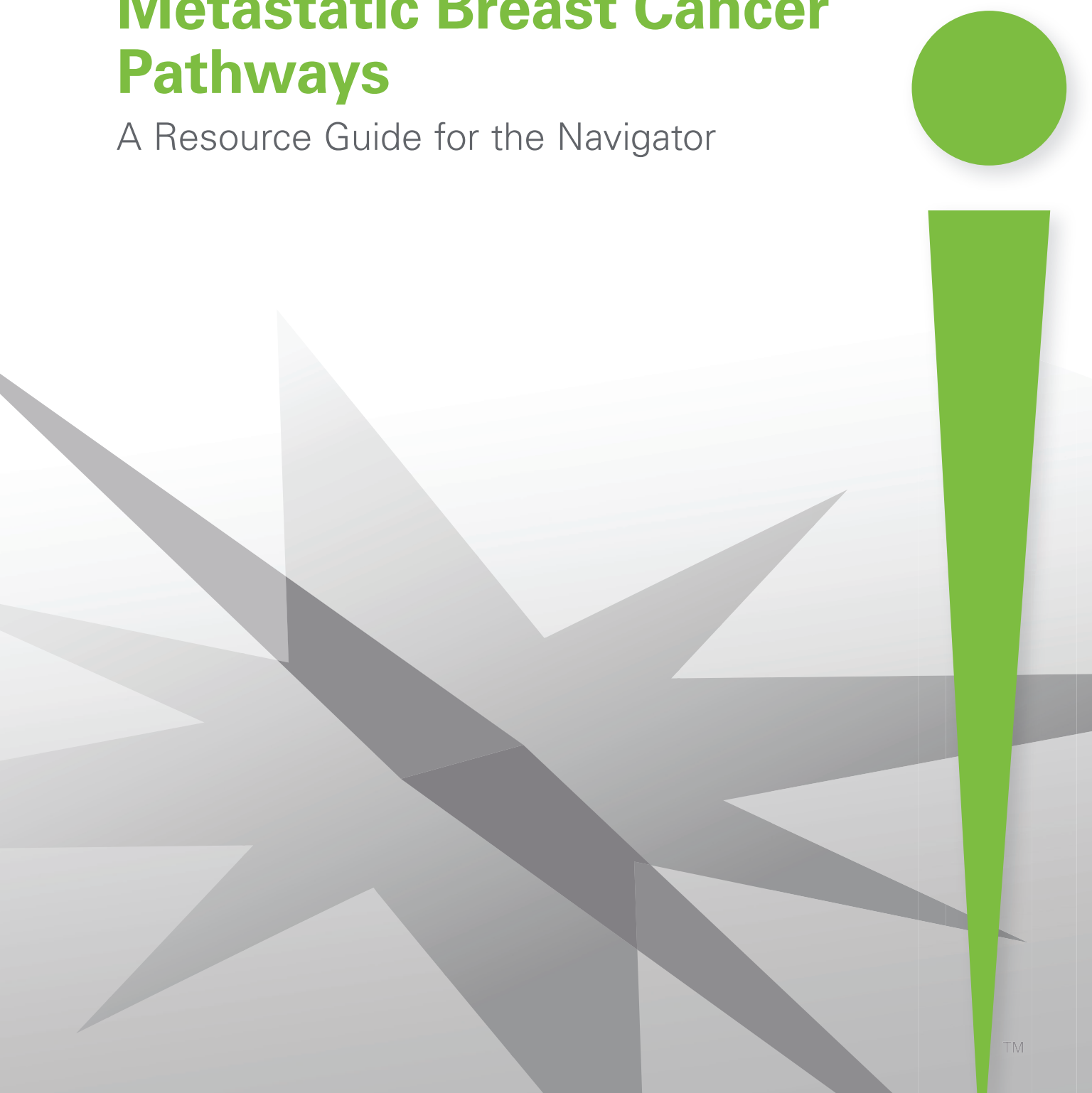
Patient Navigation in Cancer Care 2.0

Guiding patients to quality outcomes™

Metastatic Breast Cancer Pathways

A Resource Guide for the Navigator



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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.

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I. INTRODUCTION

Metastatic breast cancer (MBC) is breast cancer that has spread beyond the breast and regional lymph nodes to distant sites in the body: bones, liver, lungs, brain, and other organs.[1] MBC is also called stage IV breast cancer.[2] The number of involved sites, the volume of disease, and the genetic and genomic profile impact the available treatment options and influence the longevity of life. MBC is considered "late-stage" cancer, and it is not "curable."[3]

However, many more treatment options are available today than in the past. Numerous therapies have been developed through clinical research. Medical oncologists use genetic and genomic sequencing to personalize treatment for MBC patients. Depending on their genetic or genomic profile, patients may have multiple additional treatment options.[4]

The navigator's role can be an integral part of the delivery of patient-centered care.[5] Understanding the unique needs of the patient with MBC and the family during the diagnosis and the trajectory of an MBC diagnosis is vital.

Due to ongoing treatment and the complexity of care associated with MBC, patients, their families, and support teams require special attention and the ongoing support of a navigator. Identifying and eliminating 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 deliver multidisciplinary, patient-centered care.[5]

A navigator can provide essential support to meet the challenges of MBC patients on all levels, including physically, psychosocially, and spiritually, by acting as a liaison facilitating communication between the

patient and the multidisciplinary care team.[5] This toolkit references the *Journal of Oncology Navigation & Survivorship*'s Professional Oncology Navigation Task Force (PONT) Standards. This guide aims to equip MBC navigators with the knowledge, understanding, and skills to support, educate, and advocate for those with MBC.

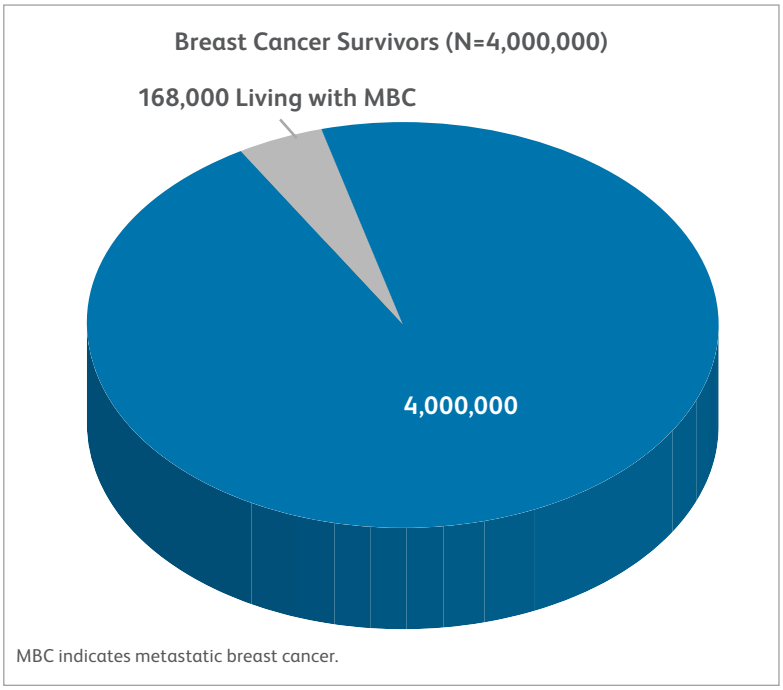
Breast cancer therapy has become more specialized as new treatment methods and genetic and genomic subtypes have been discovered.

When breast cancer metastasizes, care becomes more complex, and providing optimal support to these patients requires specific attention. For patients with MBC, a navigator provides essential support to meet the challenges of this diagnosis. 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.
- MBC-specific core competencies
- Pathway to develop MBC-specific navigation program
- Professional development for MBC navigators
- Glossary of terms

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



MBC indicates metastatic breast cancer.

Facts and Figures

As of 2020, an estimated 168,000 women in the United States were living with MBC. The increase from previous estimates may be attributed to treatment improvements and the aging population in the United States.[6,7]

This is a small proportion of the 4 million female breast cancer survivors as of April 2024 **(Figure 1)**.[6,8]

Breast cancer is the most frequently diagnosed cancer and the second leading cause of cancer death in the United States in women, with an estimated 43,700 deaths to occur in 2023. It is estimated that over 300,590 new cases of breast cancer are diagnosed in men and women in 2023.[9]

From 2005 to 2014, invasive breast cancer incidence rates were stable in White women and increased by 0.4% per year in Black women.[10]

This trend has resulted in the convergence of rates in these 2 groups. Among Black women with breast cancer, the 5-year relative survival rate is 83%, compared with 92% for White women. 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.[11]

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 groups.[12]

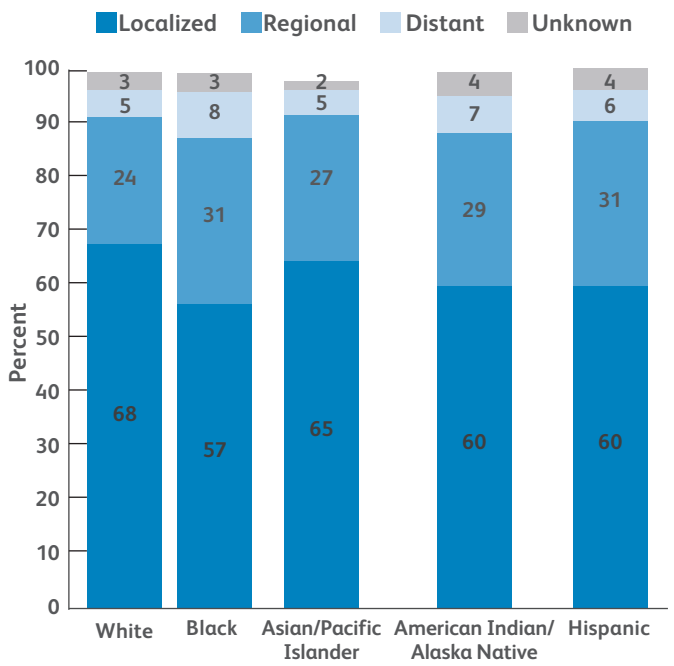
This information is further expressed in **Table 1**[13] and **Figure 2**.[14]

TABLE 1. Diagnosis of Invasive Breast Cancer in Women by Stage and Racial/Ethnic Group (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

[a]Cancer confined to the breast.
[b]Spread of cancer to nodes near the breast.
[c]Spread of cancer to bone, liver, brain, and other tissues and organs away from the breast.

FIGURE 2. Female Breast Cancer Stage Distribution by Race/Ethnicity in the United States, Ages ≥20 Years (2015-2019)



Note: Race is exclusive of Hispanic origin. Estimates may not sum to 100 due to rounding. Data for American Indians/Alaska Natives are based on Purchased/Referred Care Delivery Area (PRCDA) countries.

Moreover, a finding of MBC carries a poor prognosis, with only 27% of patients surviving for 5 years after diagnosis.[15]

Male Breast Cancer

A man diagnosed with breast cancer is rare, accounting for <1% of breast cancer cases in the United States.[16]

However, since 1975, the incidence rate has increased slightly, from 1.0 cases per 100,000 men from 1975 to 1979 to 1.3 cases per 100,000 men from 2010 to 2014.[17]

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. Like female breast cancer, the incidence of male breast cancer increases with age.[18]

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.[14]

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.[19]

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 comprises 3 main parts: lobules, ducts, and connective tissue. 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.[20]

Subtypes

The 5 main intrinsic or molecular subtypes of breast cancer are based on the genes a cancer expresses[15,21]:

- **Luminal A** breast cancer is hormone receptor (HR)-positive (estrogen receptor [ER]-negative and/or progesterone receptor [PR]-positive), HER2-negative. It has low protein levels called Ki-67, which helps control how fast cancer cells grow. Luminal A cancers are low-grade, grow slowly, and have the best prognosis
- **Luminal B** breast cancer is HR-positive (ER-negative 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 somewhat 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 is also more common among younger 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
- **Normal-like** breast cancer is like 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

Understanding MBC

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 cancer stage helps determine the prognosis, best treatment, and whether specific clinical trials are an option.[22,23]

Stage measures 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.

