

Wait watcher

by Jeri Zeder

A SOCIOLOGIST STUDIES WOMEN WITH THE CANCER GENE



Illustration: Polly Becker

Waiting for Cancer to Come: Women's Experiences with Genetic Testing and Medical Decision Making for Breast and Ovarian Cancer (University of Michigan Press, 2014) is sociology professor Sharlene Hesse-Biber's lay-accessible, qualitative study of women who test positive for BRCA1 or BRCA2—genetic mutations that place women “at high risk” for breast, ovarian, pancreatic, and other cancers. (The name derives from BReast CAncer.) The statistics are sobering: Hesse-Biber cites a 2009 study showing that, without medical intervention, individuals carrying the BRCA1 gene have only a 53 percent chance of reaching the age of 70. For BRCA2, the odds improve to 71 percent. Lacking both mutations, the likelihood is 84 percent.

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really want to take control,” one woman in the study says; “I don’t want to know, but I know,” says another) are where Hesse-Biber’s interests lie. While much research has gone on at the genetic level, and the actuarial, little work has

The disclosure of a positive BRCA result is not the beginning of the story for most women, who, when they have the test, are not yet sick. The reasons for testing, the “testing experience,” and the “myriad ways women come to terms with their genetic news” (“I

been done, she says, to understand the personal, familial, and social ramifications for women who have pioneered (over the last 20 years or so) in having their DNA tested. The inquiry carries weight beyond her BRCA focus. The first company to market BRCA testing, Myriad Genetics, of Utah, now offers myRisk™ to test, it says, for “eight important cancers.” Hesse-Biber shares the view of some sociologists that Americans are becoming an “at-risk society,” ever more aware, through advances in science and technology, of our physical vulnerabilities, and ever more involved, as patients, in the medical decisions to address them.

Women with BRCA mutations typically see their choices as: proceeding with enhanced medical surveillance to detect, then treat cancer in its earliest stages; or preventive surgery (removal of breasts and ovaries while these organs are still healthy). On the surface, the numbers make a compelling case for preventive surgery: A double mastectomy can reduce a BRCA1-positive woman’s risk of breast cancer by 95 percent. A bilateral oophorectomy can reduce the risk of ovarian cancer by 90 percent and the risk of breast cancer by 50 percent. Yet, if the goal is improved mortality, says Hesse-Biber, studies show that in the aggregate surgery is no better than surveillance.

Hesse-Biber interviewed 64 women, chosen from among respondents to postings she placed with online BRCA-support communities. All had tested positive for a BRCA-gene mutation save one, who underwent a mastectomy based on her family’s medical history. They ranged in age from 23 to 66. Demographically they were, she says, the women “who are generally tested for the BRCA mutation in the United States: white, middle to upper class, and educated.”

Hesse-Biber recorded upwards of two-hour telephone interviews with each woman, beginning with, “Can you tell me how you came to be tested for BRCA mutation, and what happened after that?” All but eight of the women also took an online survey, providing demographic information; personal and family histories of cancer; and details about medical decisions.

In a book that also examines the history of genetic testing and its rapid, direct-to-consumer commercialization (one interviewee saw an ad for testing on the subway: “Are you ready to fight disease before it starts?”), Hesse-Biber gives voice to women who sought “genetic knowledge.” They recount their struggles toward a readiness to be tested. The anniversary of her mother’s death became the day one woman got tested. The age at which another went forward with preventive surgery matched the age of her mother when she died. “That kind of thinking is not at all what you would read in the decision-making literature about how women make medical decisions,” Hesse-Biber says. Also in the book’s pages, women describe the feeling of “waiting for cancer to come.” They worry about their sisters and daughters. They make jokes.

Hesse-Biber lost her younger sister to breast cancer. The disease has struck her mother, her older sister, and herself, though all tested negative for BRCA mutations. “I have researched a variety of topics related to women’s lives and health, including women and work, the intersection of gender and race, and body image and eating disorders,” she writes in her epilogue. “This study found me.”

Read more by Jeri Zeder

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