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Patient Navigators and Breast Cancer Care: Policy Solutions to Help Survivors Access California's Complex System of Care

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SUMMARY:

- **Breast cancer patients benefit from navigation services to aid in coordination of the full spectrum of care.**
 - **Insurance companies and the health care system can take steps to provide navigation services.**
 - **State agencies can develop a repository of services for breast cancer patients that providers and health systems can access to assist patients.**
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Many women fighting breast cancer in California encounter fragmented care as they navigate the complex health system with multiple providers, insurance requirements and restrictions, and valuable support services. Some women benefit greatly from the services of a patient navigator who is tasked with helping the patient identify providers, schedule appointments, understand insurance coverage for various tests and treatments, and connect to support services. However, a woman's access to a navigator is dependent on whether or not her health insurance, health care provider, or local health system provides the service.

As part of a joint study by the UCLA Center for Health Policy Research and the UCLA Center for Cancer Prevention and Control Research, investigators conducted two rounds of interviews with patient educators and advocates, health care providers and social workers about their knowledge of the patient experience in California for women with a breast cancer diagnosis.

This fact sheet presents findings on patient navigation services and recommends policy solutions that could improve survivors' understanding of, and access to, breast cancer care.

Patient navigation shows promise and merits further study.

Patient navigation is "an individualized assistance provided to patients through the cancer care continuum to navigate the complex health care system."¹ There is considerable variation in the types of navigation programs offered to cancer patients. Navigation programs provide different kinds of support, ranging from emotional to logistical to informational. Navigation programs may employ individuals of various educational backgrounds and training, ranging from health care professionals, such as nurses, to community health workers and to lay staff offering peer experience and support.^{2,3} Largely because of this variation, it has been challenging for researchers to evaluate the impact of navigation on patient outcomes.

A systematic review published in 2016 examined 13 experimental and quasi-experimental studies of breast cancer treatment and/or survivorship patient navigation programs.⁴ Results from this review suggest that patient navigation appears to be effective in improving cancer surveillance through mammography screening rates, but there was no consistent evidence of patient navigation impact on improved treatment and survivorship outcomes. A recent study (not included in the systematic review) conducted in a public hospital system in New York City found that a patient navigation program positively impacted receipt of timely care and improved compliance with adjuvant therapy for breast cancer.⁵

There are a number of ongoing studies that, once completed, will likely shed more light on the effectiveness of navigation programs. It also remains unclear as to whether patient navigation is cost-effective in improving outcomes in breast cancer treatment and survivorship. Similar to the state of the effectiveness research, more studies examining the cost-effectiveness of patient navigation will be crucial to the field. A recent study on health care spending and resource use among geriatric patients with cancer (not limited to breast cancer) suggests there are cost savings among navigated patients compared to non-navigated patients.^{6,7}

Navigation should not stop at the hospital door.

In a series of interviews for the joint UCLA study, participants asserted that well-run navigation programs were valuable in helping women succeed in moving through the complex process of receiving high-quality breast cancer care. Interview respondents conveyed numerous patient experiences demonstrating the need for navigators. More than one acknowledged that their organization was not explicitly tasked with navigation services but often ended up playing this role for patients.

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

In 2018, over 29,000 women will be diagnosed with breast cancer in California, and an estimated 4,500 will die of the disease.⁵ Yet, uninsured and underinsured breast cancer patients continue to face delayed and restricted access to life-saving, life-extending treatments and to services that enhance quality of life.

The findings contained in this fact sheet are drawn from a two-year study by the **UCLA Center for Health Policy Research** and the **UCLA Center for Cancer Prevention and Control Research** on the barriers to breast cancer care in California. Specifically, the researchers identified five major obstacles facing survivors: Health System Fragmentation/Navigation; Insurance and Health Benefits; Cost; Individual and Cultural Characteristics; and Language/Health Literacy.

The study also found that while barriers varied by insurance status — from public programs to Covered California to private group insurance — no group was immune from challenges in every category.

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Overall, study participants reported that navigation programs varied in the range of services offered as well as the quality of services provided. There was consensus that navigation cannot stop at the hospital doors and must extend to support services in the community. Respondents felt strongly that navigators should:

- Assist with schedule coordination to help ensure timely delivery of services.
- Interact with patients enrolling in new programs to aid in timely follow-through

on paperwork, as necessary. Lack of follow-through could force changes in insurance, impacting care.

- Help interpret technical medical terms as common language to explain the diagnosis and treatment options, enabling the patient to make more informed decisions about care.
- Be available to all women, regardless of insurance status; some women who have insurance could use assistance navigating a complex health system.
- Have a repository of resources for referral to support services. Often, providers and their staff are unaware of outside programs.

Recommendations

Key informant interviews, along with the state of the evidence, shed light on how the health care system may use patient navigators in helping patients move between steps along the breast cancer care continuum. The following recommendations to policymakers are those identified as priority areas to address the barriers that remain in navigating breast cancer care:

- Provide **reimbursement** for patient navigation services, especially in private health plans that currently lack these services.
- Establish **quality standards** for patient navigation programs in cancer care.
- Expand existing screening and prevention programs to educate women diagnosed with breast cancer on **patient navigation**, including what the role of a navigator is, what services are included, and how to obtain navigation services.
- Support the development of a **repository of information** on health care service providers and support services that can be locally tailored and available to providers and navigators.
- Improve **system integration** and co-location of services, including connections to, and financial support for, social services.

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Endnotes

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