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.[22]

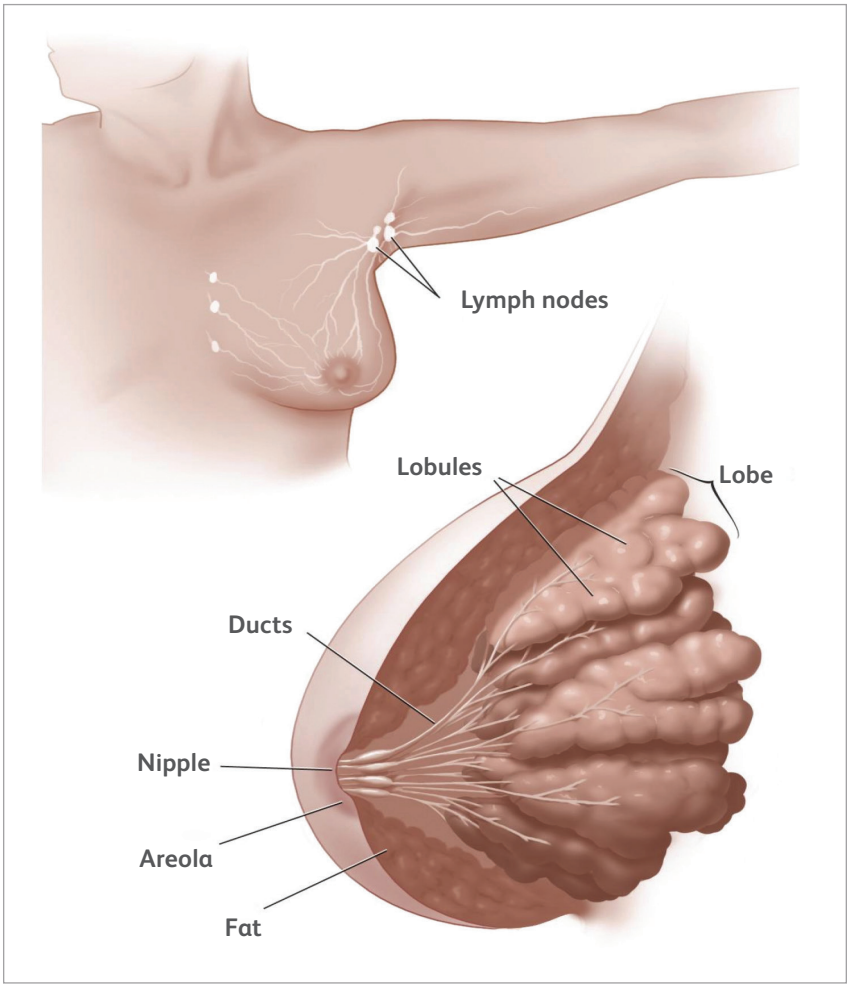
Because metastatic disease can arise when the cancer that has been treated progresses or recurs, up to 30% of patients initially diagnosed with stage I to III breast cancer will ultimately progress to stage IV.[7]

The extent and characteristics of MBC are determined via computed tomography (CT) scans, other imaging, and tumor biopsy.[24]

The risk for MBC is determined primarily by 3 factors[25]:

- 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 3. Breast and Adjacent Lymph Nodes



The primary breast tumor may invade the breast tissue (invasive breast cancer) or it may be a small gathering of abnormal cells in the duct (ductal carcinoma in situ) or lobule (lobular carcinoma in situ) of the breast **(Figure 3)**.[26]

Location, size, and invasiveness of primary tumor

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.

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).

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 more significant lung, liver, and distant lymph-node metastases. In contrast, ILC has greater ovarian and gastrointestinal metastases.[21]

Stage IV ILC is also known to metastasize to the uterus, ovaries, intestines, stomach, and adrenal glands. Research in the areas of ductal and lobular carcinomas remains ongoing.[25,26]

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 increases (proliferation rate).[27]

The subtypes exhibit notable differences in the incidence of distant metastasis and survival after relapse **(Table 2)**.[17,21,28,29]

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-positive and/or PR-positive and HER2-negative; Ki-67, <14%	27.8	2.2
Luminal B	ER-positive and/or PR-positive and HER2-negative; Ki-67, 14%	42.9	1.6
Luminal/HER2-positive	ER-positive and/or PR-positive and HER2-positive	47.9	1.3
HER2-enriched	ER-negative, PR-negative, and HER2-positive	51.4	0.7
Triple-negative, basal-like	ER-negative, PR-negative, HER2-negative, and EGFR-positive and/or CK5/6+	43.1	0.5
Triple-negative, nonbasal	ER-negative, PR-negative, HER2-negative, and EGFR-negative, CK5/6-negative	35.1	0.9

[a]This 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 (like 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 growth factor receptor 2; MBC, metastatic breast cancer; PR, progesterone receptor.

For all subtypes except triple-negative basal-like, bone is the most common metastatic site for MBC.[28]

Compared with luminal A tumors, which are the least aggressive subtype[28]:

- Luminal/HER2-positive and HER2-negative 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 metastasis rate was not lower

The breast cancer subtype so strongly predicts the course of breast cancer that it has now been incorporated into the updated staging system developed by the American Joint Committee on Cancer (AJCC).[14]

In addition to the invasiveness of the primary tumor (spread outside the breast) and the degree of abnormal appearance of the cancer cells, the 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.

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]).

The higher staging for the triple-negative primary tumor reflects the more significant risk shown for this subtype.[23,30]

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. Premenopausal and perimenopausal patients with MBC can be clinically challenging and require ovarian suppression for optimal medical management.[31]

Breast cancer tends to be more aggressive in these younger patients, and there is a higher frequency of ER-negative/PR-negative disease (ie, higher-risk subtypes).

These patients also tend to be diagnosed later in the disease process when their cancer is more advanced.

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.[32]

In pre-or perimenopausal women with tumors responsive to estrogen, ovarian suppression, or the removal of the ovary's 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). 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 the treatment).[31,32]

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 following[33]:

- 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

- 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, headaches, changes in vision, nausea)
  - —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

"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

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 disease activity assessment typically occurs when previously abnormal studies are repeated serially and regularly.

Generally, the same assessment method should be used over time (eg, an abnormality found on a chest CT should typically be monitored with repeat chest CT).[31]

Hormonal and Genomic Evaluation

Histology Evaluation

The tumor cells must be tested for the presence of hormone receptors (ER/PR) and for HER2 to help determine the subtype of breast cancer and plan treatment.

This is true of both early-stage cancer and MBC.[33]

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.[33]

Testing without formal counseling is discouraged. 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.[34]

Goals of Treatment

As no cure exists for MBC, the treatment goals are disease control and palliation to support the highest 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.

Treatment has not been considered curative, and this remains the case.[7]

The length of time someone lives with metastatic disease depends on the treatments available and their effectiveness. Some patients live only for a few years, while others live for over a decade.

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II. TREATMENT OF MBC

Treatment: General Principles

In metastatic breast cancer (MBC), treatment has 2 goals[1]:

- Control of disease: to extend life
- Palliation of disease: to relieve symptoms and suffering and to enhance the quality of life

These 2 goals overlap in treating metastatic or advanced cancer, including MBC. They overlap because choosing a 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]

Data show that in the setting of advanced cancer, when palliative care accompanies active anticancer treatment, not only does the quality of life improve, but 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]

Impact of Power/Privilege on Treatment Outcomes

Standard 4 of the Oncology Navigation Standards for Professional Practice highlights cultural and linguistic humility.

This standard explains that all navigators should understand how systems of power and privilege affect patients' ability to access services; their physical, mental, social, and spiritual health; and their overall well-being and health outcomes.

It is recommended that navigators demonstrate cultural humility, sensitivity, and responsiveness to diverse patient populations (gender/gender identity, age, culture, race, ethnicity, religion, abilities, and sexual orientation).[4]

Experts recommend that navigators should continuously seek to gain knowledge to provide culturally appropriate navigation services and implement culturally relevant and sensitive support programs.[4]

Understanding culturally sensitive barriers to treatment can be essential in delivering culturally competent care[4]:

- Patient comorbid diagnoses
- Citizenship status
- Low health literacy
- Language barriers
- Technology barriers
- Distrust of the medical system
- Psychosocial barriers
- Childcare barriers
- Housing and food insecurity
- Transportation challenges
- Financial barriers

Shared Decision-Making

Shared decision-making is "an approach where clinicians and patients share the best available evidence when making decisions, and where patients are supported to consider options, to achieve informed preferences."[5]

It is recommended that the healthcare team and the patient discuss the need to share in the care processes at the start of treatment for MBC.[1]

In shared decision-making, everyone works toward agreement; the healthcare team alone does not dictate the treatment plan **(Figure 1)**.[5,6]

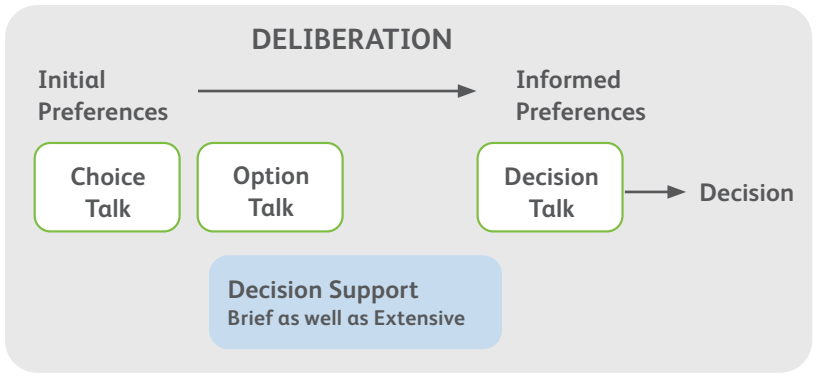
This model has 3 steps[4]:

- 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 model[5]:

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

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.

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.

For example, in some cases, the metastatic tumor will have a different profile of hormonal and genomic features, such as estrogen receptor status or HER2 status, than the primary breast tumor.

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 during metastasis.[7]

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 summarizes[8]:

- 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

Discussing treatment modalities used in MBC can entail more than 1 therapy.

Current treatment protocols can utilize systemic anticancer therapies, surgery, and radiation. The oncology team may also use a combination of treatments **(Table 1)**.[1,9-11]

In some cases, patients with MBC can switch from receiving multiple drug therapies (taxane and/or platinum) to one at a time. This can imply to the patient that the team is not "aggressive."

Current research on MBC has provided new recommendations for treatment based on hormonal and targeted therapies.[9,10]

The clinical navigator must be current regarding the latest recommended treatment modalities to further educate their patients about MBC.[11]

TABLE 1. Treatment of MBC at a Glance

Treatment type	Examples of specific treatments	Mode of action	Typical MBC patient[a,b]
Surgery	• 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	• 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 can benefit from radiation to relieve symptoms, enhance the quality of life
Hormone therapies	• 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-positive/ PR-positive tumor cells found in biopsy
Targeted therapies	• HER2 monoclonal antibodies • HER2/tyrosine kinase inhibitors • CDK4/6 inhibitors • Antibody–drug conjugates • mTOR inhibitor • PARP inhibitors • PI3K inhibitor	Identify and attack cancer cells that have specific genomic features	If the drug's genomic target only occurs in some patients: • Patients whose tumor cells that have genomic target If the drug's genomic target occurs in most breast cancers: • Potentially, any breast cancers
Chemotherapies	• 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	• Bisphosphonates • Anti-RANKL antibodies	Control bone disease, bone degradation, and pain	Patient with bone metastasis

[a]Sometimes patients enrolled in clinical trials may be treated with drugs that they typically would not be otherwise available to them.
[b]Sometimes 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; MBC, metastatic breast cancer; mTOR, mammalian target of rapamycin; PARP, poly (ADP [adenosine diphosphate]-ribose) polymerase; PR, progesterone receptor.

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 to extend a patient's life; more research is needed.

Surgery can also be performed to clear metastatic disease from various sites. Examples of these surgeries are the removal of brain metastasis and tumor obstruction of the bowel or urinary tract.[1]

Rehabilitative Surgery

Surgeons also help to palliate MBC, manage pain, and support function through 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.

