

Successful Delivery of Services Through Telehealth: A Focus on Symptom Management, Psychological Health, and Genetic Counseling in Metastatic Breast Cancer

In 2019, the Association of Community Cancer Centers (ACCC) held a Multidisciplinary Metastatic Breast Cancer (MBC) Summit focused on addressing disparities in care for patients with metastatic breast cancer. Leveraging telehealth solutions to improve access to supportive services was identified as a key action item to address this challenge. In 2021, ACCC held a series of focus groups to learn more about how cancer programs are successfully implementing telehealth to manage symptoms and treatment side effects, deliver psychosocial screening and support services, and provide genetic counseling and testing.

THE BENEFITS OF TELEHEALTH

With more programs offering telehealth services than ever before, the benefits are clear:

- Increased access to services, particularly for previously hard-to-reach geographic areas
- Decreased cancellation rates
- More flexibility for patients, particularly if the patient isn't feeling well, there is urgency to the request, and/or an in-person appointment isn't immediately available
- Decreased "waiting room" time, which can lead to increased patient satisfaction and less time away from work or other commitments
- More frequent contact with patients, which opens the door to supportive care in new ways
- Availability for interpretation for deaf patients, as well as translation for patients who are more comfortable with other languages

GENERAL TIPS FOR SUCCESSFUL TELEHEALTH SERVICE DELIVERY

Focus group participants provided a variety of tips and tricks to make telehealth service delivery more effective.

- **Orient the patient to the technology** by walking the patient—in-person or virtually—through the portal/mobile app with the help of a team member, such as a medical assistant, nurse, or IT professional.
- **Find out who is in the patient's support system** and who can help with the technology for patients challenged by it. Work with caregivers or care partners to orient them to the technology when the patient is hesitant or doesn't have devices that allow optimal access to telehealth. Schedule appointments when someone in the support system is available to help.
- **Staff a volunteer telehealth team** during outpatient hours to answer patient calls specific to the telehealth platforms and technology.
- **Embed the video link into the patient portal** to streamline the experience for less computer-savvy patients.
- **Have several backup plans to decrease the risk of technological glitches and/or operating system incompatibility issues.** Many cancer programs have at least two options for video appointments (e.g., Zoom, Doximity) and consider phone as a third option.

- **Document reliable contact information for the patient and care partner.** If a video call drops or if follow up is required after a visit, having multiple means of reconnecting with the patient increases the chance of success.
- **Be mindful of licensure issues across state borders.** Find out if the patient is planning to connect from their primary residence or a different location. Depending on the service provided, or if the patient is in a state where you are not licensed, a waiver from that state may be needed. (Laws vary state by state). Check with your professional licensing board for more details.
- **Consider where hybrid approaches to care can be most effective.** Depending on the issue, the patient may be evaluated in person to establish a baseline and have virtual follow-up appointments. Patients may attend a telehealth visit a day prior to an infusion appointment to identify symptoms or toxicities that may need to be addressed. That way, if the clinician needs to drop by the infusion room while the patient is there, they can.

TELEHEALTH FOR SYMPTOM AND SIDE EFFECT MANAGEMENT IN PATIENTS WITH METASTATIC BREAST CANCER

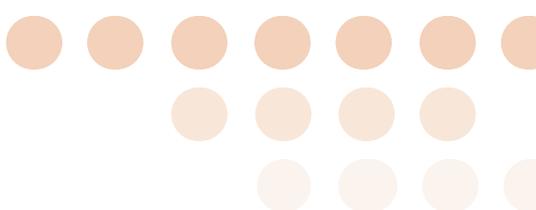
Patients with MBC are often in treatment for extended stretches of time, with periods of stable disease, but also the burden of medication side effects. If symptoms of disease progression occur, the care team must act quickly to ensure the patient is able to start a new treatment plan. In addition to working with the patient to manage symptoms and side effects, care partners can provide useful feedback and a different perspective when it comes to symptoms or side effects the patient is having. They can further provide support to ensure that prescriptions to address symptom and side effect are picked up and that follow-up appointments are scheduled and attended.

Monitoring and Evaluating Symptoms and Side Effects Remotely

Using patient-reported outcomes (PRO) measurement scales are a valuable way to monitor patients when they are not regularly in clinic. Patients not accustomed to complaining or concerned about being removed from treatment may feel uncomfortable reporting symptoms or side effects, or claim better treatment tolerance, even if that is not the case. Using a PRO reporting scale can provide the clinician with a starting point to delve into deeper discussions and elicit a more accurate picture of the impact of symptoms or side effects on the patient.

