

# Study examines 'black boxing' in breast cancer survivorship care

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Today, many women diagnosed with breast cancer live long after completing their cancer treatments and have post-treatment health and information needs. Unfortunately, across healthcare systems,

survivorship care is neither consistent nor systematically implemented.

By conducting in-depth interviews with 82 breast [cancer](#) survivors and 84 providers in the Inland Empire region of Southern California, Deborah Lefkowitz, an assistant professional researcher in the School of Public Policy and Center for Social Innovation at the University of California, Riverside, investigated how information works during the transition from [breast cancer treatment](#) to post-treatment and how it shapes women's understanding of survivorship.

Lefkowitz found that [cancer treatment](#) tends to "black box" information, with visible inputs and outputs but concealed inner workings. She employed Actor-Network Theory to open black boxes in breast cancer and [survivorship care](#) and examined how the information they contained was actually functioning.

In her article in the journal *Social Science & Medicine*, Lefkowitz focuses on black box breakdowns and concludes that black boxing can hide communication gaps between survivors and their providers. "By opening these black boxes, we can consider how information pathways might connect women differently to improve survivorship care," she said.

In the following Q&A, Lefkowitz elaborates on her study and the implications of her findings, and discusses the relevance of Actor-Network Theory for breast cancer survivorship care:

### **Q: What motivated you to do the study?**

A: A lot of research is conducted on breast cancer diagnosis and treatment; much less is known about the long-term post-treatment needs of breast cancer survivors and how to best address these needs through survivorship care. Supported by an award from the National Cancer Institute of the National Institutes of Health, my research on how women

experience the care they receive is only the first step toward rethinking how post-treatment care might be organized and delivered differently.

## **Q: What is a black box in the context of breast cancer survivorship?**

A: A black box describes something—a process or an object—that is taken for granted in its functioning. In the context of breast cancer survivorship, a physician's referral can be black boxed. When black boxed, we assume that the referral automatically enables a woman to access a particular service (such as a PET scan, mastectomy bra, or psychological counseling). We do not consider that inside the black box multiple interconnected and interdependent processes and communications must take place for the referral to result in service access.

We encounter [black boxes](#) all the time in our day-to-day lives. For example, a light switch functions as a black box. We don't need to understand how electricity works to turn on a light in our home; we just need to know that if we move the switch from one position to another, a light will turn on or off as a result. If the light does not turn on, then we might have to, metaphorically speaking, open the black box to find out what has happened to the electrical connection.

## **Q: What did your study find?**

A: Access to cancer and supportive care services is a process, and not always a straightforward process. Survivorship, unlike treatment, takes place in the real world of women's lives, and not primarily in the medical clinic. My research illuminates the need to establish better information pathways for survivorship care that connect women to services through multiple institutions—employers, social service providers, community

nonprofits—and not just through healthcare providers.

I began this research by asking women to describe which cancer survivorship services they needed and used, how they were referred to these services, and where they accessed these services. I traced out maps of service referrals and service locations across the geography of the Inland Empire. What I learned was illuminating in terms of service gaps and access disparities; but these maps did not help me understand where the problems were and what might be done to remedy them. Through iterative qualitative analysis of my interview data, I began to focus on information, and where it was present or absent for survivors.

We often think about the contents of a brochure, a website, or after-visit physician's notes as information. Information, in this way of thinking, is a discrete entity. Instead, drawing on Actor-Network Theory, I examine what information does.

## **Q: What is Actor-Network Theory, or ANT?**

A: ANT is a methodology that emerged within sociology in the 1980s. It rejects a human-centric analysis, insisting that humans are not the only "actors." In my study, I examine how information shapes healthcare interactions and guides women's future trajectories through healthcare service delivery. In this sense, information is an "actor" within breast cancer survivorship, as well as within healthcare more generally.

Another distinctive feature of ANT is its refusal to analyze objects or phenomena as discrete and isolated; in fact, perceiving something as a discrete object means essentially to have already black boxed it.

