Academy of Oncology Nurse & Patient Navigators (AONN+) 6th Annual Navigation & Survivorship Conference; October 1-4, 2015; Atlanta, GA. 3. Burhansstipanov L, Shockney LD. The Role of the Navigator During a Patient’s Cancer Treatment. In: Shockney LD (ed). *Team-Based Oncology Care: The Pivotal Role of Oncology Navigation*. Chapter 8. Cham, Switzerland: Springer International; 2018:149-176.



VII. BARRIERS TO CARE ALONG THE PATHWAYS

Barriers to care can occur at any step in the clinical course of metastatic breast cancer (MBC; **Table 1**). Across the cancer care continuum, the goals of the navigator are to¹:

- Identify and address barriers to care
- Empower patients with appropriate education and awareness to make informed decisions
- Provide psychosocial support and access to resources
- Advocate for each patient’s unique needs with cultural awareness regarding the use of facility and community resources
- Encourage patients’ engagement in their care planning
- Streamline care path transitions and logistical issues (diagnosis, treatment, survivorship, and end of life)
- Liaise between clinical and nonclinical specialists on the multidisciplinary cancer care team.

“Navigators are essential in identifying and overcoming all different types of barriers and in finding solutions.”

*Linda Burhansstipanov, DrPH, MSPH,
President, Native American Cancer
Initiatives, Incorporated*



Poorly coordinated care transitions can lead to increased emergency department utilization and hospital readmission rates, resulting in increased healthcare costs.² Having the navigator move with the patient and family throughout the cancer care continuum, providing patient-centered care, can lead to better outcomes.

Evaluation of Psychosocial Issues

Care of the patient with MBC requires a discussion of the goals of therapy and a commitment to shared decision-making between the patient and the healthcare team.³ This is important in the development of a

TABLE 1. Barriers to Care in Metastatic Breast Cancer

| Barriers to Care | | |
|--|---|---|
| Patient/caregiver | Healthcare team | Healthcare system |
| <ul style="list-style-type: none"> • Discouragement over complex process and terminology • Feeling that the patient did something to cause breast cancer • Fear that MBC is an immediate death sentence • Lack of assertiveness (eg, fear of asking questions) • Literacy barriers (eg, education level, language barriers) • Distress and its causes (eg, financial problems, emotional problems) | <ul style="list-style-type: none"> • Inefficiency in coordination of care over time and across specialties • Failure to adopt and pursue shared decision-making • Inadequate patient education, including failure to simplify medical terminology (information overload) • Cultural insensitivity in communication • Lack of written plans and documentation • Lack of time | <ul style="list-style-type: none"> • Lack of resources • Inability to offer financial incentives for the healthcare team to devote more time to care • Healthcare system fragmentation, inefficiency, and waste • Lack of insurance reimbursement for noninterventional activity (eg, planning, patient education, end-of-life discussions) |

MBC indicates metastatic breast cancer.

Sources: National Comprehensive Cancer Network. www.nccn.org/professionals/physician_gls/pdf/breast.pdf; National Comprehensive Cancer Network. www.nccn.org/professionals/physician_gls/pdf/distress.pdf; Oncology Nursing Society. www.ons.org/sites/default/files/2017ONNcompetencies.pdf; Association of Community Cancer Centers. www.acc-cancer.org/resources/pdf/MBC_Workbook.pdf; Balough EP, et al. *Oncologist*. 2011;16:1800-1805; National Comprehensive Cancer Network. <http://nccn.org/patients>. Accessed November 24, 2017.

realistic treatment plan. To facilitate this kind of care, it is important to understand each patient's mental, emotional, financial, and social needs.

A survey of the Academy of Oncology Nurse & Patient Navigators membership showed that some of the major challenges in MBC navigation include patients' financial problems and cost of treatment; food insecurity; the stress of waiting for test results; patient–clinician miscommunication; and the emotional process of MBC acceptance.⁴

Therefore, psychosocial evaluation must document the patient's^{5,6}:

- Emotional response to the diagnosis of MBC and its treatment
- Cognitive (mental) function
- Sexual/social function and work productivity
- Issues of personal care and appearance
- Mood and coping (eg, depression or other mood disorder)
- Family and caregiver relationships
- Financial status or difficulties
- Cultural attitudes.

The patient with MBC may feel isolated or alienated from others, and may even self-isolate and pull back from loved ones.⁵ Patients also have spiritual needs as they search for meaning in their suffering and come to terms with mortality.⁵ It is critical to assess the psychosocial needs of patients with MBC so that they can be referred to appropriate supportive resources.

When patients are diagnosed with MBC, they should be assessed for distress by the navigator. It is worth noting that the distress associated with metastatic disease can be worse than that associated with early disease, and can reach clinically significant levels.^{7,8} Importantly, recurrence may be viewed as a failure by the patient and treatment team, and many patients blame themselves for their disease or recurrence.⁹

Refer to Pfizer General Navigation Toolkit:

Barriers to Care, pages 19-21

References:1. Strusowski T. Navigation and Survivorship 101. Presented at: Academy of Oncology Nurse & Patient Navigators (AONN+) 6th Annual Navigation & Survivorship Conference; October 1-4, 2015; Atlanta, GA. 2. Johnston D, Strusowski T, Bellomo C, Burhansstipanov L. Navigation across the continuum of care. In: Shockney LD (ed). *Team-Based Oncology Care: The Pivotal Role of Oncology Navigation*. Chapter 5. Cham, Switzerland: Springer International; 2018:85-110. 3. National Comprehensive Cancer Network. *NCCN Clinical Practice Guidelines in Oncology. Breast cancer*. v3. 2017. www.nccn.org/professionals/physician_gls/pdf/breast.pdf. Accessed November 12, 2017. 4. AONN+ Metastatic Survey Data. Data on file. Cranbury, NJ: Academy of Oncology Nurse & Patient Navigators (AONN+). 2017. 5. Mosher CE, Johnson C, Dickler M, Norton L, Massie MJ, DuHamel K. Living with metastatic breast cancer: a qualitative analysis of physical, psychological, and social sequelae. *Breast J*. 2013;19:285-292. 6. Mayer M, Crawford-Gray K. Analysis of quality of life research on living with MBC. In: Metastatic Breast Cancer Alliance. *Changing the Landscape for People Living with Metastatic Breast Cancer*. 2nd ed. New York, NY: Metastatic Breast Cancer Alliance/Avon Foundation for Women; 2014:57-73. 7. Watts K, Meiser B, Conlon H, et al. A specialist breast care nurse role for women with metastatic breast cancer: enhancing supportive care. *Oncol Nurs Forum*. 2011;38:627-631. 8. Williams M. What Are the Experiences of Supportive Care for Women with Metastatic Breast Cancer? University of New Brunswick. <https://journals.lib.unb.ca/index.php/NURS/article/download/21171/24507>. Accessed September 24, 2018. 9. Monti DA, Mago R, Shakin Kunkel EJ. Depression, cognition, and anxiety among postmenopausal women with breast cancer. *Psychiatr Serv*. 2005;56:1353-1355.

VIII. DISTRESS SPECIFIC TO METASTATIC BREAST CANCER

Distress

Distress in cancer care is defined as an unpleasant experience composed of many factors—psychological, social, spiritual, and physical—that can interfere with a patient’s ability to cope with cancer and its treatment.¹ Each patient with metastatic breast cancer (MBC) who experiences distress has a unique profile of challenges and emotions that contribute to feelings of distress. The psychosocial care of patients with MBC should focus on alleviation of distress, delivery of health information and education, maintenance of continuity of care, provision of assistance with financial and child care needs, and support in end-of-life care.²

“There are many psychosocial issues that patients and their caregivers experience. I think the hardest part for the medical community is to figure out how to get the patient to share what those issues are. Many of our patients don’t share that information with the physician because they do not want to burden the physician. So, unless we are actually asking the question, we are not going to get the answer.”

