

Religion and the BRCA Mutation

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Illustration by Andrew Zbihlyj

IT WAS A COLD DAY in January, not long before my 22nd birthday, and I was looking out at the Boston cityscape after receiving my genetic test results. I called my boyfriend and tried to be lighthearted about it. “Hey, I just found out I’m the most boring member of the X-men.”

My genetic counselor had explained my BRCA2 mutation to me carefully. “Sometimes cells divide incorrectly, and when this process goes unchecked, a person can develop cancer. We each have a number of genes that put a stop to this process. One of them is called BRCA2.” She held up two hands “Every person is born with two copies of each BRCA gene. They control signals that say ‘stop’ to rogue cells.” She put one hand down. “But you were born with a flaw in one of your BRCA2 genes, so it doesn’t work.”

What did this mean? “Due to the mutation, you have a 40 to 80 percent lifetime risk of breast cancer, and a 25 to 50 percent lifetime risk of ovarian cancer,” my genetic counselor told me.¹ Cancers in BRCA mutation carriers often occurred at younger ages, were more difficult to treat, and were more likely to recur. My mother, a breast cancer survivor, sat white-knuckled in her chair.

I didn’t know then about the biopsy I would have not long after that appointment, a golfball-sized chunk of flesh taken out when an MRI identified a white-hot suspicious area. I didn’t know then about the exhausting experience of yearly screening tests as sure and as stressful as the sword of Damocles, or about the many doctors who would (sometimes aggressively) recommend a mastectomy to lower my risk.

These experiences brought me a profound kind of stress. Psychologist Jeannie Pasacreta, who identified extremely high rates of anxiety in women with BRCA mutations, suggests that “it may be that anticipating the development of breast cancer is more psychologically distressing than actually having it.”²

In his book *The Wounded Healer*, theologian Henri Nouwen writes: “Making one’s own wounds a source of

healing . . . does not call for a sharing of superficial personal pains but for a constant willingness to see one's own pain and suffering as rising from the depth of the human condition which all men share."³ My experiences gave me a new vantage point on the suffering of others—children who had lost parents, spouses separated from each other, family members cut down in the prime of their lives. My spirituality had always been significant to me, but now I found myself angry at God at the very moment I wanted to run and bury my face in God's skirts.

I tend to intellectualize things, so I read everything I could find on BRCA mutations and genetics (a peculiar undertaking for someone who was earning a degree in religious studies!). I didn't connect my research on BRCA mutations with religion until a young Jewish woman I met at a support group discussed her experience at a *mikveh*.⁴

The young woman planned to have a mastectomy in order to lower her risk of disease and so that she could see her children grow up, but the surgery terrified her and she was struggling with it. Though she had never been ritually observant, she went to a mikveh one day, plunged under the water, and came up saying, *I'm ready*. She went ahead with the mastectomy and has never regretted her decision.

Her story got me thinking. How did this ancient ritual help the woman to navigate modern (indeed, quite new) biomedical choices? What did she lose in that water, and what did she find?

Feminist and poet Audre Lorde wrote, "Each woman responds to the crisis that breast cancer brings to her life out of a whole pattern."⁵ The more I researched and thought about the entanglements of religion and the BRCA mutations, the more I realized that exploring this seemingly narrow area was actually a way to approach significant topics: women's religious experiences, the meaning of disease, the social role of science and technology, the problem of suffering, and the significance of family and ancestry in an increasingly individualized world.

Disease is not only a physiological event, it is a social one. The impact of illness on a person's life is mediated by numerous factors, including stigma and meaning-making. Someone who feels that the cancer is a punishment for her sins will experience her disease differently than someone who believes that it is an opportunity to experience God's love. And think of the woman who is facing an early end to her childbearing years due to chemotherapy or surgery: what might her reaction be to a religious injunction to "Be fruitful and multiply?"⁶

Psychologist Robert Klitzman observed, "In seeking such explanations [for genetic disease], people draw on a wide spectrum of conceptual models: from the purely physical to the purely metaphysical to combinations of these."⁷ The constellation of meanings associated with the mutated gene and with a diagnosis of cancer are shaped and filtered through preexisting ways of knowing and templates for understanding the world, one of which is religion. If we can articulate and illuminate some of the religious experiences and reactions of sufferers, we might be able to relieve some of the agony that cancer causes.

The best way to understand what people are thinking is to ask them. This, in simplified form, is a central truth of the social sciences.

