

Recovering Latina breast cancer patients report big gaps in 'survivorship' care

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Breast cancer patients in one of the United States' largest and fastest-growing ethnic minority groups are likely to experience numerous gaps in care following their primary treatment, research from Oregon State University suggests.

Seventy-four Latina [women](#) who'd had [breast cancer](#) participated in the "survivorship" care research, recruited through support groups and health fairs. The subjects, ages 30 to 75, took part in semi-structured focus groups that used a question guide crafted by a task force of academic researchers and community partners such as the American Cancer Society. Approximately half of the women were low-income, uninsured or publicly insured.

"Results indicate numerous gaps and unmet needs in Latinas' [survivorship care](#) experiences, including problems with finances, continuity of care, unmet needs for information, and symptom management," said Carolyn Mendez-Luck, an assistant professor in OSU's College of Public Health and Human Sciences and one of the authors of the study.

The California Breast Cancer Research Program provided primary funding for the research. Results were recently published in *Public Health Nursing*.

Optimal survivorship care, according to the Institute of Medicine, includes the prevention of recurrence, new cancer and late effects of

cancer treatment; the monitoring or surveillance for cancer and medical, mood and social issues; interventions for the effects of cancer and its treatment; and coordination among specialists and primary [care providers](#) to ensure all health needs are met.

"Many survivors experience persisting symptoms including fatigue, pain, depression and sleep disturbance, but until recent years, survivorship has been relatively neglected in education, clinical practice and research," Mendez-Luck said.

People of Mexican, Cuban, Puerto Rican, and Central and South American descent comprise 17.6 percent of the U.S. population, and about 10 percent of the women in the Hispanic/Latino population will develop breast cancer at some point in their lifetime.

Latina women are more likely to be diagnosed at later stages than non-Hispanic whites and also face linguistic and cultural barriers to diagnosis and treatment, including modesty; spiritual beliefs that cancer is God's punishment; de-prioritizing their own health care in favor of their roles as mother and wife; and passivity in interactions with [health care providers](#) out of respect for their authority.

In addition, there are often financial hurdles - more than 25 percent of Latina women live in poverty and lack health insurance.

"Understanding the cultural context in which women receive care is important," Mendez-Luck said.

Women in the study sample expressed confusion and anxiety associated with a lack of information regarding future surveillance and treatment once primary care concluded. Many were unsure who was to be in charge of their treatment in the future, what the right schedule was for follow-up examinations, what self-care activities were recommended,

and what to expect regarding their physical and psychological well-being.

"Among the women in our focus groups, survivorship care plans were scarce," Mendez-Luck said. "The vast majority of participants reported never having heard of them, or associated them with a completely different meaning - making a plan for how their families could carry on after they were gone."

The research also showed that depending on the person, "survivor" could have negative or positive connotations.

"Negative perceptions included feelings that being identified as a cancer survivor was depressing, victimizing and stigmatizing," Mendez-Luck said. "Also, that thinking about the cancer could potentially contribute to an increased likelihood of a recurrence, either by 'tempting fate' or from the stress brought on by negative thinking."

Positive views, the professor noted, included feeling special, strong, and blessed by God. Many survivors felt they had a special purpose for living, often including a mission to serve others.

"A survivorship care plan is meant to be this living document for you and your care providers, a document a patient can follow through this entire process of what's going on with the cancer and what she can do to stay healthy and reduce the chances that the [cancer](#) will return," Mendez-Luck said. "It makes the patient truly a partner in her own care with health providers. But that's not happening, clearly, at least not for these women. There's an enormous opportunity there for improvement."

More information: Diana M. Tisnado et al, Perceptions of Survivorship Care among Latina Women with Breast Cancer in Los Angeles County, *Public Health Nursing* (2016). [DOI: 10.1111/phn.12299](https://doi.org/10.1111/phn.12299)

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