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 shrinks tumors, controls pain, and supports function.[1]

For example, external beam radiation can be used to reduce a bowel obstruction caused by a tumor.[1,12]

When injected, radioisotopes (eg, strontium-89 chloride, samarium-153 lexidronam) travel preferentially into the bone, shrinking metastatic sites to control pain.[12,13]

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.[2,3]

Systemic Drug Therapies

Hormone Therapies

Hormone therapies 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.[9]

Specific classes of hormone therapy include[9]:

- 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 can also destroy it

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.[9]

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.[14]

Targeted Therapies

Targeted therapies attack a specific cellular process involved in the growth or proliferation of tumor cells.

Depending on the molecular profile of the primary cancers in MBC, these drugs may be used for patients with MBC whose cancers are HR-positive/HER2-positive, HR-positive/HER2-negative, HR-negative/HER2-positive, HR-negative/HER2-negative, and *BRCA1/2*-positive.[15,16]

The multiple targeted therapies used in MBC include[9,15-17]:

- HER2-negative targeted agents, including anti-HER2 antibodies and HER2 conjugates that deliver cell-specific chemotherapy. These agents control the growth of tumor cells with the type 2 receptor for the human epidermal growth factor protein. These drugs are primarily used in women with HER2-positive MBC
- Tyrosine kinase inhibitors (TKIs) target a pathway that, when blocked, may help inhibit tumor cell growth. These drugs are primarily used in women with HER2-positive 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-positive/HER2-negative MBC
- Mammalian 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-positive/HER2-negative 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
- 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*-positive MBC

Chemotherapies

Chemotherapies are drugs that are toxic to cells or cytotoxic. Many of these drugs have been used in cancer for decades.[10,16]

Chemotherapy is used in MBC that is HR-negative or has not responded to hormone therapy.[10]

Various classes of drugs can be used to treat MBC. These classes include taxanes, anthracyclines, and platinum drugs (Table 1),[1,9-11] but are not limited to them.

Bone-Specific Therapies

Drugs and antibodies that build bone may help patients with cancer-related bone metastasis. These agents control pain and decrease the risk of bone fractures.[18]

Combining Systemic Therapies

The healthcare team may offer the patient with MBC a combination of systemic therapies to individualize treatment.

There are numerous combinations: 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.

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]

Different combinations may be tried at various junctures along the treatment pathway, such as when MBC progresses following a control period.[1]

Understanding Clinical Trial Participation

Clinical trials are essential in improving cancer patients' outcomes. Regulators, trial sponsors, patient advocacy groups, researchers, oncologists, and national organizations such as the American Society of Clinical Oncology (ASCO) and the Association of Community Cancer Centers are aware of and concerned about the lack of racial diversity in clinical trials.[19,20]

Navigators can utilize the following skills to assist patients in clinical trial participation **(Table 2)**.[19,21,22]

Black oncology patients comprise only 4% to 6% of clinical trial participants, and Hispanic oncology patients 3% to 6%.

Including minority groups is critical to understanding potential differences in efficacy and safety for diverse populations, mitigating racial and ethnic disparities in health outcomes, and promoting equity and justice.[19]

TABLE 2. Navigator Skills for Supporting Patients in Clinical Trial Participation

Class of skill	Navigators' skills/activities
Trial identification and enrollment	• 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 the participation of racial/ethnic minorities and other underserved groups
Informed consent	• Present the trial option neutrally—do not "sell" the trial • View informed consent as a process • Emphasize the 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	• Facilitate ongoing patient education • Be aware of ethical issues and standards for clinical trials • Encourage patients to report concerns to the healthcare team
Logistics	• Help the patient address issues that interfere with ongoing trial participation: o 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 o Transportation/lodging issues––Example: Help patient secure transportation or hotel o Literacy/language/cognitive issues–– Examples: Identify translators; make reminder calls to patients for testing and treatment/post-visit calls
Communication	• Maintain open, regular communication among patient/caregiver/healthcare team • Reach out to the healthcare team to obtain status updates on patients in trialsa • Encourage patients to communicate with the healthcare team regarding: o Adverse effects of treatment o Problems following the treatment/testing plan of the study o Problems remembering to take oral medication
Clinical trial navigation	• Role/responsibility: Clinical trial nurse navigators would be responsible for educating patients on the purpose and indication of clinical trials; they would assist in the assessment and screening process of clinical trial intake • Effect on enrollment and compliance: the clinical trial navigator would be responsible for following up with the patient at predetermined points in time to assess for barriers and challenges to clinical trial participation and continuation

[a]Within 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.

Navigators can impact participation in clinical trials by identifying clinical and patient barriers **(Table 3)**.[19,20]

TABLE 3. Barriers to Clinical Trial Participation for Diverse Populations

Clinician barriers	Patient barriers	Trial barriers	Institutional barriers
Biases Knowledge of trial availability Communication Limited time, staff, & resources	Fear Lack of information Trial availability Financial burden Travel time Childcare Work Distrust of medical system Communication Personal beliefs	Restrictive eligibility criteria excludes • Sicker patients • Low performance functional status • Preexisiting conditions Numerous trial office visits Frequent lab tests, scans, biopsies	Trial location Access to trials Diversity of research/ support staff

Barriers facing ethnic and minority cancer patients often involve social determinants of health[19]:

- Financial considerations related to the cost of treatment
- Travel
- Childcare
- Time away from work

Some MBC patients and their families may express fear, distrust, and personal beliefs about clinical trials, which the navigator can address and help alleviate by providing accurate information.[19]

The Black Experience of Clinical Trials for Meaningful Engagement (BECOME) survey and comprehensive, in-depth analysis sought to uncover barriers and concerns preventing patients from participating in clinical trials. The survey was completed by 102 Black respondents of the 424 surveyed, revealing some specific obstacles for Black patients with MBC. Barriers include mistrust of the medical establishment, insurance status, limited financial resources, and social support. Rural areas are especially at risk due to medical literacy, limited English proficiency, and comorbidities limiting eligibility. The survey sought to identify interventions to propel change and increase clinical trial participation. BECOME revealed most Black MBC patients would consider participating in a clinical trial and prefer to learn about clinical trials from someone of the same racial ethnicity or similar experience. Navigators can influence ethnic and minority participation and ensure access by removing barriers for all patients regardless of socioeconomic status or resources.[23]

It is recommended that navigators seek to understand, acknowledge, and address the concerns of ethnic and minority groups to achieve diversity in clinical trials.

They are in a critical position to provide support and reliable, relatable clinical trial education to make participating in a clinical trial easier. Listening and building trust through open, honest, therapeutic communication is important to help patients understand the why, what, and how of clinical trial participation.[22]

Patient Barriers in Clinical Trial Participation

Patients with MBC are often candidates for participation in clinical trials of investigational treatments.

However, it is recommended that navigators are aware of potential issues patients with MBC may face when pursuing clinical trials **(Table 4)**.[23-25]

How Many Clinical Trials Exist?

As of July 2024, the National Library of Medicine's site, ClinicalTrials.gov, lists more than 760 actively recruiting and not-yet-recruiting MBC studies.[26]

TABLE 4. Clinical Trials: Issues and Barriers That Confront Patients With MBC

Barrier	Details
Low enrollment	• 20% of all US patients with cancer are eligible for a clinical trial • Only 6.3% participate o Higher rates at NCI-designated cancer centers, 18.9% o Lower rates at community cancer programs, 3.6%-4.4% • Minority, rural, and elderly patients have significantly lower enrollment compared with larger academic medical centers • Type of trials patients participate in: o Biorepository studies (13.4%) o Cancer registry (8.1%) o Prevention (6.4%) o Genetic (3.6%) o Economic (2.7%) o Diagnostic (2.7%) o Screening studies (1.8%) • At least 25.4% of adult cancer patients were estimated to participate in one or more cancer clinical research studies
Lack of understanding	• Patients and caregivers may be unsure about the process of trial enrollment and participation
Lack of trust	• Black patients, compared with non-Black patients, were more likely to believe unstudied treatments may be harmful (57% vs 31%) • Black patients, compared with non-Black patients, were less likely to indicate they trust trials (73% vs 91%) and trust that people of all races/ethnicities get fair treatment in trials (32% vs 56%)
Lack of approach	• 40% of Black patients and 33% of non-Black patients reported that their care team had not informed them about the opportunity to enroll in a trial
Lack of effective decision-making	• Patients and caregivers may lack the ability to make an informed decision and give ongoing consent to a trial due to: o Literacy o Language barrier o Unrelieved distress o Lack of time o Lack of capacity (attributed to psychosocial/physical barriers such as lack of transportation or pain) o Misconceptions about the nature of the trials
Financial/cost issues	• 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 security, etc), which raise fears of unexpected costs of participation
Healthcare team deficits in knowledge/time	• Busy professionals may not be up-to-date on available trials • Potential reasons include: o Lack of knowledge of the portfolio of trials available to patients o Time constraints for enrolling and managing the patient on a trial o Negative perceptions of clinical trials

MBC indicates metastatic breast cancer; NCI, National Cancer Institute.

Some of the drug classes under investigation include[27]:

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

Why Is Clinical Trial Participation Important?

Trial participation benefits patients with MBC, giving them access to clinically advanced care with meticulous attention to detail.[21]

However, navigating patients through enrollment and participation in a clinical trial can be difficult. In a survey conducted by the Academy of Oncology Nurse & Patient Navigators, specific to MBC, navigators said awareness of clinical trials and connecting patients with appropriate trials are among the major challenges they face.[28]

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.[26] Metastatictrialsearch.org is another patient-friendly search engine for clinical trials.[29]

Palliation With Systemic Therapies

Systemic therapy can palliate specific symptoms in MBC by reducing the tumor's burden on the body.

For instance, chemotherapy or hormonal therapy may be administered to relieve the pain of bone metastasis; if a tumor's growth is causing bowel obstruction, chemotherapy may help clear the obstruction.[30]

Conversely, systemic therapy is sometimes 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.[29]

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.

Notable examples include[32,33]:

- 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

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 guidelines on managing side effects; therefore, it is crucial to follow the individual guidelines of the center where one works.[32]

The Putting Evidence into Practice resources can be very helpful for navigators to learn more about interventions for specific adverse events.[34]

Grading adverse effects on a scale of 1 to 4 according to the Common Terminology Criteria for Adverse Events **(Table 5)** is essential in assessing them.[35]

TABLE 5. Common Terminology Criteria for Adverse Events Grades for Adverse Effects of Cancer Therapies

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 interventions indicated; limiting age-appropriate instrumental activities of daily living	Severe or medically significant but not immediately life-threatening; hospitalizations or prolongation of hospitalization indicated; disabling; limiting self-care activities of daily living	Life-threatening consequences; urgent intervention indicated[a]

[a]Grade 5, not shown (death from an adverse event).

Comorbidity Management

In addition to breast cancer, patients may have preexisting comorbid diagnoses as well as acute diagnoses that arise during their treatment for MBC.

Comorbidities in this setting are known to be associated with inferior outcomes.[36]

Barriers to obtaining primary care include timely awareness of their local provider on the status of their cancer, lack of familiarity with MBC treatment, side effects, and interactions of their cancer treatment with non-cancer conditions and treatment.[24,31]

The oncology nurse navigator can play a pivotal role in streamlining this communication and addressing barriers as they arise.[28]

Symptoms of MBC

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 6)**.[32,33,37,38]

In addition to organ-specific symptoms, general symptoms of advancing cancer include[28,33]:

- 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.[32,33]

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 typical drainage pattern in the lymph nodes.

It most often causes arm swelling but can also affect the breast, chest, and sometimes even the legs. An abnormal buildup of excess fluid causes lymphedema.[39,40]

Removing the axillary lymph nodes increases the risk of developing lymphedema. That risk continues for the rest of the patient's life.[41]

Palliation/Relieving Symptoms of MBC

One goal of anticancer therapy in MBC is symptom reduction.[1] Diminishing the size and extent of metastasis helps alleviate symptoms. In addition to these therapies, clinicians offer patients many forms of symptom management called palliation.

Palliation was once 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]

Palliation Guidelines

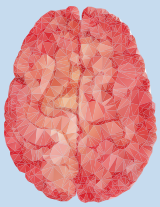
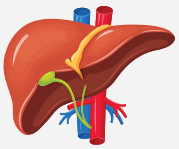
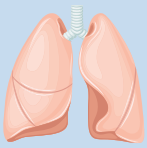
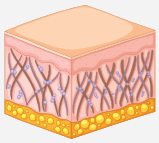
In 2017, ASCO convened ASCO Ad Hoc Palliative Care Expert Panel members to develop a guideline update.