Examples of monitoring tools include:

- **Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE):** Made available to researchers by the National Cancer Institute, this tool can evaluate frequency, severity, interferences, and presence or absence of a wide range of treatment toxicities in clinical trials. While initially designed for use in clinical trials, some programs are now testing its use in telehealth.
- **Patient-Reported Outcomes Measurement Information System (PROMIS):** Consisting of a set of measures for monitoring physical, mental, and social health outcomes for patients living with chronic illness, this tool is available for free and can be delivered through several major electronic medical record (EMR) platforms, REDCap, and through a tablet app. The PROMIS-29 is a short form assessment which includes items from the seven domains covered by the full inventory.
- **Functional Assessment of Chronic Illness Therapy – Fatigue (FACIT-F):** A tool developed to assess quality of life issues related to fatigue for patients with cancer.
- **Edmonton Symptom Assessment Scale (ESAS):** Widely used in cancer clinical trials, this free tool has a 0-10 rating scale for nine symptoms, both physical and emotional and can be incorporated into EMRs.



Whether using these validated tools or other basic sets of questions, tracking PROs at regular intervals can be an effective way to monitor patients and create systems to triage, based on self-reporting. For example, reports of mild problems could trigger self-management information to be sent to the patient, but reports of more severe problems could trigger a message for the patient to follow up with the clinical team by phone or to alert the care team to contact the patient. It is important to note that many PRO measurement tools were designed to be used in-person and have not been heavily tested in the telehealth setting. This is an area of research that will help improve symptom and side effect measurement as adoption of telehealth services continues to grow.

“For me, telehealth effectiveness for symptom management can be divided into what’s tangible and what’s intangible. If someone has shortness of breath, I can ask them questions, but it’s also important that I examine their lungs and get an X-ray. Or - if they have skin toxicity - some patients send pictures of a rash, or during a visit they’ll hold their hands up and show me. I might not get the best assessment of the severity, but I’ve done that when it’s necessary. But if there is a new finding like a new lump or a new mass somewhere, you have to be able to feel it.”

Alissa Huston, MD
Wilmot Cancer Institute

Pain

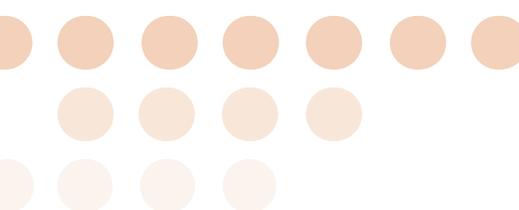
Pain in MBC may be a result of ongoing treatments or due to disease progression. It can be difficult for providers to assess the root cause of the pain and recommend an appropriate scheduling option (i.e., virtual or in-person) accordingly. For instance, aromatase inhibitors can cause joint pain. For patients with triple negative breast cancer, long-term chemotherapy can lead to neuropathy. Both can be effectively evaluated and managed using telehealth. However, pain that manifests as point tenderness over a bone is more likely to indicate disease progression. In this case, in-person evaluation is necessary as these patients will need scans to understand the cause of the pain and plan treatment accordingly. Subsequent follow-up visits can be done via telehealth once the cause is known.

Asking the patient key questions before scheduling the appointment will help team members to identify appropriate criteria for each type of visit. Questions that can help to assess pain include:

- What is (are) the location(s) of the pain?
- How would you rate the pain of each location, on a scale of 0–5, with five being the highest level of pain?
- When do you notice the pain: Continuously or only after certain activities?
- What makes the pain worse? Pressure or movement?

Other symptoms to monitor in patients with MBC may include cancer-related fatigue, general mood, and quality of life. Monitoring and evaluation by multidisciplinary integrated or palliative care programs can meet these goals using telehealth, including:

- An oncologist can evaluate pain virtually and prescribe medication to manage it.
- APRNs or nurse navigators can screen for pain and prescribe medication if the state allows it or alert the oncologist to follow up.
- A pharmacist can educate patients about new treatments or ways to manage treatment side effects.
- An exercise physiologist can conduct an assessment of baseline function, make initial recommendations, and even begin work with the patient when feasible.
- A counselor or therapist can teach the patient cognitive and behavioral strategies for pain management, which may include pacing of activity, relaxation techniques, and management of expectations.
- An oncology-certified yoga instructor can conduct a one-on-one orientation appointment with a new patient before a group class. Guided meditation, such as mindfulness training, can work similarly.
- An acupuncturist can instruct patients on acupressure to address neuropathy-related pain.