Jennifer Klemp, PhD, MPH, MA, Associate Professor of Medicine, Division of Clinical Oncology, Director of Cancer Survivorship, and Co-Program Leader for Cancer Prevention and Survivorship at the University of Kansas Cancer Center



Case Study on Distress with a Male Breast Cancer Patient

The following case study was originally adapted from the article “Male Breast Carcinoma: A Case Study,” by Ade Adesuwa Omigie and Catherine Hill. It was published in *The Internet Journal of Advanced Nursing Practice* in 2013, and was modified to show the impact of a navigator’s role.³

A healthy 51-year-old man, Sean, presented to his primary care physician with a chief complaint of a painless, rubbery lump in the right breast. Sean reported no aggravating factors and stated that the lump was smaller 2 months ago but had grown in size by 4 cm since that time. There was no nipple discharge noted. His family history was negative for any type of cancer, including breast cancer. The physician ordered a mammogram, ultrasound, and core needle biopsy with estrogen receptor (ER), progesterone receptor (PR), and human epidermal growth factor receptor 2 (HER2) testing if the biopsy was positive. The biopsy came back as positive for invasive ductal carcinoma, HER2-negative, PR-negative, ER-positive, and was noted to be a

Utilization of the National Comprehensive Cancer Network Distress Thermometer tool can effectively guide and assist the clinical navigator in providing high-quality, holistic, and patient-centered care.

Navigators can provide information on male breast cancer support groups through the American Cancer Society, Male Breast Cancer Coalition, and other organizations (see Resources section, page 57).



grade III breast cancer. The patient and his wife were informed of the diagnosis of male breast carcinoma based on the pathology findings. Sean was referred to a medical oncologist and radiation oncologist for further evaluation and treatment. Further computed tomography (CT) scan imaging of the chest and

abdomen, as recommended by National Comprehensive Cancer Network guidelines version 2012, were ordered by the medical oncologist to check for metastatic disease. The CT of the abdomen and chest came back as negative for metastatic disease. Sean was referred to the multidisciplinary oncology team for evaluation and treatment. Surgery was recommended for Sean and he was referred to a breast surgical oncologist. At the medical oncologist's office, Sean met his clinical navigator, Amy, who used a distress tool to assess his level of distress and barriers to care. Both Sean and his wife were very emotional over this diagnosis. His distress was measured at level 8. Sean knew nothing about male breast cancer, and what he had read on the Internet scared both him and his wife. Amy used the distress tool to initiate the referral process to assist Sean and his wife and to provide appropriate patient education for them. To effectively support Sean, Amy implemented the following:

- A journal was provided so that Sean could document questions and the plan of care, and so that when his wife or a family member attended appointments with him, they could document information given at each appointment
- An expandable folder from the American Cancer Society was provided to house all documentation pertaining to diagnosis—biopsy/pathology reports, consults, scan reports, advance directives, treatment information and appointment schedule for treatments, financial information, and medical bills
- Sean was given patient education materials regarding his diagnosis, the staging of breast cancer, and the pathologic results
- A referral was given for genetic counseling and testing for the *BRCA2* gene, since the standard of care is for all men diagnosed with breast cancer to be tested for the presence of a *BRCA2* gene mutation
- A referral was given for a social worker who could counsel Sean and his wife, as well as a referral to support groups for patients with male breast cancer
- A discussion was initiated with Sean and his wife regarding the need for healthcare proxy and advance directives
- Amy started a discussion on what Sean's life goals were and alternative ways they could achieve them
- A discussion was initiated regarding a referral to palliative care and the importance of such care from the beginning
- A referral was given for the financial navigator regarding insurance concerns—high premium, deductibles, and out-of-pocket maximums
- A referral to a lymphedema specialist for education and baseline measurements was initiated.

Prognosis for a higher survival rate in male breast cancer can be improved with monthly male breast self-exams, increased breast cancer awareness, and timely diagnosis.³

Prior to surgery, genetic testing results showed that Sean was *BRCA2*-negative. Sean had a modified radical mastectomy of the right breast. The lymph nodes were negative for metastatic disease. Sean received systemic adjuvant chemotherapy and then radiation therapy that was recommended by the radiation oncologist. He was also placed on hormone therapy following completion of chemotherapy. The medical oncologist and the clinical navigator stressed the importance of following up with the multidisciplinary team and continuing with the hormonal therapy. Six months after completion of treatment, Sean had started to lose weight and complained of upper back pain and a slight cough. He had further imaging done based on his symptoms and it showed metastatic disease to the lungs and thoracic spine. Biopsies of both metastatic sites were obtained and confirmed that it was metastatic breast cancer and that it was HER2-negative, ER-positive, and PR-negative. With the new metastatic diagnosis there needed to be a discussion on the risks and benefits of the recommended treatments. Many times the risks outweigh the benefits for patients. Sean needed to determine when he wanted to stop treatment and transition to hospice care. He chose to continue with a different hormonal treatment. Sean had been involved with palliative care since his initial diagnosis and was later referred to hospice care. He was able to determine when he wanted to transition to hospice care and he chose quality of life over further treatment. He died 2 years from the time of diagnosis.

Most men with breast cancer do not realize the importance of seeking prompt medical attention when a mass is discovered.³ When Sean's cancer was evaluated, it was already at a late stage.

When an individual is diagnosed with cancer, he or she frequently has many other things already going on—work, family, and life goals.⁵ The navigator can help educate the oncology team about these issues so that the patient is treated in a way that preserves his or her life goals and addresses personal and family issues, thus receiving patient-centered care.⁵

Within the multidisciplinary team, the navigator works as an advocate, care provider, educator, counselor, and facilitator to ensure that every patient receives comprehensive, timely, and quality healthcare services.⁴



Refer to *Pfizer General Navigation Toolkit*:

Distress and Psychosocial Needs, pages 23-27

References: 1. National Comprehensive Cancer Network. *NCCN Clinical Practice Guidelines in Oncology. Distress management*. v2. 2017. www.nccn.org/professionals/physician_gls/pdf/distress.pdf. Accessed September 22, 2018. 2. Williams M. *What Are the Experiences of Supportive Care for Women with Metastatic Breast Cancer?* University of New Brunswick. <https://journals.lib.unb.ca/index.php/NURS/article/download/21171/24507>. 3. Omigie AA, Hill C. Male breast carcinoma: a case study. *The Internet Journal of Advanced Nursing Practice*. 2013;12:1-6. 4. Johnston D. Evidence into Practice Subcommittee Meeting. Commission on Cancer Standard 3.1: Patient Navigation Process. Presented at: Academy of Oncology Nurse & Patient Navigators (AONN+) 6th Annual Navigation & Survivorship Conference; October 1-4, 2015; Atlanta, GA. 5. Burhansstipanov L, Shockney LD. The role of the navigator during a patient's cancer treatment. In: Shockney LD (ed). *Team-Based Oncology Care: The Pivotal Role of Oncology Navigation*. Chapter 8. Cham, Switzerland: Springer International; 2018:149-176.



