

Bilateral risk-reducing mastectomies in American culture

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Pierre Paul Broca first discussed familial breast cancer in 1866, sparking centuries of research into the heritability of cancer. The *BRCA1* sequence variation was isolated in 1994, with *BRCA2* isolated a year later. These discoveries offered not just confirmation of heredity but, with the first commercial *BRCA* identification kits in 1996, allowed for carrier identification for those who could afford it. People assigned female at birth could now learn, quickly and accessibly, if they carried a *BRCA* variation and, thus, a significantly higher risk of developing breast cancer.

About 12.5% of the population will develop breast cancer; by contrast, 55%–72% of those with *BRCA1* and 49%–62% of those with *BRCA2* will develop breast cancer by age 80 years.¹ For those with a gene variant, increased regular screening was the first and most obvious step, alongside highly sensitive magnetic resonance imaging and various medication options. But some people began to opt for something far more radical: bilateral risk-reducing mastectomies, an option presented to patients as early as 1994 but not generally used until much more recently.²

Once a topic of secrecy, bilateral risk-reducing mastectomies have become the subject of *New York Times* op-eds, celebrity endorsements and storylines on young adult soap operas. In the 21st century, representations of bilateral risk-reducing mastectomies in popular culture have become much more prevalent, public, positive and accurate, leading to an interplay between patient treatment choices, cultural representations and perceptions of control and empowerment.

This procedure provides a lens through which representations and practice can be explored, charting the feed-

back loop between history, advocacy, culture, representation and practice.

The mutilating nature of early mastectomies as a treatment for breast cancer and the high stakes for femininity, sexuality and personal identity are concepts that are often at odds.^{3,4} Representations of mastectomies as a worst-case scenario have a long cultural history. The 1930s poem by W.H. Auden, “Miss Gee,” considered cancer something that “childless women” get as “some outlet/for their foiled creative fire,” providing a rather obvious answer to the doctor’s question “Why didn’t you come before?” More recently, the 1994 episode of *Law & Order*, entitled “Second Opinion,” portrayed women who opted for alternative medical approaches rather than mastectomies. A bilateral risk-reducing mastectomy is 1 of several treatment options and, in many ways, the most radical; recent representations have helped frame mastectomies as something within the patient’s control. Several questions around this approach remain, including ideal timing, psychological implications and long-term benefits. What is known is that patients in the United States, in particular, are increasingly embracing risk-reducing mastectomies, with a meaningful increase of almost 1% per month after 2013, compared with a monthly increase of 0.2% before that time. Rates have tripled over the past 2 decades.^{5,6}

Breast cancer started to lose its stigma in the 1980s with strong patient advocacy groups and networks that enrolled corporate buy-in to support their efforts.^{7,8} Drawing from the work of AIDS activists, the pink ribbon campaign was 1 of many highly successful approaches to encouraging regular screening, public conversa-

tion about diagnosis and fundraising for grant-based research. The combination of these factors, alongside highly public representations of risk-reducing mastectomies, not only introduced the procedure, but also helped render it as a viable option. In the US, unlike a postdiagnostic mastectomy, insurance is not required by law to pay for a bilateral risk-reducing mastectomy, but it is more cost-effective than regular intensive surveillance for at-risk candidates and it is certainly cheaper than treating cancer itself, causing most insurers to voluntarily cover the procedure.

The number of people requesting risk-reducing mastectomies increased sharply after 2013, alongside increases in genetic testing and screening.⁵ A great deal of this is owing to the so-called Angelina effect, namely the rise in awareness spearheaded by Angelina Jolie’s 2013 article in *The New York Times*. In this piece, Jolie revealed her own risk-reducing mastectomy and outlined the reasons she made this choice.⁹ Jolie, who lost her mother to breast cancer, shared her personal story in a highly public way; this led to an immediate spike in interest in the surgery at a societal level.¹⁰ In her article, Jolie modelled patient empowerment, urging others who may be at risk to take control of their health and their futures by investigating this option. Many, perhaps informed or inspired by Jolie, embraced the opportunity to both test for *BRCA* variations, and, if indicated, escape the dread of frequent screenings and unknown futures with risk-reducing mastectomies.

Jolie was far from the first to have a risk-reducing mastectomy, although she has been the procedure’s highest-profile public advocate to date. The numbers

highlighting the Angelina effect are part of the story. The advocacy efforts are part of the story. Testing for *BRCA* variants — covered only for indicated patients in the US and highly expensive until a 2013 ruling against Myriad, a biotech company — is part of the story.¹¹ The insurance funding is, as ever, an incredibly complicated part of the story. And the story has changed.

To highlight the differences in attitude toward mastectomies in 1994 and today, consider the character of Jane Sloan, 1 of the 3 leads in *The Bold Type*, a soap opera. Jane, a young White woman, lost her mother at a young age to breast cancer and, in a 2019 storyline, learned that she had inherited a *BRCA* gene variant. The show devotes considerable time to Jane's process across a number of episodes, including her decision to undergo a bilateral risk-reducing mastectomy. To prepare for the narrative arc, the show writers and actors researched both the medical and experiential aspects of the surgery; they were deeply aware of their responsibility to get the details around such a sensitive topic right. Jane opted for reconstruction, and her recovery — with all its mess and physical toll — is portrayed with sensitivity and veracity. Her complicated feelings around the entire experience become a central focus of the show, including the weight of these decisions at a relatively young age, the emotional toll with respect to her mother's death, the dual sense of loss of control and deep empowerment around illness and health, the difficulties of recovering from breast reconstruction and, perhaps most notably, Jane's own sense of being estranged from her body and her new, foreign-feeling breasts. The show portrays these topics with depth and nuance; in sharp contrast to earlier representations of mastectomies, Jane's process is powerful, agential and, ultimately, positive. Although the representation is limited, with its focus on a cisgender White woman with health insurance, the story of Jane Sloan is both the continuation and the realization of the Angelina effect, itself

just 1 aspect of a longer process of the shifting approach to risk-reducing mastectomies.

Cultural representations of risk-reducing mastectomies — both by actual patients like Jolie and fictional characters like Jane Sloan — highlight the interplay between medical practice, treatment options and popular discourse. Culture can meaningfully change not only patient attitudes but the meaning of treatment itself. Such surgeries are increasingly common as both a procedure and a conversation, not only between practitioners and patients, but also between television audiences, newspaper readers and consumers of popular culture. The emotional, cultural and practical resonances for mastectomies are deep and powerful. Proactively opting for this surgery is a powerful and complicated decision on a number of levels, and one that would have been unthinkable for many before these affirming and informative examples.

People who are genetically at higher risk for breast cancer could turn to risk-reducing mastectomies as an effective option that may help them feel in control of their own health. Much is yet to be learned medically, psychologically, culturally and socially about risk-reducing mastectomies, but the perception and representation of mastectomies, particularly bilateral risk-reducing mastectomies, have changed dramatically such that the procedure presents both a viable medical option and an opportunity for people at risk of developing breast cancer to take control of their bodies and their health.

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