Skin Toxicities

Radiation and certain targeted therapies used to treat MBC can cause skin irritation that ranges from very mild to severe. Consider these tips when managing skin toxicities through telehealth:

- Ask the patient to find a location with adequate light. If the patient can angle their smartphone camera or webcam to see the skin clearly, the clinician may be able to assess skin issues virtually.
- If video does not capture the issue clearly, ask the patient to take and send a few photos from different angles and distances. It may help the patient to have someone else take the photos, if possible.

Nausea and Diarrhea

Chemotherapy, hormonal therapy (e.g., CDK 4/6 inhibitors), and targeted therapies for MBC have the potential to cause nausea and diarrhea which are more challenging to treat through telehealth. In some cases, patients with these issues may prefer telehealth so that they can stay close to home rather than travel to a clinical office. However, if these treatment side effects result in a need for IV fluids or nutrition support, the patient will likely need to visit the clinic in person or schedule a home health nurse visit. It is important to note that in certain types of breast cancer, such as metastatic lobular carcinoma, nausea and diarrhea can be signs of metastasis to the gastrointestinal tract, stomach, and other locations. This makes timely follow-up for nausea and diarrhea particularly important.

TELEHEALTH FOR PSYCHOSOCIAL SCREENING AND SUPPORT IN PATIENTS WITH METASTATIC BREAST CANCER

As with symptom and side effect management, delivering psychosocial screening and support using telehealth has several benefits, including increased access, improved workflow efficiency, and decreased logistical barriers.

General Tips for Delivering Psychosocial Services Using Telehealth

- Identify strategies to increase use of the patient portal for psychosocial screening delivery and make appointment links accessible through multiple sources, including through the patient portal and email. Develop a scheduling platform infrastructure that all oncology providers can uniformly use.
- Consider alternative approaches to send screening tools. For instance, texting screening tools or phone calls can allow for quick screening prior to appointments.
- Educate patients early about a program's psychosocial services and offer telehealth as an option for new patient appointments, as the service allows. Many patients report wanting to know sooner about the availability and benefits of these programs. If this service is something you cannot offer with in-house resources, become familiar with local or national telehealth support services (e.g., Cancer Support Community, CancerCare, etc.).
- Set up a best practice advisory through the electronic health record (EHR) to regularly send screening tools to patients. For example, screen at the appointment, then every 90 days after the appointment.
- Ask the same questions that you would ask in person to elicit goals and fears. These can include: What are you hoping for right now? What are you most worried about right now? What are three things that bring you joy?
- Encourage patients (and providers) to find a quiet space at home to minimize distractions during the appointment. Some patients may not be able to find an appropriate level of privacy and telehealth may not be the best approach for them, while other patients may only need a reminder and/or permission to prioritize their own health needs.

Using Screening Tools Effectively

Because many programs screen patients for psychosocial distress when the patient is in the clinic for in-person medical or psychosocial services appointments, transitioning to telehealth psychosocial screening requires new considerations with regards to which tool(s) to use, and how/when to deliver the tool to the patient. In addition to use of tools, verify whether the patient has a history of anxiety, depression, takes anti-depressants, or has seen a psychotherapist in the past. This information can provide useful insight into what the patient may currently be feeling.

Most frequently cited screening tools used in the psychosocial support setting include the following:

- Patient Health Questionnaire PHQ-9 and PHQ-2: A brief, patient self-reported scale to screen for depression. The PHQ-2 can be used as a quick screen. A positive screen result might trigger use of the PHQ-9 or further follow up with the patient.
- Generalized Anxiety Disorder GAD-7 and GAD-2: A brief, patient self-reported measure of anxiety.
- NCCN Distress Thermometer and Problem List: A simple, general measure of distress, coupled with a list of problems from a range of domains that can help the care team identify the reasons for the distress.
- PROMIS-29: Assesses well-being in physical and mental health domains.

Considerations for the PHQ-9

Psychologists have pointed out that the ninth question (about suicidal thoughts) in the PHQ-9 may be problematic when used to assess severity of depression in the remote setting unless responses are reviewed in a timely manner. Furthermore, since the ninth question asks about thoughts of being “better off dead,” as well as the intent to self-harm, this question may yield conflicting results as patients with cancer may answer these elements differently compared to the general population. To address these concerns in the cancer patient population, some psychologists have instead opted to use an unofficial PHQ-8, eliminating the ninth question.

“Some people in the throes of excruciating treatment may think that they may be ‘better off dead,’ but do not have thoughts of hurting themselves. So, it’s hard to know what the respondent means without a follow-up question/conversation.”