New communication technologies have allowed people with BRCA mutations to find each other and form support groups based on their shared experiences. These groups also serve the intriguing social purpose of creating shared discourses of meaning around risk and health.

Given the dearth of knowledge about the entanglements of religion and the BRCA mutations, in the spring of 2015 I designed a short survey on health status and religious belief, and posted it on a forum for people with hereditary breast-ovarian cancer (HBOC) mutations.⁸ I expected perhaps 7 or 8 responses back, maybe a dozen if I was very lucky. I received 92.

All the respondents self-identified as women, and they ranged in age from 22 to 73 years old. Most had BRCA mutations—though some had other mutations linked to HBOC, such as PALB mutations or Lynch syndrome—and they self-identified with a variety of religious traditions. Of those 92, 17 respondents (18.5 percent) named their diagnosis (either of cancer or a genetic mutation) as the catalyst for a shift in their religious beliefs. Those who described this shift most often stated that their beliefs had deepened and gotten stronger after their diagnosis (9 total responses); only one respondent stated that her religious beliefs had declined or lessened. Though this may say more about the sorts of people who would be moved to take an optional survey on HBOC and religious belief, it indicates that health crises may have an impact on religious belief.

Three central themes emerged over the course of my research: heredity and identity, the female body, and suffering. I ended up structuring my discussion around these themes rather than around the religion of the respondents, not because religious distinctions are unimportant, but because I discovered that the replies of my respondents had less to do with tradition-specific doctrine and more to do with complex individual experience. A Catholic and an atheist both had deterministic or fate-based responses to genetic risk; two Protestant Christians had radically different interpretations of a central religious text on suffering. I was surprised at the similarities among responses that emerged from people with different religious identities, and at the differences that existed among people who claimed similar identities. I found that organizing my research around these three topics actually allowed me to *better* contextualize the religious identity of the respondent, and to avoid reductionism.

Heredity and Identity

In the latter half of the twentieth century and the beginning of this one, something puzzling was happening in the American Southwest: very young women were developing extremely aggressive breast cancers. With the advent of widespread genetic testing in the early 2010s, these women and their families were tested for the BRCA mutations. Around 10 percent of them had a unique and easily identifiable sub-mutation of the BRCA1 gene, 185delAG, which had previously been found only in Ashkenazic Jewish populations.

Through analysis of oral family histories and historical documents, a clearer picture emerged. The story begins in the sixth century BCE, when 185delAG first appeared in a single unknown person in the Jewish population in the Middle East. After the Roman destruction of Jerusalem in the first century CE, the Jewish people were forced into slavery and exile. Over the centuries, some made their way to Spain, where they became the Sephardim, one of the two largest Jewish diaspora populations.⁹

After the Catholic Reconquista of Spain, Jews became marked for conversion or extermination. Many officially “converted” to Christianity in order to save their families, but a large number maintained Jewish practices in private. Known as the *conversos*, this community was one of the primary targets of the Spanish Inquisition. When the New World opened up, many seized the chance to be free of Spain, and they established new lives in the Americas, especially in the American Southwest. The gene mutation 185delAG came with them and was a root cause of the high rates of breast cancer.

In his book *The Wandering Gene and the Indian Princess*, journalist Jeff Wheelwright entwines the history of 185delAG with the personal narrative of the Medina family, descendants of the *conversos*. The Medinas are reeling over the loss of Shonnie, a woman who died of breast cancer in her late 20s. Early in the course of her disease, Shonnie made the decision to reject medical care from a particularly condescending and callous doctor. Wheelwright frames this choice in the context of her ancestry: “She was the *converso* rankling before the Old Christian, the Indian resisting the *españolole*, the Hispano resentful of the American, the Witness rejecting the world’s authority while living within the world.”¹⁰

Wheelwright’s vivid description of the confrontation between Shonnie and the doctor is in line with other narratives I’ve read and heard. Shonnie did not face the doctor and the news of her diagnosis alone—the legacy of ancestors who had resisted, endured, and survived guided her choice to reject unfeeling and inappropriate medical care. BRCA mutations are hereditary, with a 50 percent chance of being passed from parent to child. More than your grandma’s green eyes or your father’s love of sweets, having a genetic mutation linked to a fatal disease inspires a sense of connection with those who have gone before you.