The resulting publication states that patients with advanced cancer, such as MBC, should receive dedicated, interdisciplinary palliative care early on while receiving treatment for their cancer.[3]

Notable components of palliative care include[3]:

- 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

TABLE 6. Symptoms of MBC 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

Relieving Symptoms

A variety of medications are prescribed to help manage the numerous symptoms experienced by patients with MBC.

The following are some standard methods used to treat these symptoms[42-45]:

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)
- Mood disorders and insomnia can be treated with antidepressant medication, antianxiety medication, and prescription sleep aids
- Medications for control of nausea and vomiting
- Other specific symptoms may be managed with medication at the clinician's recommendation
- Nerve blocks

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. In brain metastasis, radiation therapy may be part of a multimodal strategy to reduce disease and, in doing so, manage symptoms.

Surgery

Palliative surgery relieves many symptoms of MBC, such as skin wounds and pain.

Surgical care for fractures and metastasis in the brain, liver, or chest wall may also be recommended for some patients.

Integrative Care

Patients may also find relief from pain, distress, and fatigue through integrative therapies. Interventions include but are not limited to:

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

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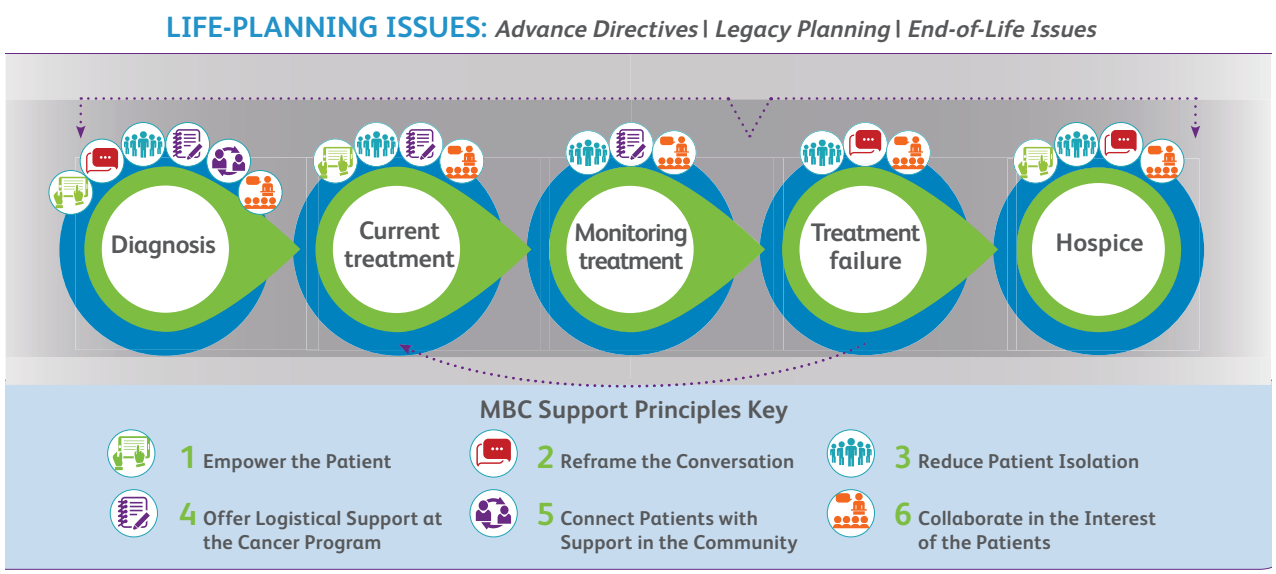
III. COMMUNICATION DURING TREATMENT

Treatment of metastatic breast cancer (MBC) is often complex and will continue for the duration of the patient's life. Navigators facilitate communication among the patient, family, and care team.

It is recommended that professional oncology navigators develop therapeutic communication skills following Standard 6 of the Oncology Navigation Standards of Professional Practice.[1]

The Association of Community Cancer Centers maps the communication process through diagnosis, treatment, treatment monitoring, treatment failure, retreatment, and end of life **(Figure 1)**.[2]

FIGURE 1. ACCC Communication Process Map for MBC



ACCC indicates Association of Community Cancer Centers; MBC, metastatic breast cancer..

The map emphasizes how communication applies "support principles" in navigation[2]:

1. Empower the patient
2. Reframe the conversation (to remove self-blame and negativity)
3. Reduce patient isolation
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[1]:

- Professional navigator: a trained individual who is employed and paid by a healthcare-, advocacy-, and/or community-based organization to fill the role of oncology navigator. Positions that fall under the professional navigator category include oncology patients and clinical navigators. Clinical navigators comprise oncology nurse navigators and oncology social work navigators

- Clinical navigator/oncology nurse navigator: a professional registered nurse with oncology-specific clinical knowledge who assists patients, families, and caregivers to help overcome healthcare system barriers. Using the nursing process, an oncology nurse navigator generally provides education and resources to facilitate informed decision-making and timely access to quality health and psychosocial care throughout all phases of the cancer continuum
- Oncology patient navigator: a professional who assists patients and families affected by cancer to improve access to healthcare services. A patient navigator may work within the healthcare system at the point of screening, diagnosis, treatment, or survivorship across the cancer care spectrum outside the healthcare system at a community-based organization or as a freelance patient navigator. A patient navigator may be employed by a clinic or a community-based organization and work throughout the community, crossing the clinic threshold to continue providing consistent contact and support within the healthcare system. A patient navigator typically does not have or use clinical training
- Clinical navigator/oncology social work navigator: a professional social worker with a master's degree in social work and often a clinical license with oncology-specific and clinical psychosocial knowledge who offers individual assistance to patients, families, and caregivers to help overcome healthcare system barriers. Using the social work process, an oncology social work navigator provides education and resources to facilitate informed decision-making and timely access to quality health and psychosocial care throughout all phases of the cancer continuum

Navigators must remember to comply with the privacy provisions in the Health Insurance Portability and Accountability Act when discussing patient information.[1,2]

Experts recommend that oncology patient navigators be knowledgeable of cancer screening guidelines, diagnostic processes, treatment options, and survivorship, as well as related physical, psychological, and social issues that may confront cancer patients.

Clinically licensed navigators (such as nurse navigators or social work navigators) are typically employed within the healthcare system. It is recommended that they possess the knowledge and skills to deliver high-quality, competent, and ethical services to people with cancer and focus their evaluation on clinical outcomes and quality indicators.[3]

Impact of COVID-19 on Telehealth

The challenges experienced during the COVID-19 pandemic prompted oncology clinics to improve and expand the use of telehealth medicine. While obvious limitations are associated with virtual visits, they enable patients to continue communicating with their oncologist and multidisciplinary team. This facilitates effective care coordination to ensure patients continue treatment and receive support. Many clinicians believe that telehealth medicine and access to the multidisciplinary team will continue.[4]

Navigator Communication – Distress

Since the implementation of the American College of Surgeons Commission on Cancer Standard 3.2, screening people with cancer for psychological distress is a requirement for accreditation.[5]

The requirement has been modified, and the current, updated Standard 5.2 requires cancer programs to "implement a policy and procedure for psychosocial, social, financial, and behavioral issues that may interfere with a patient's treatment plan and adversely affect treatment outcomes."[6]

The tool must be administered "at least once during the patient's first course of treatment."[5] Cancer programs are also responsible for referring patients with cancer to appropriate supportive services as indicated.[5]

How Navigators Can Manage Patient Distress

Patients with metastatic cancer may experience distress, which can interfere with their willingness or ability to adhere to treatment.[5,6]

Nearly all patients diagnosed with breast cancer diagnosis have some level of distress. For those facing a diagnosis of MBC, distress is certain as they navigate the uncertainty, ongoing treatments, financial, relational, end-of-life, and countless other sources of stress. In addition, there are certain times during the cancer experience that may increase the level of distress.[9]

Patients with MBC frequently experience distress and anxiety before having imaging scans to ascertain treatment effects or progression. The term "scanxiety" has been coined to describe this common experience.[8]

It is important for MBC navigators to be aware of and regularly assess distress throughout the patient's journey. The navigator is in a unique position to address psychosocial distress.[9]

Early identification of distress, addressing concerns, and providing prompt interventions to improve care coordination and adherence to treatment are essential functions of navigation.[10]

One study shows that distress screening and referral programs positively impact healthcare utilization, including the efficient and appropriate use of resources. Distress screening and referrals are associated with fewer emergency department visits and more frequent use of multidisciplinary, integrative services and patient and family counseling.[11]

"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

Screening Tools

One common method of assessing distress is with a thermometer graphic. The thermometer asks the patient to rate distress numerically from 0 to 10. Like the pain score used routinely in healthcare, the patient indicates their stress level—0 is no distress, and 10 is extreme distress.[12]

A problem list allows patients to identify sources of distress.[13]

The Cancer Support Community Helpline offers access distress screening for patients and loved ones by calling 1-888-793-9355.

Coping With Mental Health Concerns | Cancer Support Community

Navigator Communication – Financial Toxicity and Adverse Event Management

Distress related to insurance issues, medication cost, and side effects can impact patient adherence to medications. MBC patients are at risk of an increased risk of financial toxicity because of the cost of therapies and longer time on treatment.[11,13]

Professional Navigator: Communication Competency

- Tailor communication based on the patient's educational, developmental, and health literacy level
- Communicate effectively to ensure patient safety and satisfaction
- Communicate effectively to advocate with and on behalf of patients
- Apply insight and understanding concerning human emotional response and development to create and maintain positive interpersonal interactions leading to trust and collaboration between the patient and the healthcare team
- Communicate effectively in a variety of formats in all domains of practice
- Communicate effectively with patients, families, and the public to build trusting relationships across various socioeconomic and cultural backgrounds

Patients may be underinsured or uninsured, limiting access to costly treatments. They may also have low health insurance literacy when selecting a health insurance plan and a limited understanding of its coverage.[14]

It is important for MBC navigators to be aware of patients' financial needs to avoid financial toxicity that may result in coping behaviors such as medication nonadherence or discontinuation.[1]

Navigator Communication – Oral Oncolytic Adherence

Sometimes, the patient may not be honest about the adverse events (AEs) or symptoms she/he is experiencing, fearing 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.[2]

Clinical navigators can help reiterate medical information to 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.[15]

An increasing number of anticancer medications are given orally. Unlike injectable medications requiring a visit to a treatment center, the patient is responsible for taking them at home on a schedule. However, with the convenience of oral medications comes the risk of poor adherence to therapy.

Reasons for nonadherence span factors related to the patient, disease, treatment, provider, and healthcare system, but all result in poorer clinical outcomes.[16]

Overall, patients with all types of metastatic solid tumors, their caregivers, and healthcare professionals report fairly high levels of adherence to oral medication—more than 80% take their medication always or almost always as prescribed.

However, 2 factors complicate this scenario. First, assessment of adherence may differ from the perspectives of patients, caregivers, and the healthcare team.

Patients may state that they took the medication when they did not. Second, 5% to 10% of patients with a metastatic solid tumor fail to adhere to oral anticancer medication.[17]

Two tools the clinical navigator can utilize to improve oral adherence among patients are[18,19]:

- Medication nonadherence risk tool assessment: http://adultmeducation.com/downloads/Nonadherence_Risk_TOOL.pdf
- Oncology Nursing Society (ONS) oral adherence toolkit: www.ons.org/clinical-practice-resources/oral-adherence-toolkit

Ensuring Adherence

The role of MBC navigators can positively impact oral chemotherapy adherence by providing education, monitoring side effects, and helping to manage them. It is recommended that navigators be familiar with the side effects of therapies for MBC and when to contact the medical oncology team.[2,5]

The ONS Oral Chemotherapy Education resource provides cancer patients and caregivers with a comprehensive library of oral chemotherapy drugs and their side effects. The oral medication sheets are available for print and download and can be edited and tailored to the needs of the patient and the caregiver.[20]

Navigators need to be familiar with the side effects of therapies for MBC and when to contact the medical oncology team. The navigator should also understand the patient's comorbidities, which may exacerbate expected side effects and increase the risk for AEs.