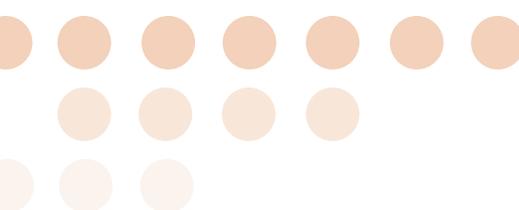
Justin Yopp, PhD

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Tailoring Your Approach

Frequently, more than one tool is used, possibly in different settings and depending on the assessment goal. Regardless of how the screening is delivered (e.g., paper format, tablet, or patient portal), the timing of delivery can make a difference in how the information can be used.

- **Prior to the patient appointment.** If the screening tool is delivered right before the patient’s telehealth appointment, it can provide useful information for the clinician and allow the opportunity to address the patient’s issues during the appointment. However, it may also pick up anticipatory anxiety about the visit, particularly if the patient is expecting scan results or challenging conversations about the treatment plan.



If screening occurs too far before the appointment and certain results are picked up - such as suicidal ideation(s) - cancer program staff must have a system in place to follow up appropriately, even if that means checking in with the patient before their appointment.

- **After the patient appointment.** Screening tools may be useful for ongoing monitoring of the patient's well-being after the patient's appointment. Some programs screen patients at intervals, as in the use of PRO measures to track patient symptoms and/or side effects over time. But if psychosocial screening tools are used after a visit, it may be more difficult to follow up with a patient if the screening indicates such a need.

CHOOSING PROGRAMS THAT WORK WELL

It is important to think about what types of psychosocial support delivery work well using telehealth. Focus group participants considered psychotherapy, support groups, and mindfulness coaching as successful for most patients. Other functions requiring participation in active crisis management or real-time support for the clinical team may be less effective with telehealth.

Individual Psychotherapy

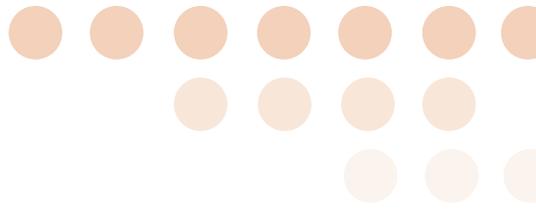
- It can take longer to build rapport with new patients via telehealth. Be patient and use more verbal statements versus relying on non-verbal cues to show interest and that you are actively listening.
- Whenever possible, use video to allow for assessment of non-verbal cues and to facilitate connection; telephone therapy may also be used.
- Use email or the patient portal to share handouts or other supporting materials (relaxation scripts, values exercise) with patients.

Group Therapy

- Have patients fill out an informed consent and confidentiality agreement to ensure they are in a place that allows privacy and confidentiality of other participants.
- Have a second facilitator who can address technological challenges that arise during the group, without derailing the meeting.
- Encourage participants to use a computer with video options versus a phone, if possible, to create a more personal and engaged atmosphere.
- Share handouts which participants can print out or look over prior to the session.
- Account for the fact that everything may take a bit longer to complete in a virtual setting.
- Don't forget about the ability to include partnered activities (e.g., using breakout session functionality) or smaller subgroups during the meeting.

"We have seen excellent support and participation in groups, especially end-of-life, and found it so important. We have had many members participate in hospice that wouldn't have otherwise been able to. It has been a gift to others in the group to see others on hospice and share the journey. I also still think there are several that can't participate this way and we should think about these populations."

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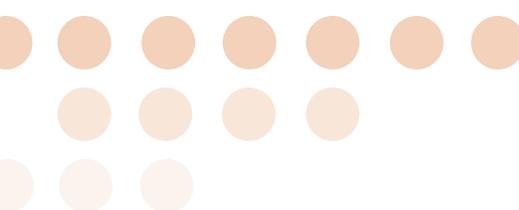
TELEHEALTH FOR GENETIC COUNSELING AND SCREENING IN PATIENTS WITH METASTATIC BREAST CANCER

Genetic counseling and screening have a robust history of telehealth delivery. There are two prevailing models of telehealth in genetic counseling and testing:

1. A patient comes to a clinical office and uses clinic equipment to talk with the off-site genetic counselor.
2. A patient stays at home and meets with the genetic counselor by phone or video.