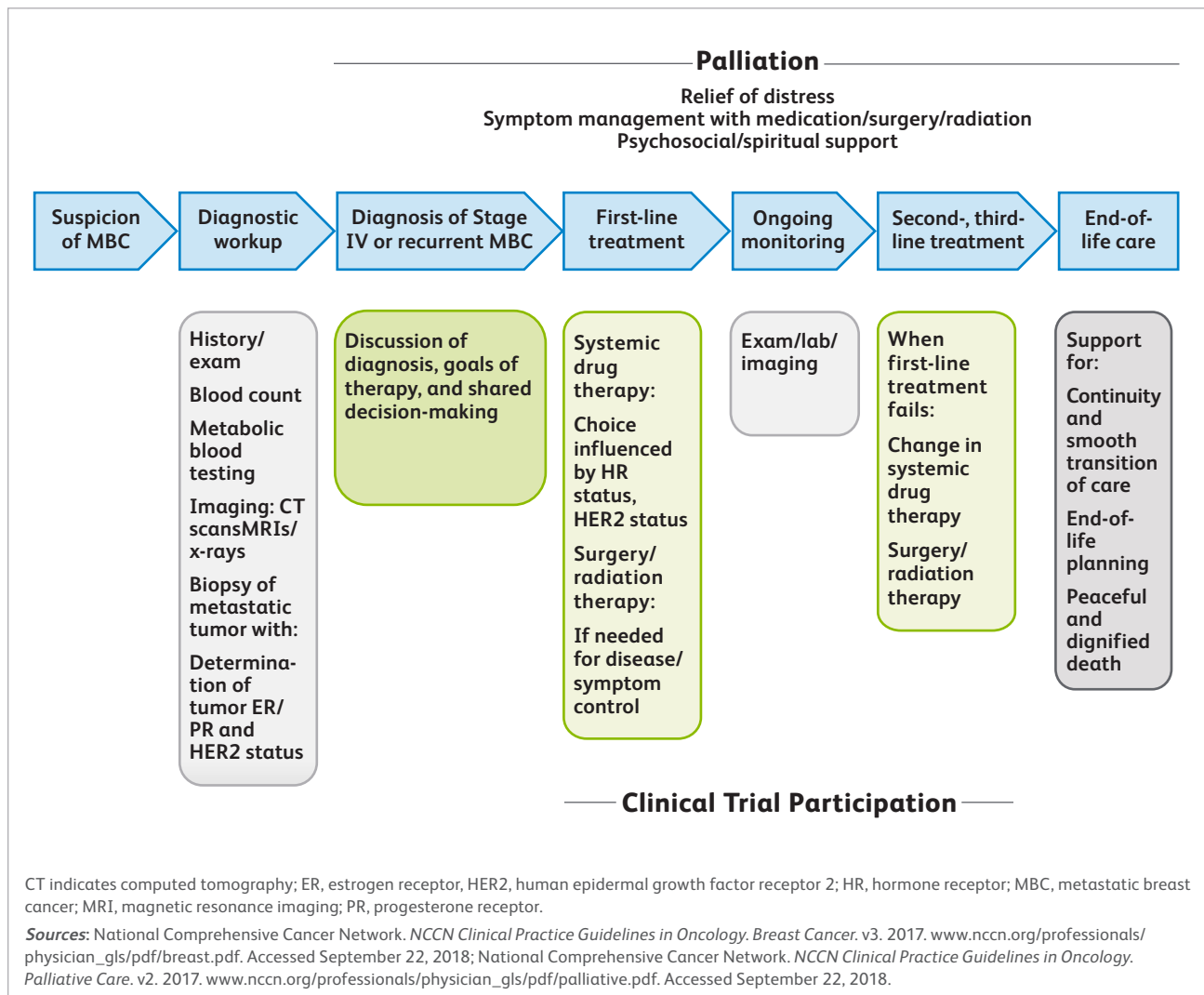
IX. PUTTING IT ALL TOGETHER: CONTINUUM OF CARE FOR PATIENTS WITH METASTATIC BREAST CANCER

The journey of a patient with metastatic breast cancer (MBC) has several stages and phases from diagnosis to the end of life. The navigator steers the patient with MBC through a complex course: diagnosis, first treatment of MBC, subsequent treatment, clinical trials, and end of life (**Figure 1**).^{1,2} For each patient, this process is unique—lasting many years for some, and just a few months for others. The navigator can play a critical role throughout the cancer care continuum.

Patients may embark on their course of care from 2 different points, with different implications for the navigator^{3,4}:

- Patients initially diagnosed with stage IV breast cancer—These patients do not have a personal history of breast cancer, and when diagnosed, are already found to have metastatic disease
- Patients for whom MBC is due to a recurrence of their initial disease—These patients have been treated

FIGURE 1. Pathways of Metastatic Breast Cancer



“Navigation has become the window in which we see what happens to the patient throughout the cancer care continuum, how patients can move seamlessly through the system and how we can certainly order their care in a way that makes sense both medically and for the patient. The lessons we have learned is that coordinated care is the care that is the safest for the patient, it is the most efficient as far as cost-effectiveness but it is also most efficient in the long-term care of the patient.”

Pamela Viahakis, ASH, RN, MSN, CBCN, Account Executive/Manager Administrator, WVUHealthcare/ Mary Babb Randolph Cancer Center



for local or regional disease in the past. Many have been clinically appearing to be cancer-free for a long time, but the disease was actually dormant within their body in a distant organ and something caused it to start growing, now being declared in metastatic form.

These 2 types of patients with MBC may have similar yet different navigation needs. For example, regardless of whether the metastasis is attributed to a recurrence (actually progression) after an early-stage breast cancer diagnosis or de novo disease, when patients are informed that

their disease is not curable, they will be devastated. As another example, the patient with early-stage breast cancer may have thought he or she was “cured” and the patient with de novo MBC may be angry that he or she never had a chance to have a potential cure for early-stage disease. Likewise, a patient with de novo disease may have far less knowledge about breast cancer and a greater need for disease-specific education than a patient whose disease has recurred. The patient with a recurrence may feel disappointment, frustration, and even a sense of betrayal, and will need help coping with these difficult feelings.

Case Study on Continuum of Care for the Patient with Metastatic Breast Cancer

Cathy L. is a 52-year-old single, postmenopausal woman who had previously worked as an accountant. She had been diagnosed with stage IIIA breast cancer, and the tumor histology showed that it was human epidermal growth factor receptor 2–negative, estrogen receptor–positive, and progesterone receptor–positive. She received neoadjuvant therapy, followed by breast-conserving surgery and further adjuvant treatment. Cathy completed the recommended radiation therapy to her chest wall and regional lymph nodes. She was closely followed, and 8 months after completing neoadjuvant and adjuvant chemotherapy treatment, and receiving hormonal therapy, she developed bone pain. She became unable to work but could carry out self-care and some home upkeep. Bone scan and computed tomography scan showed several areas of metastatic disease in her femur, liver, and lung. All biopsies showed the liver, lung, and femur were consistent with the original breast cancer prognostic testing, indicating that Cathy now has stage IV MBC. It was determined that her disease was potentially resistant to one of the previous chemotherapy drugs, because she progressed within 12 months of her last adjuvant therapy. Cathy began treatment with medications for bone therapy and oral chemotherapy. Cathy began treatment with bisphosphonates for the metastatic bone lesion, was started on a CDK4/6 inhibitor, and placed on a different hormonal therapy than she had been on.

Sharon, the clinical navigator, had been working with Cathy since her initial diagnosis. Now 10 months later, Sharon was still involved, following the patient along the continuum of care. At this pivotal moment in the patient’s journey, Sharon administered a distress tool. Cathy’s distress was measured at level 8, which was double her distress score of level 4 at the time of her initial diagnosis with early-stage breast cancer.

