Development of an evidence-based patient guide to support symptom management in individuals with metastatic breast cancer

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Conclusions

- "Your Guide to Managing Symptoms from Metastatic Breast Cancer Treatment" (MBC Guide) is a practical, user-friendly tool to support whole-person care by addressing key gaps in patient disease state and financial support education, symptom management, and shared decision-making.
- More than 30,000 MBC Guides have been distributed to providers nationwide, with survey results indicating nurses most often use this Guide with patients.
- Providers like that the Guide is easy for patients to understand, can be taken home, and is visually appealing.
- The Guide empowers patients with practical tools for managing symptoms and encourages more informed, shared decisions with healthcare providers.

Plain Language Summary

- Interviews with patients and healthcare providers identified gaps in available information and guided the creation of an educational Guide to help people with metastatic breast cancer (MBC) manage their symptoms.
- This Guide, endorsed by the professional nurse navigator society AONN+, can be used by people with MBC and their providers to better manage their symptoms and support their day-to-day lives.
- More than 30,000 Guides have been handed out to US providers, and it is available for providers to order for free for their patients by scanning the QR code.
- Feedback shows that this Guide fills an information gap, giving patients practical tools to take a more active role in managing their symptoms and making care decisions with their providers.

Introduction

- Metastatic Breast Cancer (MBC) is breast cancer that has spread beyond the breast and regional lymph nodes.[1] For MBC, treatment goals are typically controlling disease progression and maintaining quality of life (QoL).[2]
- Disease-related symptoms and treatment-related side effects often impair QoL[3] and may result in decreased treatment adherence. Indeed, treatment-related side effects are among the leading reasons patients with MBC discontinue recommended therapies.[4]
- A targeted literature review, as well as patient and healthcare providers (HCPs) interviews, revealed an unmet need for resources to help with symptom management, address gaps in disease education, and promote shared decision-making with HCPs.[5]

Objectives

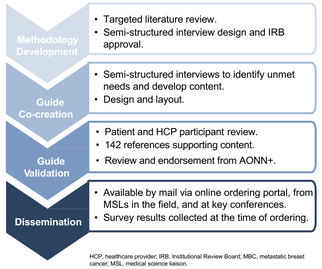
- To address key education gaps in symptom management and shared decision-making by employing a rigorous methodology to co-create an evidence-based tool for individuals with MBC and their HCPs.
- To engage patients, HCPs, and nurse navigators as stakeholders in the conceptualization, co-creation, and review of the final resource, titled "Your Guide to Managing Symptoms from Metastatic Breast Cancer Treatment."
- To quantify Guide reception and impact using survey data collected during dissemination.



Methods

- The creation of the Guide included an evidence-based process involving a targeted literature review and semi-structured interviews with diverse stakeholders, including individuals with MBC and HCPs.
- Each stage of development included stakeholder input on Guide content (**Figure 1**).
- Semi-structured interviews were conducted with a diverse group of 9 female participants with MBC (**Table 1**), as well as HCPs at leading institutions across the US who treat MBC.
- The semi-structured interview protocols were approved by WCG Clinical Services Institutional Review Board (IRB).
- The same interview participants validated the completed Guide for clarity, usability, and relevance to their needs.

Figure 1. Stepwise Process for Creating the Guide.



HCP, healthcare provider; IRB, Institutional Review Board; MBC, metastatic breast cancer; MSL, medical science liaison.

Table 1. Demographics of Individual Interviewees With MBC.

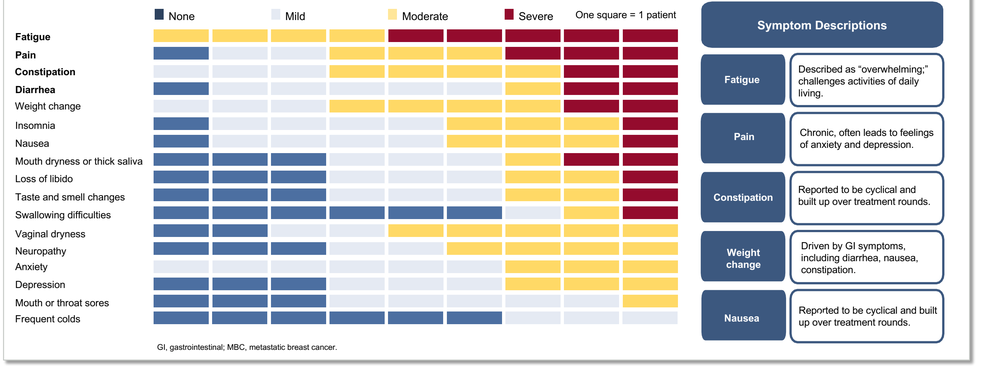
	Individuals With MBC (N = 9)
Age, years, range	29–62
Time since BC diagnosis, years, median	7
Race and Ethnicity, n (%)	
White	4 (44)
Black	2 (22)
Hispanic	2 (22)
Asian	1 (11)
Location of home, n (%)	
Suburban	5 (56)
Urban	3 (33)
Rural	1(11)
Insurance type, n (%)	
Commercial	3 (33)
Tri-care	1 (11)
Medicare and Medicaid	1 (11)
Medicare	2 (22)
Medicaid	2 (22)

BC, breast cancer.