There are benefits and disadvantages to both models:

	BENEFITS	DISADVANTAGES
Telehealth in Clinic Office	<ul style="list-style-type: none">• Patients without adequate technology at home can access services• Staff on-site can assist patient with technology• Health system can recoup some costs of the service through the facility fee• Easy to collect sample specimen	<ul style="list-style-type: none">• Schedule may be restricted to clinic hours• Patients who live far away may face geographic barriers
Telehealth from Patient's Home	<ul style="list-style-type: none">• Scheduling is more flexible, often with evening and weekday appointment options• Family members can be conferenced in• Fewer cancellations	<ul style="list-style-type: none">• Still requires staff at the clinic to manage logistics to be successful• Easier to forget to send in a sample specimen for testing

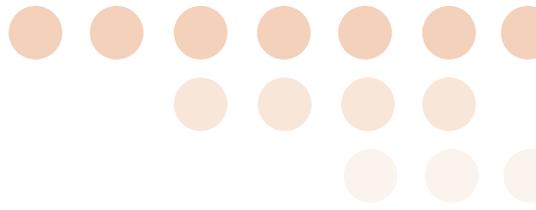


To increase the success of service utilization of genetic counseling, focus group participants recommended the following communication and patient education strategies:

- **Referring Provider Message.** It is critical that the referring provider clearly explains the value of genetic testing and what the patient can expect. The provider is a critical link to genetic counseling because patients are more likely listen to their familiar providers rather than someone in a new and unfamiliar role.
- **Timing of Testing.** Encourage testing as early as possible once the diagnosis has been made. Once a patient begins treatment, there are often more logistical barriers (e.g., previously scheduled appointments, or side effects such as fatigue). Patients who are in treatment and do not feel well may be less likely to follow through.
- **Communicating the Purpose Clearly.** In many cases, the results of a genetic test will guide treatment decision making and may be included in a biomarker test panel. In counseling the patient, be clear that testing is important because there are treatments that are available exclusively for patients with metastases who carry a gene mutation. Patient consent and comfort level is critical, as results may impact their family or hold other implications.
- **Facilitate Understanding.** Create patient education materials that include information about genetic test result recommendations from a source such as the [National Comprehensive Cancer Network \(NCCN\)](#), the next steps for the patient to understand after testing happens, and tips on how to share information with family.

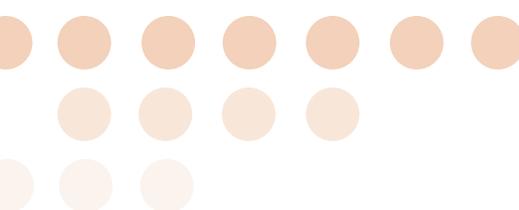
Improving Sample Collection and Submission

- Make sample collection as easy as possible. If the patient is not in the clinic, use home saliva kits or send a phlebotomist to the home for a blood draw.
- Try to get the sample before the patient starts chemotherapy.
 - Chemotherapy may result in dry mouth, which makes saliva samples harder to obtain.
 - Mobile phlebotomists may not be able to draw blood from a port, or patients with a port may not want blood drawn from their arm. As a result, the patient will have to wait until their next chemotherapy appointment to have blood drawn and delay the test.
- There is much room for error when someone is collecting their own sample, and saliva samples have slightly higher failure rate than blood samples. If genetic test results might drive treatment options, it may be best to start with a blood sample.
- Follow-up may be needed for patients to return the saliva kit or schedule the blood draw. Many patients who did not follow through initially may simply need a reminder or help coordinating. This call is also another touchpoint to provide patient education and answer any questions they may have before the test.
- Have a designated staff member in the clinic to help with logistics when working with third party genetic testing companies.



NEXT STEPS FOR CANCER PROGRAMS PROVIDING TELEHEALTH TO PATIENTS WITH METASTATIC BREAST CANCER

Cancer programs have adjusted well to recent expansion of telehealth delivery of supportive care services for patients with MBC. The transition to incorporate telehealth services has resulted in increased service use, decreased logistical and geographic barriers to supportive care, and overall decreasing disparities to access for supportive care. Despite these successes, cancer programs still must think creatively to ensure that lack of appropriate devices, restricted internet access, and low technology literacy do not interfere with patient access to telehealth services. It is important to consider patient readiness and willingness to utilize telehealth. Factors such as difficulty hearing or speaking, dementia, difficulty seeing, or other disabilities may require accessibility accommodations to make the appointment successful. Focus group participants agreed that flexibility is the key to ensuring access for all. Patients have different preferences for many reasons, so being able to offer both telehealth and in-person options will help increase service utilization. Providing a tablet during treatment - possibly with a limited data plan - for patients who prefer telehealth but may not have access to appropriate devices could be the bridge to expanded accessibility. Improvements in integrating telehealth solutions into existing patient portals or EMRs can help overcome technology literacy barriers. Cancer programs have already made meaningful improvements in access to supportive care for patients with metastatic breast cancer through telehealth service delivery. The next step is to refine these approaches and adapt to diverse patient needs to ensure that telehealth delivery benefits as many patients as possible.



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