Sharon initiated a discussion with Cathy regarding the new diagnosis, goals of therapy, and the importance of shared decision-making. She also searched for appropriate clinical trials and discussed this with the oncologist and the clinical trials coordinator. Sharon then took the opportunity to educate Cathy on clinical trials and discuss trials that were appropriate and available for her. Sharon also spoke with Cathy to identify her life goals, and they discussed the importance of determining alternative ways to fulfill these goals in the future. She also asked Cathy how she would determine when she wanted to stop treatment and enroll in hospice. Each time a new line of therapy is discussed, it needs to include the risks and benefits. When the risks outweigh the benefits, the patient needs to know that it may be very appropriate now to consider hospice care, which can provide them a better quality of life for their remaining time. In most cases, this also extends their lives a bit longer because they are not receiving toxic agents that tax their immune system and organ functions. To effectively support Cathy, Sharon implemented the following:

- Referral to the social worker to assist with counseling; discussion of housing and food needs, work status (because Cathy had been unable to work); discussion of the need to fill out a Social Security Disability application; determination of the need for a discussion on advance directives
- Referral to the financial navigator to assist with insurance concerns; discussion on checking into Social Security Disability Insurance; assistance with other nonmedical financial needs
- Referral to palliative care for relief of distress, symptom management with medication/radiation, and psychosocial/spiritual support
- Referral to an oncology dietitian to assess and develop a nutritional plan based on patient's desires to maintain good nutritional status
- Referred Cathy to support groups and provided her with contact information on an MBC support group and showed her the MBC advocacy websites on the Internet
- Sharon started a discussion on Cathy's support system since she is single. Cathy has a sister whom she is very close to and she will accompany her to all her appointments. Sharon provided Cathy with information about the American Cancer Society caregiver support groups and other resources available to both of them.

Until recently, a diagnosis of MBC meant that death from breast cancer was likely to occur within a few years or less. Today, with the development of new therapies that target the drivers of breast cancer and improved palliative care, MBC is not the immediate death sentence it once was. With optimal care, patients with MBC can, and often do, live for years with reasonable quality of life, albeit undergoing continuous treatment to keep their disease under control.⁵ The navigator plays a critical role in helping patients understand their situation, identify and express their goals, and connect with valuable services to support them throughout their journey.

References: 1. National Comprehensive Cancer Network. *NCCN Clinical Practice Guidelines in Oncology. Breast cancer*. v3. 2017. www.nccn.org/professionals/physician_gls/pdf/breast.pdf. Accessed September 22, 2018. 2. National Comprehensive Cancer Network. *NCCN Clinical Practice Guidelines in Oncology. Palliative care*. v2. 2017. www.nccn.org/professionals/physician_gls/pdf/palliative.pdf. Accessed September 22, 2018. 3. National Comprehensive Cancer Network. *NCCN Quick Guide™. Stage IV Breast Cancer*. v1. 2015. www.nccn.org/patients/pdf/guidelines/quick_guide/nccn_quick_guide-breast_stage_iv.pdf. Accessed September 22, 2018. 4. Redig AJ, McAllister SS. Breast cancer as a systemic disease: a view of metastasis. *J Intern Med*. 2013;274:113-126. 5. Mariotto AB, Etzioni R, Hurlbert M, Penberthy L, Mayer M. Estimation of the number of women living with metastatic breast cancer in the United States. *Cancer Epidemiol Biomarkers Prev*. 2017;26:809-815.



X. END-OF-LIFE CARE

Metastatic breast cancer (MBC) is not curable, and the toll of the symptoms and treatments, as well as the psychological burden, is significant not only for the patients themselves, but for their caregivers, family, friends, and support networks.¹ Although many patients with MBC live years after their diagnosis, they will eventually succumb to their disease. Navigators make important contributions by assisting patients in maintaining hope while having clear expectations regarding their prognosis.

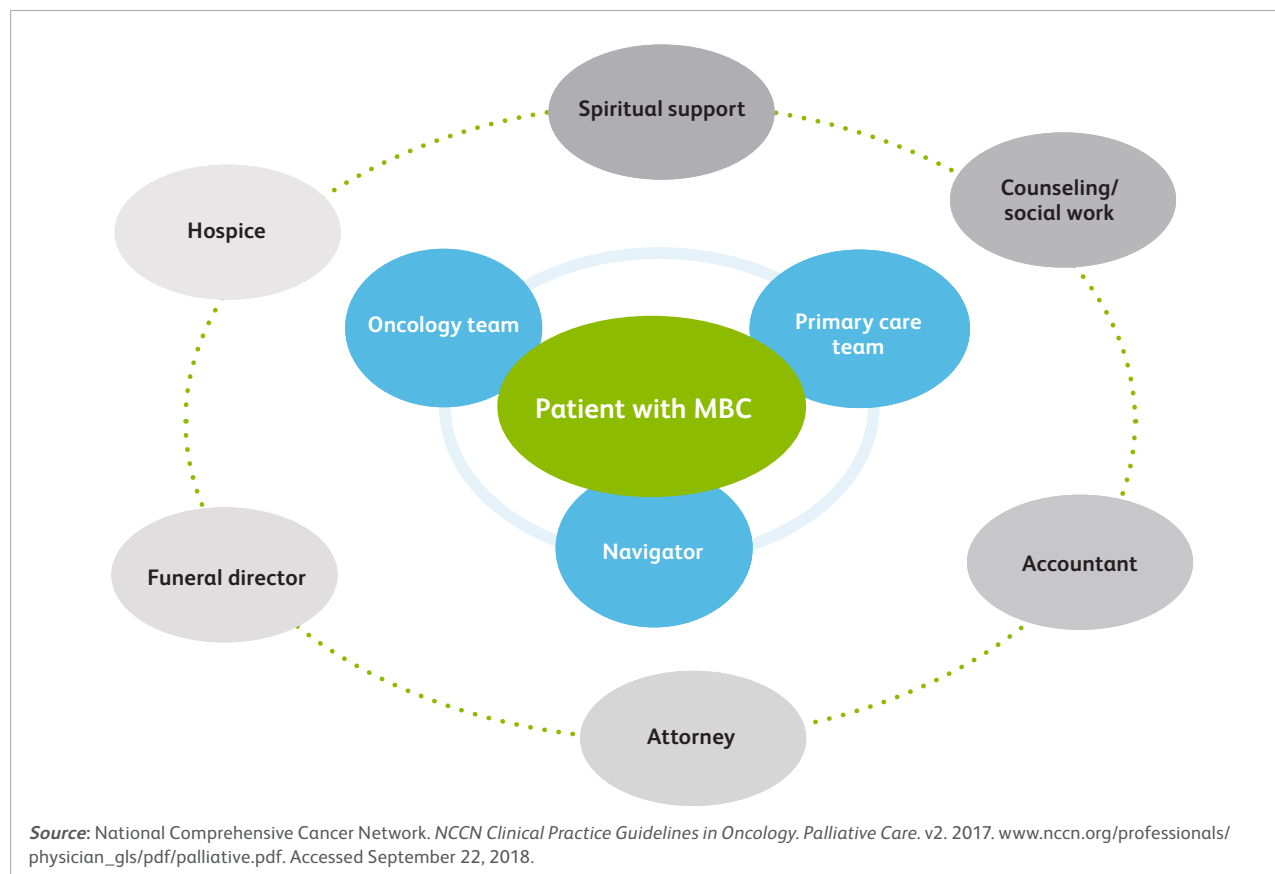
Fulfillment of Elements of Experiencing a Peaceful, Good Death

When approaching the end of life, 3 guiding principles are essential—continuity of care, planning, and the support of dignity.