The physician's referral I discussed above is an example of an actor-network: the piece of paper only works to enable access if it is connected with a referring physician, referred-to services, a health issue that can be

addressed by the referred-to services, and an insurer that agrees to cover the services. Yet we generally perceive the referral as a singular object, not as composed of the providers, the health problem, and the insurer that enable it to function as a referral.

**Q: What are some of the challenges where black boxes and breast cancer post-treatment survivorship are concerned?**

A: The biggest challenge is how to connect survivors with services when they need them. Breast cancer survivorship is not one-size-fits-all; there is wide variability in what kind of services might be needed, and when, during a woman's post-treatment life.

For many survivors, there is the desire to be "done" with cancer treatment and resume their lives. Black boxing reinforces the sense that cancer lies behind them, or that they can leave cancer behind. Some survivors may carry very little forward from their cancer treatment; they may have no long-term side effects, experience no adverse treatment effects, suffer no anxiety or fear about recurrence, etc. But for many survivors, a range of physical, emotional, and psychological effects from their cancer treatment will need to be addressed after treatment ends.

**Q: Your study recommends "opening black boxes to examine how information pathways could connect women differently to improve survivorship care." How might this be done?**

A: Tracing how information pathways work (or fail to work) in connecting women to post-treatment survivorship services is a first necessary step before information pathways can be dismantled and/or reconfigured to improve survivorship care.

Rather than attempting to improve services, I suggest improving the information pathways that connect women with services. In a medically underserved region such as the Inland Empire, increasing the availability of services may be difficult to achieve. The Inland Empire has one of California's worst healthcare workforce shortages, particularly for mental health. Strengthening the network of relations among existing service providers, and among providers and survivors, may therefore be a more realistic—and effective—strategy.

**Q: What were some challenges you encountered when doing this study?**

A: One of the main challenges was recruitment, which means finding and enrolling breast cancer survivors to participate in my study. My recruitment of survivors benefited from my many years of volunteer work and professional affiliation with organizations in the Inland Empire that support breast cancer patients. I relied on these organizations to post and distribute recruitment flyers (in both English and Spanish), and I attended many of the events these organizations sponsored. I also recruited survivors through breast cancer support groups.

I traveled extensively throughout the Inland Empire. I visited city halls, senior centers, community recreation centers, urgent care facilities, and social service agencies. I distributed flyers at health fairs, attended Bingo and Zumba classes at community centers, and participated in health ministry events at churches serving the African American community.

Women participated in my study from 27 cities across Riverside and San Bernardino counties; about a third of the women came from the region's sparsely populated desert regions. All were able to access surgery, chemotherapy, and radiation, as recommended by their physicians. But in examining access to supportive care services, my study reveals

disparities that are not visible when we only look at access to cancer treatment.

**Q: What is your message for breast cancer survivors after having done this study?**

A: An important message—which has wider relevance for healthcare interactions more generally and not just for breast cancer survivors and their providers—is that information is not just about content; it's about establishing connections. Most [breast cancer survivors](#) recall receiving lots of "information" at the time of their diagnosis in the form of brochures, checklists, detailed explanations of recommended treatment, and advice from friends and well-wishers. But it is not clear that these materials function as information—particularly if they are not read.

Understanding information as relational means that information is not just something providers can give to survivors; information is something providers and survivors do together.

**Q: What's next?**

A: Financial hardship often impedes women from obtaining the care and supportive services they need—even women with health insurance. In addition, most [breast](#) cancer patients/survivors are not currently benefiting from available [information](#) and services that could help them with financial problems; they also often wait too long to reach out for help.

I am currently exploring [financial hardship](#) for women during and after [breast cancer](#), focusing on low-wage women in the Inland Empire and Southern California.



**More information:** Deborah Lefkowitz, Black boxes and information pathways: An actor-network theory approach to breast cancer survivorship care, *Social Science & Medicine* (2022). [DOI: 10.1016/j.socscimed.2022.115184](https://doi.org/10.1016/j.socscimed.2022.115184)

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