Results

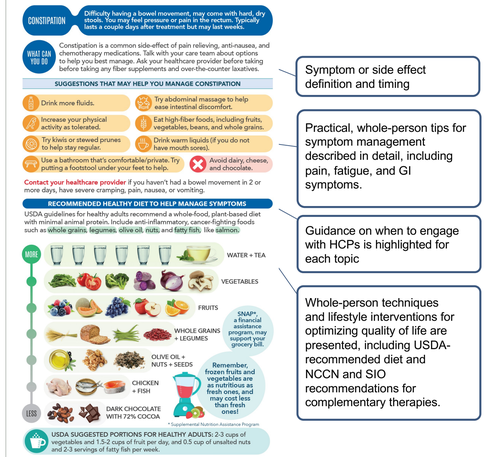
- Symptoms including fatigue, pain, and gastrointestinal (GI) issues (constipation, nausea, and weight change) were commonly reported as moderate or severe (**Figure 2**).
- Our targeted literature review and interview findings underscored the unmet need for a patient-focused educational resource to support symptom management and provider-patient communication.
- The resulting resource, Your Guide to Managing Symptoms from Metastatic Breast Cancer Treatment (MBC Guide), focuses on evidence-based, whole-person interventions to help manage symptoms and enhance patients' QoL.
- The MBC Guide supports shared-decision making and includes integrative, whole-person strategies to manage physical, emotional, nutritional, and financial concerns, including practical tips for managing fatigue, treatment-related side effects, and cost-of-care resources (**Figure 3**).
- Second-round interviews with stakeholders, including nurse navigators from AONN+, confirmed the MBC Guide's accuracy and applicability.
  - AONN+ reviewed and endorsed the Guide ahead of dissemination, stating they "love the WHOLE person approach!" and that the Guide "encourages patient empowerment."
- Healthcare-based disease management is the assumed environment for the use of the MBC Guide.
- More than 30,000 MBC Guides have been distributed to providers nationwide.
- Survey results indicated nurses (65%) would most often use this Guide with patients (**Figure 4**).
- Providers like that the Guide is "easy for patients to understand" (81%), can be taken home (80%), and is visually appealing (69%) (**Figure 4**).
- HCPs and patients expressed high satisfaction and emphasized the unmet need this resource addresses, with an HCP noting, "[it] encourages conversation and allows for an engaged patient."
- One HCP noted the "fatigue panel should be given to everyone."

Figure 2. Symptoms (A) and Symptom Descriptions (B) Identified in Semi-structured Interviews of Participants With MBC.



GI, gastrointestinal; MBC, metastatic breast cancer.

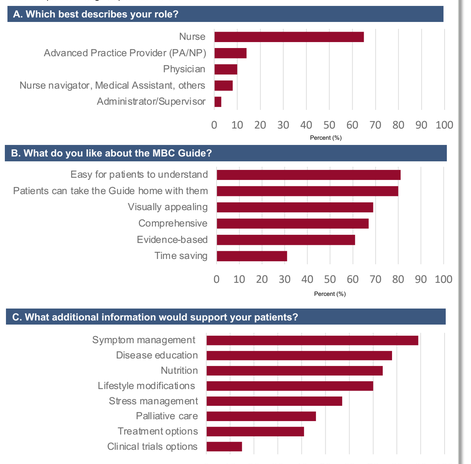
Figure 3. Key Features of the Resulting Symptom Management Resource, the MBC Guide.



MBC, metastatic breast cancer; NCCN, National Comprehensive Cancer Network; SIO, Society for Integrative Oncology; USDA, United States Department of Agriculture.

Figure 4. Survey Results Collected at the Time of Ordering and Reordering

Data is reported through September 2025



MBC, metastatic breast cancer.

References: **1**. American Cancer Society. Treating Breast Cancer. 2019. https://www.cancer.org/cancer/types/breast-cancer/treatment/treatment-of-breast-cancer-by-stage.html. **2**. National Cancer Institute. Chemotherapy and You. 2024. NIH Pub #24-7157https://www.cancer.gov/publications/patient-education/chemo-and-you. **3**. Cardoso F, et al. *Oncologist*. 2023;28(10):856-865. **4**. daCosta DiBonaventura M, et al. *Am Health Drug Benefits*. 2014;7(7):386-396. **5**. Kasgri KA, et al. *Cancer Control*. 2024;31.

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