Continuity of Care

A key goal in navigating patients and caregivers to end-of-life care is ensuring a smooth transition.² Achieving continuity has been made easier by current recommendations to offer palliation earlier in the course of disease, while the patient is undergoing active treatment (see **Palliation/Relieving Symptoms of MBC, page 22 in MBC toolkit**).^{3,4} However, it is still necessary to be active in addressing the need for transition; maintaining connection to the medical team (**Figure 1**); and engaging specialized care, support, and advocacy to make the transition as seamless as possible.⁵

FIGURE 1. Specialized Care, Support, and Advocacy at the End of Life



Planning

As the end of life approaches, patients, families, and friends need to make plans; navigators can put them in touch with local resources—attorneys, accountants, funeral directors, and hospice services (**Figure 1**)—to facilitate⁵:

- Advance directives (if not already addressed)
- Wills, finances, and legacy planning
- Funeral/memorial planning
- Decision-making on how to spend last days/place of dying.

In helping to navigate this difficult process, goals include reduction of distress and burdens, supporting patient and caregiver sense of control, optimization of quality of life and relationships, and encouragement of personal growth and the search for meaning.⁵

The overarching goal in end-of-life care is ensuring that every patient can die with dignity and peace of mind.

What is unacceptable, however, is to work to intensify interventions—for example, to urge the patient to undergo more surgeries or chemotherapy.⁵ Navigators must be careful not to let their own feelings for the patient and those of the family tempt them to push for aggressive treatment.

A new resource is now available to clinical and nonclinical navigators in the management of patient care at this time in the continuum, *The Guiding Light Between Shorelines: A Resource, Education, and Support Guide for Patients and Their Families Living with Advanced Cancers*.⁶ This guide provides resources, education, and support for patients with cancer and their caregivers. The included videos will be helpful to clinical navigators when interacting with patients with advanced cancer.

Dignity

At the end of life, it is of paramount importance to respect the goals and needs of the patient and caregiver regarding the dying process.⁵ Respect takes many forms, such as listening to the values and preferences of patients and caregivers, and giving patients, family, and friends respectful space and uninterrupted time together when death is approaching.⁵ Respect is the cornerstone of end-of-life care, because it supports the overarching goal—ensuring that every patient can die with dignity and peace of mind.⁵

Finding Hope

Although MBC cannot be cured, it is not a hopeless state. The wide array of treatment options can extend lives and provide good quality of life. In fact, one-fourth of all patients with MBC live for at least 5 years after diagnosis.⁷

Hopelessness in MBC is neither rational nor practical. Hope, an attitude of resilience, and a spiritual or philosophic view are all components of effectively coping with the disease and its treatment.^{8,9}

However, hope must be realistic and appropriate to the disease. Unjustified optimism can damage patients' quality of life.⁵ Professionals and navigators are obligated to be honest with patients and to protect them from false hopes for miraculous cures or for a return to the way life was before MBC.⁹ Data have shown that many patients receiving therapy for incurable, advanced cancers do not understand that their treatment is not a cure for their cancer, compromising their ability to make truly informed decisions.¹⁰ Preventing unrealistic hope is one reason patient education in MBC is so important.

Based on recent recommendations in palliative care, navigators are encouraged to redirect patients' hopes toward what is achievable under the circumstances.⁵ The aim is to cultivate the virtue of moderation between the extremes of hopelessness and over-optimism—a clear-eyed hope that may include:

- Hope for a good quality of life
- Hope for dignity and choice in treatment through shared decision-making
- Hope for personal growth and a fruitful search for meaning
- Hope for comfort, closure, and death with dignity.

Elements of a Good Death

What is a good death? Research has been conducted to provide a means of understanding from patients what constitutes a good death, and the results provide insight into the major components of a good death. These are¹¹:

- Management of pain and suffering
- Clear decision-making
- Preparation for death
- Completion
- Contribution to others
- Affirmation of the whole person.

There must be a discussion with the patient and his or her loved ones about each of these attributes of a good death to provide them the information they need at specific points in time. No one should die in pain, feel confused about the decisions being made, or feel that their final wishes are not being honored.¹¹ Clinical and nonclinical navigators can assist in making sure the patient's concerns and wishes are being followed.

Palliative Care

Palliative care is a specialized care model for individuals with a serious illness that is designed for preservation or restoration of quality of life.¹² This involves symptom management, as well as preservation or restoration of quality of life in regard to pain control, fatigue, difficulty sleeping, loss of appetite, constipation, and nausea. Palliative care and hospice care have become stigmatized, because they have traditionally been offered later in the cancer continuum. Palliative care can be offered at any stage of disease in a serious illness. It can be provided along with curative treatments. It was designed to improve the quality of life for both the patient and the family.

Navigators can utilize a palliative care assessment tool. One tool that is often used is the Edmonton Symptom Assessment System (ESAS).¹³ This tool is designed to assist in the assessment of 9 symptoms common in cancer patients: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, and shortness of breath.¹³ ESAS provides a clinical profile of symptom severity over time, which assists the team in treatment decision-making.¹³ As noted earlier, palliation should be addressed at the time of initial diagnosis and not later in the cancer continuum. Hospice and palliative care become integrated with each other once decisions are made to discontinue treatment, either at the patient's request or due to the severity of the illness.¹²

Hospice Care and Addressing Family Needs

Hospice care also involves a multidisciplinary team that specializes in medical care, pain management, and emotional and spiritual support for patients whose life expectancy is no longer than 6 months. Although it is difficult to predict when death will come, when oncologists misgauge the length of time a patient may have before their death, it can result in patients not getting the full benefit of hospice care.¹¹

The impact of the clinical and nonclinical navigator is evident here by their ability to improve communications and decision-making.¹¹ They can promote advance care planning and provide educational

materials to help patients with MBC prepare for consultations with their oncologists and other team members.¹¹ Clinical navigators assume several essential roles related to palliative care and hospice. Relevant care skill sets are symptom control, goal-setting, communication, interdisciplinary team collaboration, and assistance with healthcare system navigation.¹² Navigators can advocate for the patient and be aware of the patient's caregivers, who also need support and education. Sometimes, family members can have different goals from the patient and may only want to extend the patient's life, but not consider the quality of life. This is where the specialized services of hospice can assist the patient and family members.

Metastatic Breast Cancer Case Study: Patient Approaches End of Life

This case study was adapted from *Team-Based Oncology Care: The Pivotal Role of Oncology Navigation*. It provides insight into the difficulties patients and their oncology providers face that can be improved or even prevented by having effective communication skills, comfort in discussing death, and a supportive clinical navigator who serves in the pivotal role of the patient's advocate.¹¹

Mary, a 31-year-old mother of 2 preschool-aged children, was diagnosed with stage IV triple-negative breast cancer 18 months after completion of treatment for stage IIb disease. The locations of the metastases were her bones, brain, liver, and lungs. She had told her doctor that she wanted to "receive treatment up until her last breath" as a way to demonstrate to her children how hard she fought to live and be with them as long as possible. Mary's medical oncologist agreed to follow this plan, recognizing it as the patient's goal of care. Pam, the clinical navigator, met with Mary to discuss goals of care and learned about the plan that had been put into motion. Pam discussed with Mary what these 2 goals of care meant to her.¹¹

Challenges

Pam explained that these 2 goals were actually in conflict with each other. If Mary received the toxic therapy until her last breath, it was inevitable that she would be in the hospital for the majority of her final weeks, and because of the ages of her children, she would not be able to have them with her at all. Therefore, an important discussion ensued to determine which of the 2 goals was most important to Mary.¹¹

Opportunities

Mary wanted her children to remember her, and she wanted to spend as much time with them as possible. With this priority in mind, the goals of care changed, and a discussion about beginning palliative care and treatment followed.¹¹ Pam also talked with Mary about hospice care in an effort to eliminate the stigma associated with it. It was imperative to Mary that her oncologist maintain some level of involvement in her care. She expressed that it would suffice if the oncologist just reached out every so often to check in on her while she received hospice care at home. Mary did not want to feel abandoned by her treatment team—especially her oncologist. Learning that patients who transition to hospice earlier often have a longer life and better quality of life was comforting to Mary. For her, it also meant she would be able to enjoy more time at home with her children.¹¹

Pam provided Mary with boxes of greeting cards to give her a way to maintain a presence in her children's lives after her death. On these cards, Mary wrote messages for her children so that they would have a note from her for each milestone they would reach in the future, including birthdays, first communion, driver's licenses, graduations, weddings, and even the birth of their first children. Her husband preserved these cards, storing them away for their respective events.

