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Better Access to Palliative Care Can Improve the Experience for Metastatic Breast Cancer Patients

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SUMMARY

- Palliative care is an important part of care for patients with metastatic breast cancer (MBC), yet it is widely misunderstood.
- Palliative care is too often perceived solely as end-of-life care rather than as a way to manage pain and improve quality of life.
- Investment in clinician training can help promote palliative care as an important part of care for MBC patients.

In 2019, 30,650 individuals were diagnosed with breast cancer in California, and 4,620 died from the disease.¹ Metastatic breast cancer, also called stage 4 or advanced breast cancer, was the cause of nearly all of these deaths.

An estimated 30% of women diagnosed with early-stage breast cancer will go on to develop MBC. The five-year survival rate for MBC is only 27%, compared to 91% for breast cancer that has spread to lymph nodes and 99% for cancer that is confined to the breast.¹

In this fact sheet, we present findings from interviews, discussions, and studies (see boxed section) on barriers to accessing palliative care, and we recommend policy solutions that could improve survivors' understanding of and access to care for breast cancer that has metastasized.

Pain management, psychological and social support, assistance with nutrition, functional rehabilitation, and end-of-life care are all part of palliative care, which addresses many of the needs of MBC patients and can help improve their quality of life.²⁻⁶ The National Cancer Institute notes that the goal of palliative care is to prevent or treat, as early as possible, the symptoms and side effects of the disease, in addition to any related psychological, social, and spiritual problems. However, palliative care is an area in which there appears to be considerable

misunderstanding and lack of awareness among providers, potentially making them less likely to recommend this care to patients.⁴

Misconceptions around palliative care were also discussed extensively at the 7th Annual Metastatic Breast Cancer Conference (September 2020) and revealed in the key informant interviews. Conference attendees felt that education programs were needed to promote palliative care among providers, insurers,

and patients as a valuable part of treatment that helps with the management of pain and symptoms associated with MBC. Interview participants also expressed a lack of understanding about what palliative care entails. Several respondents either equated it to hospice or end-of-life care or noted that providers and insurers treated it as such. As one support service provider said:

Again, it goes back to lack of knowledge and fear. People, when they hear palliative or even hospice care, {are} freaking out already. Your brain automatically goes to end of life, and that's scary for people.

MBC patients who understood that palliative care is intended to help manage symptoms had inconsistent experiences in being connected to such services. One respondent noted that while she was on private insurance, the company contacted her about receiving coordinated palliative care. However, when she transitioned to Medicare, she did not receive any such outreach. Patients for whom palliative care was integrated into the treatment plan reported positive experiences.

Policy Recommendations

The need for better integration of MBC treatment with palliative care and support services was a common theme across all sources of information for this study. Some legislation has been passed in California to improve support services:

In 2018, the state legislature enacted SB 1004, which required Medi-Cal managed care providers to offer home-based palliative care to seriously ill patients. However, participation in the managed care program was lower than expected, likely due in part to lack of physician awareness, challenges in providing

education about palliative care to patients, cultural and language barriers, lack of time, competing demands of physicians, patient mistrust of the health care system, and limited services for meeting basic needs.⁴

In 2019, the legislature enacted AB 1287 to help give older adults, caregivers, and people with disabilities greater access to community services and support.

Health officials could improve access to palliative care by acting on the following recommendations:

- Provide training on palliative care to providers (to address lack of referral) and educate patients about the scope and benefits of palliative care.
- Improve awareness among providers and patients of Medi-Cal's home-based palliative care program.

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Endnotes

- 1 American Cancer Society. 2020. *Cancer Facts & Figures 2020*. Atlanta, Ga.: American Cancer Society.
- 2 Bergqvist J, Strang P. 2017. The Will to Live—Breast Cancer Patients Perceptions' of Palliative Chemotherapy. *Acta Oncologica* 56(9):1168-1174.
- 3 Cherny NI, Paluch-Shimon S, Berner-Wygoda Y. 2018. Palliative Care: Needs of Advanced Breast Cancer Patients. *Breast Cancer* (Dove Medical Press) 10:231-243.
- 4 Enguidanos S, Rahman A, Hoe D, Meyers K. 2019. Provider-Identified Barriers to Palliative Care for Medicaid Patients. *Innovation in Aging* 3:S689.
- 5 MacDonald T, Krishnan V, Wilson WA. 2019. Palliative Care Access in the Elderly Metastatic Breast Cancer Population: Obstacles and Opportunities. *Translational Cancer Research*: S110-S115.
- 6 Thrift-Perry M, Cabanes A, Cardoso F, Hunt KM, Cruz TA, Faircloth K. 2018. Global Analysis of Metastatic Breast Cancer Policy Gaps and Advocacy Efforts Across the Patient Journey. *Breast* 41:93-106.

Addressing Barriers to Metastatic Breast Cancer Care in California: Levers for Policy Change

Metastatic breast cancer occurs all across the United States, but differences in health care systems, health insurance products, and population characteristics create state-level differences in the experiences of patients. While there are national standards and laws governing different aspects of care for MBC patients, state-level policies still have significant impact.

The findings contained in this fact sheet are drawn from a study by the UCLA Center for Health Policy Research and the UCLA Center for Cancer Prevention and Control Research on the barriers to metastatic breast cancer care in California. The study report synthesized information collected by listening to patients and to both clinical and nonclinical caregivers, as well as by accessing published research, the grey literature, and Twitter chat.

Read the full report:

<https://healthpolicy.ucla.edu/publications/search/pages/detail.aspx?PubID=2101>



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