Navigator Communication – AE Management

Caring for MBC patients receiving oral chemotherapies is complex and must be managed efficiently and safely.

In addition to the navigator, the multidisciplinary team may include a financial navigator, social worker, pharmacist, and nurse clinician, who communicate and collaborate to provide efficient, safe administration and improve outcomes by keeping patients on treatment longer.

Communication: Patient Engagement & Responsibilities

It is recommended that patients with MBC be educated and encouraged to be engaged and communicate with the medical team, with emphasis on the following:[1-3,10]

- Provide the treatment team information about any medications/supplements taken, as well as side effects and symptoms she/he is experiencing so they can be managed effectively
- Adhere to medications as prescribed and maintain appointment schedules
- Inform the healthcare team members of her/his goals of care (these will likely change over time)
- Inform the appropriate team members (such as the clinical navigator and medical oncologist) of 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 participate 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 be honest with the team members about how she/he is feeling, what she/he is most worried about, and what she/he needs spiritually, emotionally, and physically

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IV. MBC MYTHS AND FACTS

Although the level of awareness about early-stage breast cancer is high, knowledge of metastatic breast cancer (MBC) remains low.

60% of people reported knowing little to nothing about MBC when asked.[1]

This lack of knowledge leads to misconceptions about MBC, as shown in **Table 1**.[2-10]

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. Thirty percent of women who had early breast cancer will eventually develop MBC, and 5-8 patients present with de novo metastasis
Most people believe breast cancer rates are the same across various ethnic groups	Five-year survival is much lower in certain ethnic groups: • African American women are 40% more likely to die than White women even though African American women are diagnosed less frequently than White women • For Hispanic women, breast cancer is the leading cause of cancer death
"Once you have MBC, you don't have long to live"	People with MBC can live for many years after diagnosis—about 25% of patients with MBC live for 5 years or more: • Close to 30% of all races, 32% of White patients, and 21% of Black patients live more than 5 years after diagnosis
"When people have MBC, they have to withdraw from life because no one understands"	There are ways for patients with MBC to stay connected, including: • 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 • Understanding that their need for support and encouragement is ongoing as they journey through treatment
"You cannot keep working when you have MBC"	In total, 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 cancer"	Most patients treated with medications for MBC will not achieve a cure

MBC indicates metastatic breast cancer.

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 with patients, caregivers, and the community can contribute to navigator communication and education.[11]

Navigators can make a big difference in replacing patients' mistaken beliefs with facts.[1]

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V. NAVIGATION IN THE CONTEXT OF MBC

Navigators in MBC

There is no specific evidence-based navigation model for metastatic breast cancer (MBC); therefore, it is recommended that MBC navigators follow the general navigation models outlined in the oncology navigation standards set by organizations like the Professional Oncology Navigation Task Force.[1]

Several different navigator roles may be involved in supporting patients with MBC.

Clinical navigators support the patient with MBC from diagnosis to 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.[2]

Clinical navigators[2-4]:

- 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 preference
- Should know 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)
- 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 process
- 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)
- The palliative care team can review the elements that must be fulfilled to experience a peaceful death

Social work navigators[5]:

- Address practical, family, and emotional barriers
- Complete a psychosocial assessment and offer interventions as deemed appropriate
- Address advance care planning and answer patient questions

Financial navigators work closely with the patient to discuss[5]:

- Insurance benefits and out-of-pocket cost obligations
- Resources available to assist needy patients regarding defraying out-of-pocket costs

Nonclinical patient navigators assist with[6]:

- 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.

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VI. NAVIGATION CORE COMPETENCIES SPECIFIC TO MBC

Navigators must demonstrate competence in oncology and the psychosocial and spiritual aspects of patient and family care.

The National Navigation Roundtable has created 7 nationally recognized competency domains for navigators.[1]

Patient care coordination is among the most important core competencies for the metastatic breast cancer (MBC) clinical and nonclinical navigator.[2]

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.[3]

"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

The nonclinical navigator can assist with evaluating barriers to care and health disparities within the community against quality indicators of the healthcare system.[4]

Patients with MBC also need a clinical navigator to assist them in shared decision-making based on their needs, goals, strengths, barriers, solutions, and resources.[3]

Educating the patient and family is a key role for the clinical navigator and Professional Oncology Navigation Task Force (PONT) Standard 3.[2]

This education helps patients more confidently engage in decision-making about treatment and ensures the quality of navigation practice. It also helps promote adherence to care and evidence and research findings.[1,3]

Health knowledge is paramount to navigating patients with MBC. Participation in multidisciplinary tumor boards can provide opportunities for navigators to continue learning MBC treatment regimens.[1,3]

Refer to *Pfizer General Navigation Toolkit*:

Navigation Core Competencies, pages 11-12

Sensitivity and responsiveness to diversity in gender, age, ethnicity, and abilities, as well as respect for confidentiality and ethical principles, are also necessary when supporting patients with MBC and reflect PONT Standard 4.[2]

It is recommended that navigators understand how systems of power and privilege reflect and affect patients' ability to access services. It is recommended that they also demonstrate humility and equitable responsiveness to all patient populations.[3]

Navigators can help to ensure patients receive health-literate educational materials with an appropriate reading level, and translators are included as needed to optimize patient interactions with clinical teams.[4]

In addition, the navigator's role includes assessing and addressing social determinants of health. This includes but is not limited to assessing the needs of all genders/gender identities, ages, cultures, races, ethnicities, religions, abilities, and sexual orientations to address any present barriers to care and provide equitable healthcare for all.[2,3]

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VII. BARRIERS TO CARE ALONG THE PATHWAYS

Barriers to care can occur at any step in the clinical course of metastatic breast cancer (MBC), as seen in **Table 1**.[1-3]

TABLE 1. Barriers to Care

Barriers to Care		
Patient/caregiver	**Healthcare team**	**Healthcare system**
• Financial burden • Insurance barriers • Communication/information barriers • Navigation and support services • Social risk factors	• Inefficiency in the coordination of care over time and across specialties • Inadequate patient education • Lack of time • Burnout	• Lack of resources

Across the cancer care continuum, the goals of the navigator include[4]:

- Identifying and addressing barriers to care
- Empowering patients with appropriate education and awareness to make informed decisions
- Providing 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

Poorly coordinated care transitions can increase emergency department utilization and hospital readmission rates, increasing healthcare costs.[5]

Having the navigator move with the patient and family throughout the cancer care continuum, providing patient-centered care, can lead to better outcomes.[6]

"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

Evaluation of Psychosocial Issues

Care of the patient with MBC requires a discussion of therapy goals and a commitment to shared decision-making between the patient and the healthcare team.

This is important in developing a realistic treatment plan. Understanding each patient's mental, emotional, financial, and social needs facilitates this care.[1,7]

Major challenges in MBC navigation include patients' financial problems and the cost of treatment, food insecurity, the stress of waiting for test results, patient–clinician miscommunication, and the emotional process of MBC acceptance.[8,9]

Therefore, the psychosocial evaluation must document a patient's[10,11]:

- 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 disorders)
- Family and caregiver relationships
- Financial status or difficulties
- Cultural attitudes

Patients with MBC may feel isolated or alienated from others and may even self-isolate and pull back from loved ones. It is critical to assess the psychosocial needs of patients with MBC so that they can be referred to appropriate supportive resources.[12]

Understanding Patient Trepidation in Pursuing Healthcare

The fear of progression associated with frequent scans and fluctuating tumor markers can be a barrier to the patient's willingness to follow up. Navigators must be alerted to frequent missed appointments and follow up with the patient to identify barriers.[13]

Refer to *Pfizer General Navigation Toolkit*:

Barriers to Care, pages 19-21

References: 1. Breast Cancer Initiatives 2.5. Improving Access to Breast Cancer Care. Accessed January 24, 2025. https://www.fredhutch.org/content/dam/www/research/divisions/public-health-sciences/epidemiology/bci-25/KSPDF/KS%20Planning%20Access%20030617.pdf **2.** Shreyamsa M, Singh D, Ramakant P, et al. Barriers to Timely Diagnosis and Management of Breast Cancer: Observations from a Tertiary Referral Center in Resource Poor Setting. *Indian J Surg Oncol*. 2020;11(2):287-293. **3.** Hallgren E, Yeary KHK, DelNero P, et al. Barriers, facilitators, and priority needs related to cancer prevention, control, and research in rural, persistent poverty areas. *Cancer Causes Control*. 2023;34(12):1145-1155. **4.** 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. **5.** Mansukhani RP, Bridgeman MB, Candelario D, et al. Exploring transitional care: evidence-based strategies for improving provider communication and reducing readmissions. *P T*. 2015;40(10):690-694. **6.** Role of the oncology nurse navigator throughout the cancer trajectory. *Oncol Nurs Forum*. 2018;45(3):283. **7.** Roberson ML, Henricks A, Woods J, et al. Re-imagining metastatic breast cancer care delivery: a patient-partnered qualitative study. *Support Care Cancer*. 2023;31(12):735. **8.** Biddell CB, Waters AR, Angove RSM, et al. Facing financial barriers to healthcare: patient-informed adaptation of a conceptual framework for adults with a history of cancer. *Front Psychol*. 2023;14:1178517. **9.** Sadigh G, Coleman D, Switchenko JM, Hopkins JO, Carlos RC. Treatment out-of-pocket cost communication and remote financial navigation in patients with cancer: a feasibility study. *Support Care Cancer*. 2022;30(10):8173-8182. **10.** Thanasansomboon B, Choemprayong S, Parinyanitikul N, et al. Development and validation of a rapid psychosocial well-being screening tool in patients with metastatic breast cancer. *Int J Nurs Sci*. 2022;9(3):303-312. **11.** Burke S, Dean M, Franklin E, et al. Oncology Navigation Standards of Professional Practice. *Clin J Oncol Nurs*. 2022;26(3):E14-E25. **12.** Liang Y, Hao G, Wu M, Hou L. Social isolation in adults with cancer: an evolutionary concept analysis. *Front Psychol*. 2022;13:973640. **13.** Reb AM, Borneman T, Economou D, Cangin MA, Patel SK, Sharpe L. Fear of cancer progression: findings from case studies and a nurse-led intervention. *Clin J Oncol Nurs*. 2020;24(4):400-408.

VIII. DISTRESS SPECIFIC TO MBC

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. Studies show patients experience a high prevalence of fatigue and psychological distress and the associated decrease in quality of life (QoL).[1]

People with metastatic breast cancer (MBC) and their loved ones/caregivers have unique emotional, physical, and informational needs. There is a risk of being stigmatized and isolated from support systems, which may contribute to distress and may impact QoL.[2]

Talking with others facilitates cognitive and emotional processing of the MBC experience, which can enhance well-being.[3]

Almost half of those with MBC report communication issues with their social support system due to[3]:

- Denial
  - o Exaggerating treatment and prognosis
  - o Minimizing experience
- Avoidance
  - o Social support does not discuss treatment or prognosis
  - o Emotional distress
- Discomfort
  - o Feelings of frustration and loneliness following conversations

MBC patients and their caregivers often struggle to find meaning and hope in their suffering. Cultural beliefs and values greatly influence people's capacity to give meaning to suffering and ultimately accept and understand its purpose.

The table below lists the multidimensional elements and influences of culture that impact this process throughout the trajectory of the MBC experience[4]:

Multidimensional Elements and Influences of Culture				
Elements	**Influence of elements**	**Cultural barriers**	**Cultural barriers effects**	**Cultural influences/ effects**
• Language • Environment • Social structure • Spirituality • Religion • Existential worldview • Economy	• Health status • Disease perception/ reaction to diagnosis • Response to illness • Medical care	• Primary language (not English) • Health literacy • Financial • Insurance • Immigration status • Low social/emotional support • Social isolation • Inadequate resources	• Access to quality care • Treatment decision-making • Communication with medical team • Disparities in access to care • Disparities in quality of care • Poor outcomes	• Family's definition of caregiving • Caregiver's understanding of their role • Creates meaning • Creates structure

Navigators have an opportunity and responsibility to provide support, education, and adequate resources to family members and the patient. Navigators must expand their knowledge and understanding of cultural practices to provide culturally sensitive, therapeutic support.