Mary's mother was the person in her life who struggled most with accepting her daughter's impending death to MBC.¹¹ In an effort to control the situation, she treated Mary like a child. Pam connected the mother with a national nonprofit organization called Mothers Supporting Daughters with Breast Cancer to help her come to terms with the situation.

When the cancer further metastasized, requiring thoracentesis, Mary decided to enroll in hospice care at home. She died a good death, with the following elements in place:

- A purpose for living and a life that was valued by others
- A legacy unrelated to money—demonstrating how to live each day, rather than dying each day, with cancer
- Forgave and was forgiven
- Absence of pain
- Death with dignity and in the environment of her choosing—home with family, receiving hospice care
- No financial debt left behind for her family associated with her cancer care
- Confidence about being spoken of and remembered fondly
- Spiritual connection to a higher power.

Mary's funeral was a true celebration of the life she lived and the profound impact she had on many of those who knew her. Her husband and mother went on to receive a year of hospice support after Mary's death.

It was 13 months from when Mary was diagnosed with stage IV triple-negative MBC until her transition to hospice care. She achieved her goal of spending quality time with her husband, children, and extended family. The 4 months of hospice care she received helped her to meet this objective, in addition to other benefits.¹¹

References: 1. Pfizer Oncology. *Breast Cancer: A Story Half Told*. www.pfizer.com/files/news/Statement_ofNeed.pdf. Accessed September 22, 2018. 2. Oncology Nursing Society. *2017 Oncology Nurse Navigator Core Competencies*. www.ons.org/sites/default/files/2017ONNcompetencies.pdf. Accessed September 22, 2018. 3. Smith TJ, Temin S, Alesi ER, et al. American Society of Clinical Oncology provisional clinical opinion: the integration of palliative care into standard oncology care. *J Clin Oncol*. 2012;30:880-887. 4. Ferrell BR, Temel JS, Temin S, et al. Integration of palliative care into standard oncology care: American Society of Clinical Oncology Clinical Practice Guideline update. *J Clin Oncol*. 2017;35:96-112. 5. National Comprehensive Cancer Network. *NCCN Clinical Practice Guidelines in Oncology. Palliative Care*. v2. 2017. www.nccn.org/professionals/physician_gls/pdf/palliative.pdf. Accessed September 22, 2018. 6. Shockney LD. *The Guiding Light Between Shorelines: A Resource, Education, and Support Guide for Patients and Their Families Living with Advanced Cancers*. <https://aononline.org/education/modules>. Accessed September 24, 2018. 7. Rugo HS, Rumble RB, Macrae E, et al. Endocrine therapy for hormone receptor-positive metastatic breast cancer: American Society of Clinical Oncology guideline. *J Clin Oncol*. 2016;34:3069-3103. 8. Mayer M, Crawford-Gray K. Analysis of quality of life research on living with MBC. In: *Changing the Landscape for People Living with Metastatic Breast Cancer*. 2nd ed. New York, NY: Metastatic Breast Cancer Alliance/Avon Foundation for Women; 2014:57-73. 9. Penson RT, Gu F, Harris S, et al. Hope. *Oncologist*. 2007;12:1105-1113. 10. Weeks JC, Catalano PJ, Cronin A, et al. Patients' expectations about effects of chemotherapy for advanced cancer. *N Engl J Med*. 2012;367:1616-1625. 11. Shockney LD. Transitioning to End-of-Life Care. In: Shockney LD (ed). *Team-Based Oncology Care: The Pivotal Role of Oncology Navigation*. Chapter 10. Cham, Switzerland: Springer International; 2018:197-225. 12. Shockney LD. End-of-Life Considerations. Continuing education module. Release date: April 8, 2016. <https://aononline.org/education/modules/15-end-of-life-considerations>. Accessed September 24, 2018. 13. Edmonton Symptom Assessment System. http://www.npcrc.org/files/news/edmonton_symptom_assessment_scale.pdf. Accessed September 27, 2018.



XI. DEVELOPING A METASTATIC BREAST CANCER NAVIGATION PROGRAM

The Metastatic Breast Cancer (MBC) Navigation Program should build upon the general navigation program. With a general navigation program in place, this program can be expanded to determine the needs, barriers, and issues that specifically affect patients with MBC. Navigators should have a good understanding of the most recent community needs assessment and identify the supportive stakeholders and champions of the navigation program.¹ This will help to clarify needs, priorities, and available community resources. With additional input from focus groups from the community, patients, families, and medical and nonmedical staff members, navigators can glean a more concise picture of barriers and issues that need to be addressed.¹

Role Delineation

Clarifying roles prior to successfully launching an MBC navigation program is important, and role delineation includes a comprehensive, clearly defined list of critical tasks to be included in the roles and responsibilities for a specific job.² A definitive job description of the expectations of the clinical navigator and nonclinical navigator positions is necessary.

In 2013, the Oncology Nursing Society created Oncology Nurse Navigator Competencies, which included the categories of professional role, education, coordination of care, and communication.² The collection of data related to specific metrics and outcomes will help to further develop a navigation program. With the standardization of metrics, navigators can be “change agents” for their own sustainability and promote evidence-based practice with proven outcomes.³ Evaluation and outcome measures, including patient-reported outcomes, for assessing the impact of navigation are essential for the success, sustainability, and future of navigation services and the navigation role.⁴

Clinical Navigator Competencies

Although any of the navigator competencies would be applicable, the following 4 core clinical navigator competencies can be used in the MBC setting as examples:

1. Care Coordination: Patient care coordination is invaluable. Navigators help individuals overcome barriers to care and navigate through the diagnostic, treatment, survivorship, and end-of-life care continuum.⁵ The

“It is imperative that oncology clinical navigators and non-licensed patient navigators understand that active participation in data collection, analytics and reporting outcomes is not added responsibilities but is already a part of the professional role.”

Danelle Johnston, MSN, RN, ONN-CG OCN, Chief Nursing Officer, Sr. Director of Strategic Planning and Initiatives, The Lynx Group



navigator acts as a liaison among all team members to advocate for the patient and to improve access to services. Equally important is the participation in the development of evidence-based practice that leads to better outcomes and patient-centered care.

2. Psychosocial Support Services/Assessment: Communication and interpersonal skills are invaluable with patients with MBC. The navigator must be able to effectively communicate in their interactions with patients with MBC to be able to assist them in shared decision-making based on their needs, goals, strengths, barriers, and resources. Using the distress tool in the initial consultation with patients with MBC can facilitate better outcomes, with timely referrals to resources. Navigators are instrumental in the development and

implementation of a plan for psychosocial health services in their cancer program that supports patients (by providing personalized information, identifying strategies to address psychosocial needs, providing emotional support, and helping patients manage their illness and health), links patients and families with psychosocial services, and coordinates psychosocial and biomedical care.⁵

3. Research/Quality/Performance Improvement: The Institute of Healthcare Improvement's Triple Aim seeks to improve the patient experience, improve population health, and reduce per capita cost of healthcare. Navigators can utilize research and outcomes to develop and validate the programs and services provided. The components of research and evaluation are to define the problem and establish goals, implement

Utilization of metrics for patients with MBC will enhance competency for the clinical navigators in end-of-life care for this population and improve quality of care for patients.



strategies based on objectives and time, and measure outcomes.⁵ Specific metrics that can be utilized are listed under the section **Metastatic Breast Cancer Best Practices** (see page 55 in the MBC toolkit).

4. Survivorship/End of Life: Navigators have an essential role in ensuring that quality survivorship begins at diagnosis

and continues throughout the balance of patients' lives.⁵ Navigators advocate for quality patient care by acknowledging and monitoring the changing needs of the patient. The patient with MBC needs to be involved in palliative care as soon as possible, if not already involved early on in the continuum. The navigator must be knowledgeable regarding the role and benefits of palliative care and end-of-life issues. Navigators should advocate the use of palliative care and hospice services by recognizing the seasons of survival and changes in a patient's quality of life, and understanding that patients may have end-of-life tasks to complete.

Refer to Pfizer General Navigation Toolkit.

Community Needs Assessment, pages 15-17

Navigation Program Development, pages 45-48

Navigation Program Monitoring and Outcome Measures, page 49

References: 1. Johnston D. Evidence into Practice Subcommittee Meeting. Commission on Cancer Standard 3.1: Patient Navigation Process. Presented at: Academy of Oncology Nurse & Patient Navigators (AONN+) 6th Annual Navigation & Survivorship Conference; October 1-4, 2015; Atlanta, GA. 2. Shockney LD (ed). *Team-Based Oncology Care: The Pivotal Role of Oncology Navigation*. Chapter 5, Section 5.6. Cham, Switzerland: Springer International; 2018:85-110. 3. Strusowski P, Sein E, Johnston D, et al. Standardized evidence-based oncology navigation metrics for all models: a powerful tool in assessing the value and impact of navigation programs. *J Oncol Navig Surviv*. 2017;8:220-237. 4. Shockney LD (ed). *Team-Based Oncology Care: The Pivotal Role of Oncology Navigation*. Chapter 14, Section 14.1. Cham, Switzerland: Springer International; 2018:291-314. 5. AONN+ Certification Oncology Nurse Navigator-Certified GeneralistSM (ONN-CGSM) Certification. <https://aononline.org/certification/nurse-navigator-certification>.

XII. PROFESSIONAL DEVELOPMENT IN THE METASTATIC BREAST CANCER SPACE

Ongoing professional development is imperative for both clinical and nonclinical navigators to stay current and competent in effectively managing the care of patients with metastatic breast cancer (MBC) and their families. According to the Academy of Oncology Nurse & Patient Navigators (AONN+) navigator competencies, under the domain of Professional Roles and Responsibilities, practice-based learning involves critical thinking and problem-solving.¹ By building on critical thinking and problem-solving, the navigator will be able to improve professional practice by utilizing scientific evidence to improve patient care. This is an important area

Navigators must care for themselves to deliver quality care for their patients.²



in the changing field of MBC where the navigator may have gaps in knowledge. It is important for navigators to attend professional conferences and network with other navigators to share best practices and gain knowledge. This can be done through

one of the healthcare professional organizations and societies dedicated to the education and support of navigators.

A navigator can lend further credence to their position by becoming credentialed in a particular area of expertise. The following is a list of some of the current credentialing available:

- AONN+ offers generalist certification for both oncology nurse navigators (ONN-CGSM) and, in collaboration with the GW Cancer Center, oncology patient navigators (OPN-CGSM)
- The National Consortium of Breast Centers (NCBC) offers the NCBC Breast Patient Navigator Certification Program
- The Oncology Nursing Society offers the Certified Breast Cancer Nurse (CBCN) certification.

These certifications are identified further in the *Pfizer General Navigation Toolkit*.

Compassion Fatigue

Helping patients manage their distress and dealing with MBC can take a toll on staff. Therefore, compassion fatigue is an area that warrants further attention and professional development. Compassion fatigue is a state of tension and preoccupation with the individual or cumulative traumas of patients.² If exposure to suffering is a contributing factor to compassion fatigue, oncology navigators may be getting extra doses of suffering, considering that a small population of navigators is managing an ever-expanding caseload of patients with cancer throughout the country.³ It takes a great deal of energy and concern to deal with MBC over the long-term, knowing that the patients will eventually succumb to the disease. Recognizing the symptoms and making changes that lead to personal transformation are necessary to combat compassion fatigue.² If not addressed, compassion fatigue can have far-reaching effects. It can cause increased and chronic absenteeism, increases in Workers Compensation claims, high staff turnover rates, and friction between employees, staff, and management.²

Refer to *Pfizer General Navigation Toolkit*:

Professional Development, pages 55-57

Navigation Topics for Professional Development, pages 59-61

Navigation Topics for Professional Development, Compassion Fatigue, pages 59-61

References: 1. AONN+ Certification Oncology Nurse Navigator–Certified GeneralistSM (ONNCGSM) Certification. <https://aonnonline.org/certification/nurse-navigator-certification>. 2. Gamblin K, Francz S. Compassion fatigue: When caring takes its toll. Oncology Nursing News website. www.oncnursingnews.com/publications/oncology-nurse/2011/sepember-2011/compassion-fatigue-when-caring-takes-its-toll. Accessed September 24, 2018. 3. Shockney LD (ed). *Team-Based Oncology Care: The Pivotal Role of Oncology Navigation*. Chapter 16. Cham, Switzerland: Springer International; 2018:336-349.



XIII. METASTATIC BREAST CANCER BEST PRACTICES

Many best practices contribute to patient-centered care in metastatic breast cancer (MBC). The introduction and evolution of standardized metrics have improved patient care and helped to provide better outcomes. Several metrics that have been used for other advanced cancers that may improve MBC practice are¹⁻³:

- **Palliative care referrals** – Number of navigated MBC patients per month referred for palliative care (This metric impacts patient experience [PE], clinical outcomes [CO], return on investment [ROI])
- **30-, 60-, 90-day readmission rate** – Number of navigated MBC patients readmitted to the hospital at 30, 60, and 90 days. Report quarterly (This metric impacts ROI)
- **Emergency department utilization** – Number of navigated MBC patient visits to the emergency department per month (This metric impacts ROI)
- **Patient goals** – Percentage of analytic MBC cases per month in which patient goals were identified and discussed with the navigator (This metric impacts PE, CO)
- **Social support referrals** – Number of navigated MBC patients referred to support network per month and/or number of navigated MBC patients and family/caregivers referred to weekend retreats for patients, couples, or caregivers per month (This metric impacts PE, CO).

A best practice model for developing MBC patient retreats is *A Journey of Courage and Hope: Metastatic Breast Cancer Retreat Planning and Resource Kit*, developed and written by Lillie D. Shockney and published by Pfizer. This is available for navigators through Pfizer.⁴

Navigators must focus on the patient care experience for patients with MBC, ensure best practices are implemented, and provide patient-centered care, all of which are paramount to improving patient outcomes. Additional resources for navigators caring for patients with MBC can be found on the following pages.