The navigator should recognize family members and caregivers suffer along with the MBC patient and may experience hopelessness or anger when their loved one is in distress. The medical team is not responsive to the reported needs, impacting QoL.

Clear instructions on when and how to communicate with the medical team are vital in preventing avoidable frustration and suffering. Caring for a loved one with MBC is complex and impacts aspects of the family's well-being and QoL.[4]

Caregivers may experience psychological, spiritual, behavioral, and physical adjustments resulting in depression and physical health implications, including, but not limited to, decreased exercise, poor nutrition, and accessing social support systems.[5]

Studies have shown caregivers of patients with advanced-stage cancer reported severe fluctuations in sleep, depression, and less time and energy pursuing leisure activities.[6]

Caregivers who fail to care for themselves adequately are at risk for diminished effectiveness in their role.

The result of these changes can result in guilt and shame. Family members of those with MBC can experience similar levels of distress as the person with the illness. Healthcare providers have a significant opportunity to support family members as the caregiver role changes in response to the patient's ongoing, changing needs.

The best practice is to use validated tools to assess individuals' ongoing and diverse needs with MBC. It is vital to recognize that they are more than cancer, and a holistic approach is recommended to determine physical, emotional, social/relational, functional, nutritional, financial, and spiritual well-being.[4]

"With sufficient support and education, providing care for a vulnerable loved one can be viewed as a tremendously powerful life event that creates opportunities for meaningful memories that will be deeply treasured."[4]

Assessment Tools		
Focus	**Tool**	**Resource**
Physical	FACT-B	Brady MJ, Cella DF, Mo F, et al. Reliability and validity of the Functional Assessment of Cancer Therapy-Breast quality-of-life instrument. *J Clin Oncol*. 1997;15(3):974-986.
Social/family	FACT-B	
Emotional	FACT-B	**Note:** Assess where the patient gets information about the diagnosis
Functional	FACT-B	
Additional concerns	FACT-B	
Health questionnaire	PHQ-9	
Anxiety	GAD-7	Esser P, Hartung TJ, Friedrich M, et al. The Generalized Anxiety Disorder Screener (GAD-7) and the anxiety module of the Hospital and Depression Scale (HADS-A) as screening tools for generalized anxiety disorder among cancer patients. *Psychooncology*. 2018;27(6):1509-1516.
Spiritual	FACIT-Sp-12	Peterman AH, Fitchett G, Brady MJ, et al. Measuring spiritual well-being in people with cancer: the functional assessment of chronic illness therapy--Spiritual Well-Being Scale (FACIT-Sp). *Ann Behav Med*. 2002;24(1):49-58.

Refer to *Pfizer General Navigation Toolkit*:

Distress and Psychosocial Needs, pages 23-27

References: 1. Rodriguez-Gonzalez A, Velasco-Durantez V, Martin-Abreu C, et al. Fatigue, emotional distress, and illness uncertainty in patients with metastatic cancer: results from the prospective NEOETIC_SEOM study. *Curr Oncol*. 2022;29(12):9722-9732. **2.** McNally GA. Stigma in clinical oncology. *Clin J Oncol Nurs*. 2024;28(1):43-51. **3.** Mosher CE, Johnson C, Dickler M, et al. Living with metastatic breast cancer: a qualitative analysis of physical, psychological, and social sequelae. *Breast J*. 2013;19(3):285-292. **4.** Otis-Green S, Juarez G. Enhancing the social well-being of family caregivers. *Semin Oncol Nurs*. 2012;28(4):246-255. **5.** Fordyce M. Caregiver Health. Family Caregiver Alliance®. Accessed August 9, 2024. https://www.caregiver.org/resource/caregiver-health/ **6.** Chen Q, Terhorst L, Lowery-Allison A, et al. Sleep problems in advanced cancer patients and their caregivers: who is disturbing whom? *J Behav Med*. 2020;43(4):614-622.

IX. PUTTING IT ALL TOGETHER: CONTINUUM OF CARE FOR PATIENTS WITH MBC

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 through a complex course: diagnosis, first treatment, subsequent treatment, clinical trials, and onto the end-of-life stage **(Figure)**.[1]

This process is unique to each patient, 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 varying implications for the navigator[2,3]:

- Patients initially diagnosed with stage IV breast cancer 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 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

The navigator's roles and responsibilities may include MBC continuum-of-care phase. The navigator can facilitate smooth transitions and patient advocacy throughout each continuum phase. Professional Oncology Navigation Task Force (PONT) Standards 12, 13, 15, and 16 inform a broader and more detailed scope of the navigator's role and responsibilities. PONT Standards 1 to 11, 14, and 17 to 19 refer to the professional and personal development of the navigator.[1]

The figure below outlines the roles and responsibilities commonly deployed to support patients with MBC[1]:

FIGURE. Pathways of MBC

Pathways of MBC: Navigator Roles and Responsibilities						
Suspicion of MBC	**Diagnostic Workup**	**Diagnosis of Stage IV or Recurrent MBC**	**First-Line Treatment**	**Ongoing Monitoring**	**Multiple Treatment Lines**	**End-of-Life Care**
• Education • Coordination of care • Psychosocial support • Effective communication	• Education • Coordination of care • Psychosocial support • Financial insurance • Caregiver support	• Education • Psychosocial support • Coordination of care • Palliative care • Referrals to supportive specialists • Caregiver support	• Education • Coordination of care • Psychosocial support • Referrals to supportive specialists • Side effect management • Palliative care • Knowledge of pt's life goals • Financial/ Insurance • Caregiver support	• Education • Coordination of care • Psychosocial support • Financial/ Insurance • Side effect management • Referrals to supportive specialists • Palliative care • Knowledge of pt's life goals • Caregiver support	• Education • Coordination of care • Psychosocial support • Financial/ Insurance • Side effect management • Palliative care • Knowledge of pt's life goals • Caregiver support	• Education • Coordination of care • Psychosocial support • Financial/ Insurance • Side effect management • Knowledge of pt's life goals • Caregiver support
	Smooth transitions			Patient advocacy		

"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

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 (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 complicated feelings.

Case Study on the Continuum of Care for the Patient With MBC

Cathy L. is a 52-year-old single, postmenopausal woman who had previously worked as an accountant. She had been diagnosed with stage II breast cancer, and the tumor histology showed that it was HER2-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 could not work but could carry out self-care and some home upkeep.

A bone scan and computed tomography scan showed several areas of metastatic disease in her femur, liver, and lung. All biopsies showed that 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 cyclin-dependent kinase 4/6 inhibitor, and was placed on a different hormonal therapy than she had been on.

The clinical navigator, Sharon, worked with Cathy since her initial diagnosis. Now, 10 months later, Sharon was still involved, following the patient along the continuum of care. Sharon administered a distress tool at this pivotal moment in the patient's journey.

Cathy's distress was measured at level 8, which was double her distress score of level 4 at the time of

her initial diagnosis of early-stage breast cancer. Sharon initiated a discussion with Cathy regarding the new diagnosis, the goals of therapy, and the importance of shared decision-making.

She also searched for appropriate clinical trials and discussed this with the oncologist and coordinator. Sharon then took the opportunity to educate Cathy on clinical trials and discuss relevant and available trials 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 evaluate when she wanted to stop treatment and enroll in hospice. Each time a new line of therapy is discussed, it must 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 with a better quality of life for their remaining time. In most cases, this also extends their lives a bit longer because they do not receive toxic agents taxing 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 Insurance 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 the 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 discussing Cathy's support system since she is single. Cathy's close sister will accompany her to all her appointments. Sharon provided Cathy with information about the American Cancer Society caregiver support groups and other available resources

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.[1]

The navigator is critical in helping patients understand their situation, identify and express their goals, and connect with valuable services to support them throughout their journey.

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X. EOL 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 essential contributions by assisting patients in maintaining hope while having clear expectations regarding their prognosis.

It is recommended that navigators develop and practice communication skills to have complex, emotional conversations. These conversations can be initiated intentionally and gently throughout the continuum of care with disease progression and treatment changes.

"To die is to be human and anything human is mentionable. Anything mentionable is manageable. When we can talk about our feelings, they become less overwhelming, less upsetting, and less scary. The people we trust with that important talk can help us know that we are not alone."

~Fred Rogers

The Professional Oncology Navigation Task Force (PONT) Standard 15 provides a framework for oncology navigators to prepare for, assess, and support to address cancer patients' end-of-life (EOL) needs. Standard 15 details the expectations for all navigators to create an individualized, patient-centered, smooth transition from treatment to EOL care.[2]

The trusting relationship developed between the navigator, the patient, and their loved ones throughout the MBC journey is the foundation for shared decision-making in these complex, emotional decisions and transitions.

Jane's Story:

It had been 10 years since Jane's diagnosis of stage III, hormone receptor–positive, human epidermal HER2-negative breast cancer. She was diagnosed with liver metastasis and did well on a cyclin-dependent kinase 4/6 inhibitor and letrozole for 2.5 years. At the time of disease progression, genomic testing revealed she was HER2-positive and targeted therapies were initiated.

After several months, she had disease progression and started an antibody–drug conjugate. The disease and treatments had taken their toll with severe diarrhea, hypokalemia, cachexia, and severe weakness and fatigue.

When she came for an office visit and treatment, the navigator sat down to talk with Jane and her husband, Jim.

Navigator: How are you doing?

Jane: I'm tired and worn out.

Navigator: Do you want to continue treatment?

Jane: I feel like I will let my family and the doctor down if I don't.

Navigator: You are not letting anyone down. You have fought this for a long time. Jim, would she be letting you down?

Jim: No, she won't be letting me down.

She and her family decided to transition to home hospice care. She spent the next 2 weeks until her death spending time with family and close friends. She died peacefully in her husband's arms.

The clinical nurse navigator should provide psychosocial support to patients as they transition into EOL decision-making and supportive care. In addition, the navigator can help prepare the patient for the signs and symptoms of EOL and how to manage those symptoms.

The clinical social work navigator should facilitate psychosocial services and assist with arranging palliative and hospice services through the transition into EOL decisions and supportive care.[2]

The real question, after all, is not the quantity of life, but its quality, its depth, its purity, its fortitude, its fineness of spirit and gesture of soul."

~Joseph Fort Newton

Cultural Awareness and Differences in EOL

Navigators need to recognize and continually develop cultural competency. Many factors and influences contribute to an individual's attitude, preferences, perceptions, and practices regarding EOL, including the following[3]:

Factors Contributing to EOL Practices	
Age	Socioeconomic status
Race	Education
Ethnicity	Health status
Sex assigned at birth	Health literacy
Gender identity	Geographic location
Religion	Immigration status

Fulfillment of Elements of Experiencing a Peaceful, Good Death

When approaching EOL, 3 guiding principles are essential: continuity of care, planning, and the support of dignity[4]:

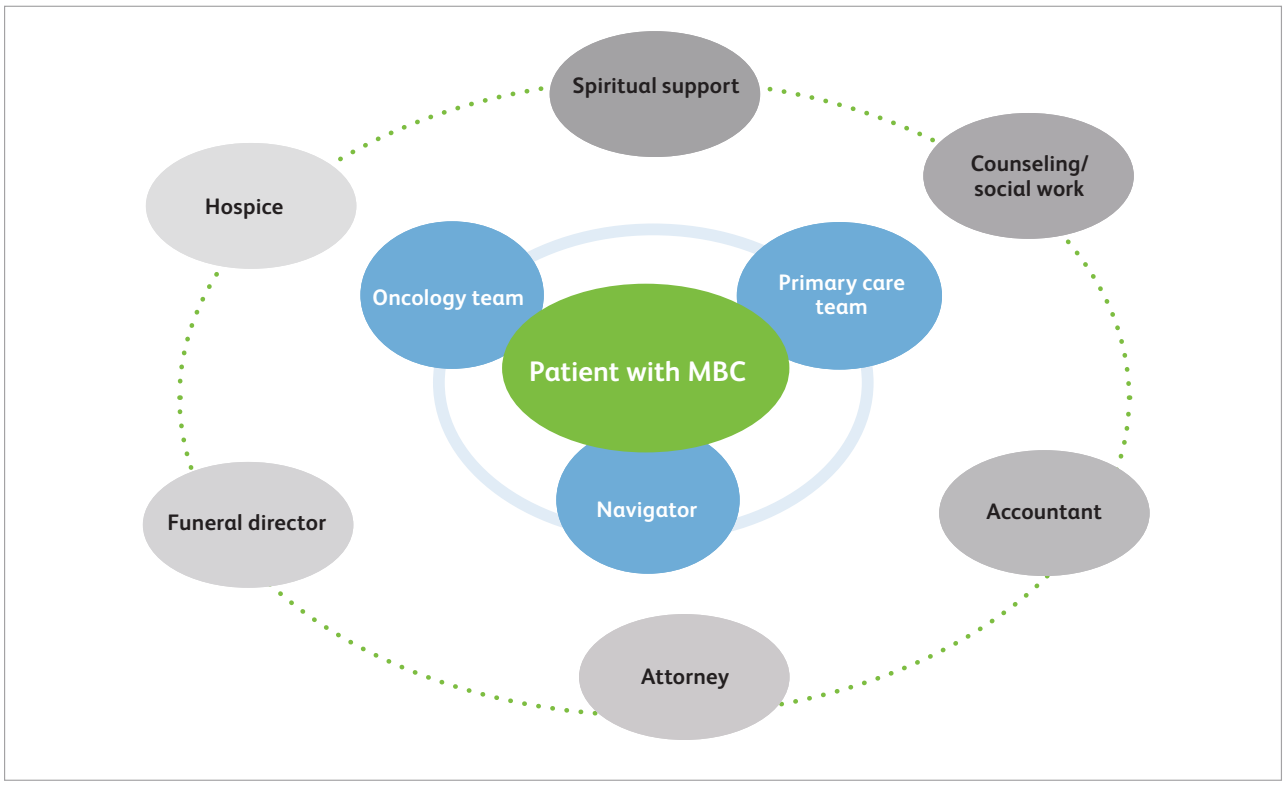
- Palliative care practices may promote "adaptive coping strategies." These strategies focus on problem-solving strategies rather than coping strategies alone. Patients may benefit from an accurate understanding of MBC and acknowledge the incurable nature of the disease. The medical oncologist and "interprofessional"
- The team can encourage patients and their loved ones to develop adaptive coping methods to improve goal-concordant care and quality-of-life (QoL)-specific disease state and progression
- It is recommended that palliative care be initiated at the MBC diagnosis. The medical team may consider nonpharmacologic and integrative interventions in addition to pharmacologic intervention throughout the disease trajectory

Continuity of Care

A smooth transition is key in navigating patients and caregivers to EOL care. Achieving continuity has been made more accessible by current recommendations to offer palliation earlier in the course of the disease while the patient is undergoing active treatment.[5,6]

However, it is still necessary to be active in addressing the need for transition, maintaining a connection to the medical team **(Figure 1)**, and engaging specialized care, support, and advocacy to make the transition seamless, as seen below[4]:

FIGURE 1. Adaptive Coping Strategies, Support and Advocacy at EOL



Planning

As the EOL 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 facilitate[4]:

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

In helping to navigate this complex process, goals include the reduction of distress and burdens, supporting the patient and caregiver's sense of control, optimizing the QoL and relationships, and encouraging personal growth and the search for meaning. What is unacceptable, however, is to work to intensify interventions—for example, to urge the patient to undergo more surgeries or chemotherapy.[4]

Navigators must be careful not to let their feelings for the patient and those of the family tempt them to push for aggressive treatment.

A new resource, *The Guiding Light Between Shorelines: A Resource, Education, and Support Guide for Patients and Their Families Living with Advanced Cancers*, is now available to clinical and nonclinical navigators in managing patient care at this time in the continuum. 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.[7]

Dignity

During EOL, respecting the goals and needs of the patient and caregiver regarding the dying process is paramount.

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.

Respect is the cornerstone of EOL care because it supports the overarching goal—ensuring that every patient can die with dignity and peace of mind.[4]

Finding Hope

Although MBC cannot be cured, it is not a hopeless state. The wide array of treatment options can extend lives and provide a good QoL. One-fourth of all patients with MBC live for at least 5 years after diagnosis.[8]

Hopelessness in MBC is neither rational nor practical. Hope, resilience, and a spiritual or philosophic view are all components of effectively coping with the disease and its treatment.[9,10]

However, hope must be realistic and appropriate to the disease. Unjustified optimism can damage patients' QoL.[4]

Professionals and navigators must be honest with patients and protect them from false hopes for miraculous cures or a return to how life was before MBC.[10]

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. Preventing unrealistic hope is one reason patient education in MBC is so essential.[11]

Based on recent recommendations in palliative care, navigators are encouraged to redirect patients' hopes toward what is achievable under the circumstances.[4]

The aim is to cultivate the virtue of moderation between the extremes of hopelessness and over-optimism—a clear-eyed hope that includes[4]:

- Hope for a good QoI
- 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 help patients understand what constitutes a good death, and the results provide insight into its major components, including[12]:

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

The patient and their loved ones must discuss these attributes of a good death to give them the necessary information at specific times. No one should die in pain, feel confused about the decisions being made, or think that their final wishes are not being honored.

Clinical and nonclinical navigators can ensure the patient's concerns and wishes are followed.[12]

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.[13,14] 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]

Oncology Rehabilitation

It is recommended that oncology rehabilitation be integrated throughout the oncology care continuum and delivered by trained professionals to treat patients' physical, psychological, and cognitive impairments to maintain or restore function, reduce symptom burden, maximize independence, and improve QoL.[15]

The focus of oncology rehabilitation is on functional deficits that impact disability and QoL. The benefits of oncology rehab are well-documented yet underutilized and under-resourced.[16]

Supportive oncology rehabilitation benefits those with MBC and depends on the patient's goals. Patients may have difficulty maintaining motivation as the disease progresses.

Understanding the synergy between palliative care and oncology rehabilitation is critical to supporting patients during the progression of MBC. Both have a role in providing the support needed to maintain QoL throughout the continuum, including EOL.[16]

The development of a multidisciplinary plan utilizing both palliative care and oncology rehabilitation professionals provides compassionate, holistic care with a mutual goal of relieving suffering and maintaining the highest QoL possible for the patient and their loved ones. Both disciplines benefit and fulfill the objectives of the other.[15]

The synergy between oncology rehabilitation and palliative care[15,16]:

Palliative care

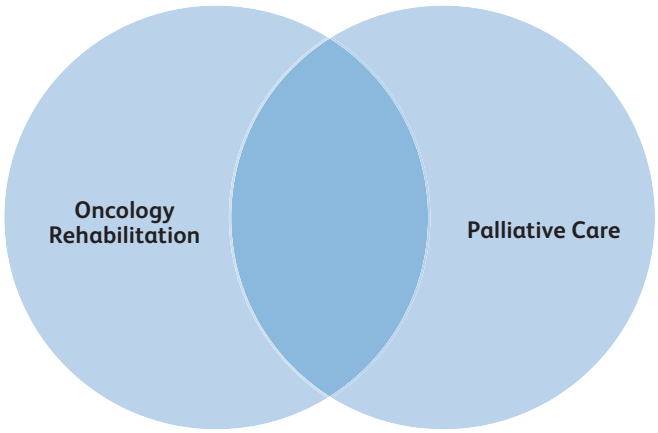
- Holistic approach to suffering
- Identify/assess/manage symptoms
- Psychological distress
- Spiritual distress
- Advocacy

Oncology rehabilitation

- Assess functional status/activities of daily living
- Improve/restore functional deficits
- Reduce symptom burden
- Maximize/maintain independence

Intersection

- Improve cancer-related symptoms
- Improve treatment-related symptoms
- Improve QoL



"When a person's wishes for the end of life have not been communicated, chaos can ensue within a family. So, it can be incredibly comforting for patients and their families to know that they will not have make decisions in a time of panic and high emotion."

~Megan Solinger, MHS, MA, OPN-CG

Hospice Care and Addressing Family Needs

Hospice care also involves a multidisciplinary team specializing 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 misuse the length of time a patient may have before their death, it can result in patients not getting the full benefit of hospice care.

The impact of the clinical and nonclinical navigator is evident here by their ability to improve communications and decision-making. 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.[12]

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.[13]

Navigators can advocate for the patient and be aware of the patient's caregivers, who also need support and education. Sometimes, family members have different goals from the patient and may only want to extend the patient's life without considering the QoL.

This is where specialized hospice services can assist the patient and family members.

MBC Case Study: Patient Approaches EOL

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 practical communication skills, comfort in discussing death, and a supportive clinical navigator who serves in the pivotal role of the patient's advocate.

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" 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 the goals of care and learned about the plan that had been put into motion. Pam mentioned with Mary what these 2 goals of care meant to her.[12]

Challenges

Pam explained that these 2 goals conflicted with each other. If Mary received the toxic therapy until her last breath, it was inevitable that she would be in the hospital for most of her final weeks.

Because of the ages of her children, she would not be able to have them with her at all. Therefore, a critical discussion ensued to determine which of the 2 goals was most important to Mary.[12]

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.

Pam also talked with Mary about hospice care to eliminate its associated stigma. 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 QoL was comforting to Mary. It also meant she could enjoy more time at home with her children.

Pam gave Mary boxes of greeting cards to help her remain present in her children's lives after her death.

On these cards, Mary wrote messages for her children so 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. 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.[12]

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 her home with her 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 she transitioned 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.[12]

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XI. DEVELOPING MBC NAVIGATION PROGRAMS

Metastatic breast cancer (MBC) navigation programs should build upon an existing general navigation program. Once 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.

This will help to clarify needs, priorities, and available community and internal 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 before successfully launching an MBC navigation program is essential. Role delineation includes a comprehensive, clearly defined list of critical tasks to be included in the roles and responsibilities for a specific job.

A definitive job description of the expectations of the licensed navigator and nonlicensed navigator positions is necessary. In 2013, the Oncology Nursing Society created Oncology Nurse Navigator Competencies, which included professional roles, education, coordination of care, and communication.[2]

Collecting data related to specific metrics and outcomes will help develop a navigation program further. With the standardization of metrics, navigators can be "change agents" for their 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]

Licensed Navigator Competencies

Although many of the navigator competencies would be applicable, the following 4 core clinical navigator competencies can be used in the MBC setting as examples[5]:

1. Care coordination: Patient care coordination is invaluable. Professional Oncology Navigation Task Force (PONT) Standard 5 (interdisciplinary and interorganizational collaboration) highlights how licensed navigators help individuals overcome barriers to care and navigate through the diagnostic, treatment, survivorship, and end-of-life care continuum. The licensed navigator is a liaison among all team members to advocate for the patient at the team's center and improve access to services. This entails the licensed navigator promoting collaboration and communication among all healthcare team members and discussing with patients the different roles and responsibilities of each team member. Equally important is developing 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 and highlight PONT Standard 13. The licensed navigator must be able to effectively communicate in their interactions with patients with MBC through empathy,

"It is imperative that oncology licensed 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

patient-centered interviewing, and listening. These skills are imperative for licensed navigators to be able to assist them in shared decision-making based on their needs, goals, strengths, barriers, and resources. The licensed navigator is responsible for providing anticipatory guidance and managing patient expectations. Using the distress tool in the initial consultation with patients with MBC can facilitate better outcomes with timely resource referrals. Licensed navigators are instrumental in providing a psychosocial assessment and promoting the development and implementation of a plan for psychosocial health services in their cancer program that supports patients (by delivering 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. Non-licensed navigators can assist patients by referring them to licensed navigators to complete a psychosocial assessment and provide more specific psychosocial information and treatment.

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

3. Research/quality/performance improvement: The Institute of Healthcare Improvement's Triple Aim seeks to improve the patient experience, improve population health, and reduce the per capita cost of healthcare and is by PONT Standards 18 and 19. Licensed navigators can utilize research, metrics, and outcomes to develop and validate the programs and services provided. The research and evaluation components are to define the problem and establish goals, implement strategies based on objectives and time, and measure outcomes. The licensed navigator is responsible for identifying research and evidence-based clinical questions to describe the changing navigation practice's current and future state. This information should be disseminated to the cancer committee and other relevant stakeholders within and outside one organization to build the current knowledge base and further develop the professional navigation field.