XIV. RESOURCES FOR METASTATIC BREAST CANCER

General Information

ACCC. Metastatic Breast Cancer Resources & Tools for the Multidisciplinary Team

<https://resources.accc-cancer.org/metastatic-breast-cancer/>

ACCC. Metastatic Breast Cancer Toolkit

www.accc-cancer.org/docs/projects/resources/pdf/mbc-workbook.pdf?sfvrsn=c0b2ccc_0

American Cancer Society

www.cancer.org

American Cancer Society Breast Cancer in Men

www.cancer.org/cancer/breast-cancer-in-men.html

American Joint Committee on Cancer (AJCC)

<https://cancerstaging.org>

Breastcancer.org

www.breastcancer.org

CancerCare

www.cancercare.org

Edmonton Symptom Assessment System

www.npcrc.org/files/news/edmonton_symptom_assessment_scale.pdf

Medication Nonadherence Risk Assessment

http://adultmededucation.com/downloads/Nonadherence_Risk_TOOL.pdf

Metastatic Breast Cancer Network

www.mbcn.org

METAvisor—Metastatic Breast Cancer Awareness, Research and Support

www.metavior.org

National Breast Cancer Foundation

www.nationalbreastcancer.org

National Comprehensive Cancer Network, Guidelines for Patients

www.nccn.org/patients/guidelines/cancers.aspx

Oncology Nursing Society (ONS) Oral Adherence Toolkit

www.ons.org/practice-resources/toolkits/oral-adherence

Pfizer “A Story Half Told”

www.storyhalf told.com/additional-resources

***The Guiding Light Between Shorelines: A Resource, Education, and Support Guide for Patients and Their Families Living with Advanced Cancers*, written by Lillie D. Shockney and Tyler Trahan**

<https://aononline.org/education/navigation-tools>

Young Survival Coalition

www.youngsurvival.org

Susan G. Komen

<https://ww5.komen.org>

Communication

ACCC. Metastatic Breast Cancer Toolkit

www.accc-cancer.org/projects/metastatic-breast-cancer-project/toolkit-study

Communication Toolkit from the Dandelion Project, Metastatic Breast Cancer Alliance

www.mbcalliance.org/education-access-initiatives/dandelion

Shared Decision-Making Model

www.ncbi.nlm.nih.gov/pmc/articles/PMC3445676/

Palliation

American Society of Clinical Oncology. Palliative Care in Oncology/Resources

www.asco.org/practice-guidelines/cancer-care-initiatives/palliative-care-oncology

Center to Advance Palliative Care

www.capc.org

National Comprehensive Cancer Network. Clinical Practice Guidelines in Oncology. Palliative Care

www.nccn.org/professionals/physician_gls/default.aspx#supportive

Palliative Care Network

www.palliativecarenetwork.com

Finances and the Law

ACCC. Financial Advocacy Guidelines 2018

www.accc-cancer.org/home/learn/financial-advocacy/guidelines

ACCC. Financial Advocacy Network (FAN) Toolkit

www.accc-cancer.org/home/learn/financial-advocacy/toolkit

ACCC. Patient Assistance and Reimbursement Guidelines

www.accc-cancer.org/docs/documents/publications/2018-accc-patient-assistance---reimbursement-guide.pdf?sfvrsn=75d6dec0_0

Cancer and Careers

www.cancerandcareers.org

Cancer Legal Resources

<http://cancerlegalresources.org/>

CancerCare

www.cancercare.org

National Cancer Institute. Advance Directives

www.cancer.gov/about-cancer/managing-care/advance-directives

Patient Advocate Foundation

www.patientadvocate.org

Triage Cancer Finances

<https://cancerfinances.org/>

Mental Health, Self-Care, and Spirituality

ACCC. *Metastatic Breast Cancer—Effective Principles & Practices in Patient Support: Reframe the Conversation*

www.accc-cancer.org/resources/pdf/MBC_Workbook.pdf

Elisabeth Kubler-Ross Foundation

www.ekrfoundation.org

HealthCare Chaplaincy Network

www.healthcarechaplancy.org

Susan G. Komen Coping with Stress

ww5.komen.org/BreastCancer/CopingWithStress.html

Support Groups and Retreats

A Story Half Told—Metastatic Breast Cancer Patient Retreats

www.storyhalfold.com/meet-esther-garza

Cancer Support Community

www.cancersupportcommunity.org/

Male Breast Cancer Coalition

<https://malebreastcancercoalition.org/>

Male Breast Cancer Online Support

<http://community.breastcancer.org/forum/51>

Metastatic Breast Cancer Alliance

www.mbcalliance.org/support

METAvivor—Finding a Support Program

www.metavivor.org/support/finding-a-support-program

Mothers Supporting Daughters with Breast Cancer

www.mothersdaughters.org

Project SHARE Cancer Support/Metastatic Breast Cancer Alliance

www.mbcalliance.org/project/share

Clinical Trials

American Society of Clinical Oncology. Insurance coverage of clinical trials

www.asco.org/research-progress/clinical-trials/insurance-coverage-clinical-trials

BreastCancerTrials.org

www.breastcancertrials.org/bct_nation/home.seam

National Cancer Institute. Find NCI-Supported Trials

www.cancer.gov/about-cancer/treatment/clinical-trials/search

National Institutes of Health. Talking to Your Patient About a Clinical Trial

www.nih.gov/health-information/nih-clinical-research-trials-you/talking-your-patient-about-clinical-trial

National Metastatic Breast Cancer Network/Metastatic Trial Search

www.mbcn.org/clinical-trials-finder



GLOSSARY OF KEY TERMS

Aromatase inhibitors: drugs that block the production of estrogen.

Biosimilars: a version of a “biologic” agent that is very similar to the reference FDA-approved product and does not have clinically meaningful differences from that approved product.

CDK4/6 inhibitors: CDK4/6 inhibitors are a class of drugs that target enzymes, called CDK4 and CDK6. These enzymes are important in cell division. CDK4/6 inhibitors are designed to interrupt the growth of cancer cells.

Estrogen antagonists: drugs that prevent estrogen from binding to its receptor and that can destroy the receptor.

HER2: human epidermal growth factor receptor 2—a marker for an intrinsic breast cancer subtype that responds to HER2-targeted treatment.

HR: hormone receptor for estrogen or progesterone that occurs on some breast tumor cells and responds to hormone-blocking therapy.

IDC: invasive breast cancer of the duct—cancer that grows in the duct of the breast.

ILC: invasive breast cancer of the lobe—cancer that grows in the lobe/lobules of the breast.

Immunotherapy: therapy that decreases the body’s immune response to cancer cells.

mTOR inhibitors: drugs that suppress the mammalian target of rapamycin, a protein that can stop hormone therapy from working.

Nerve blocks: the injection of an anesthetic or anti-inflammatory agent directly to an area of nerves for the purpose of pain relief. Nerve blocks are typically used to relieve pain in the rib, upper and lower abdomen, or the back, but are also helpful for any site when a patient cannot take or has intolerable side effects from opioid or nonopioid pain medication.

PARP inhibitors: drugs that block the enzyme that is important in cancer cell survival, called poly (ADP [adenosine diphosphate]-ribose) polymerase.

SERMs: selective estrogen receptor modulators—drugs that prevent estrogen from binding to its receptor.

Tyrosine kinase inhibitors: drugs that target a pathway, when blocked, may help to inhibit the growth of tumor cells.

January 2019

PP-O4B-USA-2218 -01

© 2019 Pfizer Inc. All rights reserved.