4. Survivorship/EOL: Licensed navigators have an essential role in ensuring that quality survivorship begins at diagnosis and continues throughout the balance of patients' lives and is by PONT Standards 14 and 15. Licensed navigators advocate for quality patient care by acknowledging and monitoring the patient's changing needs. The patient with MBC needs to be involved in palliative care as soon as possible, if not already involved early in the continuum, to promote optimal survivorship care of the MBC patient. Additionally, the licensed navigator should promote self-management of wellness and health promotion. The licensed navigator must know the role and benefits of palliative care and EOL. Licensed navigators should advocate using 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 EOL tasks to complete. The licensed navigator can assist MBC patients by assessing the patient's values, preferences, beliefs, expressed needs, and understanding of the death and dying process. The licensed navigators can promote optional quality of life by coordinating with the patient and the interdisciplinary team to ensure patients' values and goals are incorporated into care plans. Licensed navigators are crucial in educating patients and caregivers on EOL decision-making and the signs and symptoms of the EOL.

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

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XII. PROFESSIONAL DEVELOPMENT IN THE MBC SPACE

Emphasizing the critical role of ongoing professional development in the metastatic breast cancer (MBC) space, clinical and nonclinical navigators must stay current and competent in effectively managing the care of patients with MBC and their families.

According to the Academy of Oncology Nurse & Patient Navigators (AONN+) navigator competencies, practice-based learning involves critical thinking and problem-solving under the domain of Professional Roles and Responsibilities.[1]

By building on critical thinking and problem-solving, the navigator can significantly improve professional practice by utilizing scientific evidence to enhance patient care. This is not just an essential area but a pivotal one in the changing field of MBC, where the navigator's role is crucial and empowering in bridging gaps in knowledge.

In support of Professional Oncology Navigation Task Force (PONT) Standard 7, professional development is not just a suggestion but a personal responsibility for navigators. It's up to each of us to attend professional conferences, network with other navigators, share best practices, and gain knowledge. This proactive approach ensures our competence within our scope of practice and is critical to enhancing our profession.

Per PONT Standard 9, mentorship and leadership are opportunities and avenues for you to empower and influence the field of MBC navigation. Seek leadership opportunities within your healthcare, professional, and nonprofit organizations. This empowerment will shape the future of the navigation profession and make you feel influential and empowered in your field.[2]

Leadership growth from leadership positions and mentoring opportunities will support your career development and contribute significantly to the field of oncology navigation. Your leadership will inspire others and promote the growth and development of our profession. This is something to be proud of and a source of motivation for your ongoing professional development.

A navigator can lend further credence to their position by becoming credentialed in a particular area of expertise.

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

Compassion Fatigue

Navigators must care for themselves to deliver quality care for their patients.[3]

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 patients' individual or cumulative traumas.[3]

Suppose exposure to suffering is a contributing factor to compassion fatigue. In that case, 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.[4] 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. 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 among employees, staff, and management.[3]

In response to the COVID-19 pandemic, nurses have reported increased rates of depression, anxiety, and insomnia.[5]

Resiliency and self-efficacy are skills linked to maintaining balance in one's life. When resiliency or self-efficacy is present, nurses are more prone to physical and emotional exhaustion, which may lead to burnout. This trend was extensively seen during and while recovering from the COVID-19 pandemic. A wealth of research has been dedicated to supporting nurses' mental health during and after the pandemic.[6]

In addition to employer-based education and training, self-care is identified as PONT Standard 10; the oncology navigator should practice self-care as a personal responsibility, identify personal and professional stressors, and exhibit appropriate coping mechanisms.

Self-care practices should be built into daily routines and provide emotional and physical repose to aid the navigator in achieving self-care opportunities. Lastly, the oncology navigator should work within their organization to create a culture that promotes self-care for all employees.[2]

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XIII. MBC BEST PRACTICES

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 are[1-3]:

Domain	Metric
Care coordination/care transition	• Treatment compliance • Barriers to care: measure the number and list the specific barriers to care identified by the navigator per month • Interventions • Patient education
Operation management organizational development health economics	• 30-, 60-, 90-day readmission rate: the number of navigated MBC patients readmitted to the hospital at 30, 60, and 90 days • Emergency department utilization: the number of navigated MBC patient visits to the emergency department per month • Caseload: the number of new, open, and closed cases navigated monthly
Psychosocial support services/assessment	• Palliative care referrals: the number of navigated MBC patients per month referred for palliative care • Social support referrals: the number of MBC patients referred to the support network per month and/or the number of navigated MBC patients and family/caregivers referred to weekend retreats for patients, couples, or caregivers per month • Distress screening: the number of navigated patients per month who received psychosocial distress screening at a pivotal medical visit
Survivorship/end-of-life	• Palliative care referral: the number of navigated patients referred for palliative care per month • Support services referral: the number of MBC patients referred to the support network per month and/or the number of navigated MBC patients and family/caregivers referred to weekend retreats for patients, couples, or caregivers per month
Patient advocacy/patient empowerment	• Patient goals: the percentage of analytic MBC cases per month in which patient goals were identified and discussed with the navigator • Learning style preference: measure the number of navigated patients per month whose preferred learning style was discussed during the intake process
Professional roles and responsibilities	• Navigation knowledge at the time of orientation: measure the percent of new hires who have completed institutionally developed navigator core competencies • Navigator core competencies
Research quality/ performance improvement	• Patient experience: the measure of patient experience or patient satisfaction results • Community needs assessment

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.

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.

References: 1. 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. **2.** Strusowski T, Johnston D. AONN+ evidence-based oncology navigation metrics crosswalk with national oncology standards and indicators. *J Oncol Navig Surviv.* 2018;9:214-221. www.jons-online.com/issues/2018/june-2018-vol-9-no-6/1852-aonn-evidence-based-oncology-navigation-metrics-crosswalk-with-national-jons-oncology-standards-and-indicators **3.** Standardized metrics source document. Academy of Oncology Nurse & Patient Navigators. Accessed July 11, 2024. www.aonnonline.org/images/articles/standardized_metrics/Metrics-Source-Document.pdf

XIV. RESOURCES FOR MBC

General Information

Academy of Oncology Nurse & Patient Navigators (AONN+)
www.aonnonline.org

Association of Cancer Care Centers (ACCC): MBC Resources & Tools for the Multidisciplinary Team
www.accc-cancer.org/home/learn/cancer-types/breast-cancer/metastatic-breast-cancer/resource-library

ACCC: MBC 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
www.facs.org/quality-programs/cancer-programs/american-joint-committee-on-cancer/

Angelmira's Center
www.angelmira.org/

Cancer*Care*
www.cancercare.org

Edmonton Symptom Assessment System
www.npcrc.org/files/news/edmonton_symptom_assessment_scale.pdf

Infinite Strength
www.infinitestrength.org/

Living Beyond Breast Cancer
www.lbbc.org/

MBC Brain Mets
www.mbcbrainmets.org

Medication Nonadherence Risk Assessment
http://adultmeducation.com/downloads/Nonadherence_Risk_TOOL.pdf

Metastatic Breast Cancer Alliance
www.mbcalliance.org/

Metastatic Breast Cancer Network
www.mbcn.org

METAvivor: Metastatic Breast Cancer Awareness, Research and Support
www.metavivor.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: Oral Adherence Toolkit
www.ons.org/practice-resources/toolkits/oral-adherence

Susan G. Komen
www.komen.org

***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**
www.jons-online.com/telehealth?view=article&artid=2036:the-value-of-palliative-care-early-in-the-treatment-process

Tigerlily Foundation
www.tigerlilyfoundation.org/

Unite for HER
www.uniteforher.org/

Young Survival Coalition
www.youngsurvival.org

Communication

ACCC: Metastatic Breast Cancer Toolkit
www.accc-cancer.org/projects/metastatic-breast-cancer-project/toolkit-study

Dandelion Project Communication Toolkit: 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

ACCC: Financial Advocacy Guidelines, 2018
www.accc-cancer.org/home/learn/financial-advocacy/guidelines

ACCC: Financial Advocacy Network Toolkit
www.accc-cancer.org/home/learn/financial-advocacy/toolkit

ACCC: Patient Assistance and Reimbursement Guidelines
www.accc-cancer.org/home/learn/financial-advocacy/patient-assistance-guide

Cancer and Careers
www.cancerandcareers.org

Cancer Legal Resources
www.cancerlegalresources.org/

Cancer*Care*
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
www.cancerfinances.org/

Mental Health, Self-Care, and Spirituality

ACCC: Metastatic Breast Cancer - Effective Principles & Practices in Patient Support
www.accc-cancer.org/resources/pdf/MBC_Workbook.pdf

Elisabeth Kubler-Ross Foundation
www.ekrfoundation.org

HealthCare Chaplaincy Network
www.healthcarechaplaincy.org

Susan G. Komen Coping with Stress
ww5.komen.org/BreastCancer/CopingWithStress.html

Support Groups and Retreats

Cancer Support Community
www.cancersupportcommunity.org/

Male Breast Cancer Coalition
www.malebreastcancercoalition.org/

Male Breast Cancer Online Support
www.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

Our MBC Life

www.ourmbclife.org/

Clinical Trials/Research Advocacy Foundations

Alamo Breast Cancer Foundation
www.alamobreastcancer.org/

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

ClinicalTrials.gov
www.clinicaltrials.gov/

Guiding Researchers & Advocates to Scientific Partnerships
www.graspcancer.org/

MBC Connect
www.mbcconnect.org/

Metastatic Breast Cancer Project
www.mbcproject.org/

Metastatic Breast Cancer Trial Search
www.breastcancertrials.org/metastatic-trial-search.html

Metastatic Trial Talk
www.metastatictrialtalk.org

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

Theresa's Research Foundation
www.theresasresearch.org/

Twisted Pink
www.twistedpink.org/

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.

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NOTES

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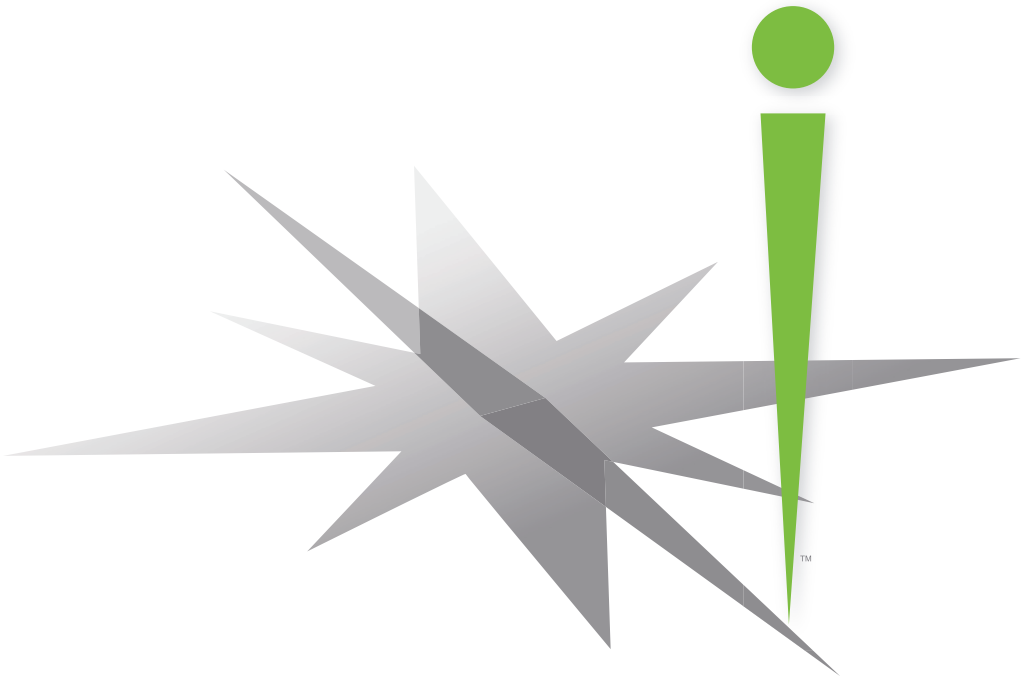

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