Not infrequently, this also intersects with Jewish identity, sometimes in families where the news is quite unexpected. The Medina family wrestles over the immediate, pragmatic concerns that arise as a consequence of this genetic inheritance, but they also struggle with wider questions about their identity—what place do Jewish and *converso* ancestors have in a family of good Jehovah’s Witnesses?¹¹

For women who identify as Jewish, BRCA status has a way of reifying a biological component to Jewish identity. Because one already has to have a Jewish mother to be considered Jewish, it is a relatively short leap for some women to identify Judaism with genetic characteristics. Anthropologist Jessica Mozersky notices that, for one of her interviewees, having a BRCA mutation brought anxiety about health status, but it also offered “a sense of connection to her mother and family, other women and Jews in general.”¹²

In response to my survey, a young Reform Jewish woman named Maayan noted that “knowing that my

specific mutation is thousands of years old and dates back to the first temple in Israel makes it feel less like a burden and more like a piece of history that I carry with me.” Maayan’s understanding allows the mutation to take on a new meaning. It is no longer just a medical liability; it is also a thread linking her to her ancestors.

This connection between Jewish identity and genetics is not without its problems, depending as it does on an understanding of Jewish identity as biologically immutable. Yet there is comfort here as well. For those who know their ancestors and roots, this aspect of identity can be meaningful and grounding.

The Female Body

It is no secret that religious doctrine is interested in the proper functioning of the female body: how to properly cover it, nourish it, ensure its proper sexual conduct, and make sure it bears (or does not bear) children at the desired time. So what happens when religious injunctions on the female body collide with medical recommendations? And what happens when these attitudes intersect with American popular cultural values, which identify women’s bodies as sites that require constant improvement and intervention?

For some women in my survey, religiously based values around the purpose of the female body clashed with the medical decisions they planned to make. Candice, a 26-year-old woman who was raised in the Church of Jesus Christ of Latter-day Saints but is currently unaffiliated, said: “Any religious messages about having children and that the sole purpose of a woman is to have children really irritates me. What if I had ovarian cancer/breast cancer and could not get pregnant? Does that make me less of a woman/person?” Candice referenced a pervasive attitude summed up in 1 Timothy 2:15: “But women will be saved through childbearing.” Her comments raised important questions about the place and status of women in faith communities, most notably: to what extent is the value and influence of women in the community premised on their role as mothers or potential mothers?

The importance of the wholeness and integrity of the body (especially when female) was highlighted by other respondents as well. Stephanie, a 24-year-old liberal Catholic who had undergone a prophylactic mastectomy only a few weeks before responding to my survey, had a delightfully fierce response to potential critics: “I’m sure the strictest of the strict Catholics would say I’m mutilating/changing a body God gave me, and I don’t even have cancer. I would just tell them F*** you! You don’t know what it’s like watching a family member die of cancer. Then you have to live with the fact that you have such a high risk of that happening to you, too.”

Stephanie’s response raised other questions for me. Catholic doctrine is heavily centered around natural law, and, though famously rigid on birth control and certain kinds of bodily manipulation, it does permit the removal of ovaries and the uterus when the intended purpose is unrelated to birth control. Bodily integrity is not emphasized to an extent that it precludes potentially life-sustaining surgeries. Nevertheless, it’s possible that certain zealous—if misguided—individuals might assume that Catholic doctrine prohibits

mastectomy and oophorectomy. Nuanced and subtle theological positions can become somewhat distorted as they filter down into the diverse ranks of believers, leading to difficulties for people like Stephanie.

For some Christians, genetics evokes the idea of original sin. When asked how her perspective on religious texts or messages changed after her diagnosis with a BRCA mutation, survey respondent Jenn, a Protestant evangelical woman in her 30s, noted that the “story of Adam & Eve made me doubt God’s goodness, as all generations have been made to live with the consequences of their actions (including the introduction of disease and sickness).”

Despite her discomfort with the similarities between hereditary gene mutations and original sin, Jenn’s faith also provided her with more empowering perspectives on the female body. She noted that her faith helped her to “challenge unconsciously accepted unhealthy cultural values (re: beauty, femininity, sexuality, woman’s role/value etc.), sometimes referred to as ‘lies’ in Christian circles.” For Jenn, hegemonic cultural notions of female beauty and fertility were secondary to her identity as a committed Christian.

Suffering

Women with cancer or at high risk for it deal with a great amount of suffering: the discomfort and pain of medical tests, surgery, and chemotherapy; the physical pain of metastasized tumors; and the psychological pain of fear and loss. Religions have a number of approaches to suffering and offer a variety of conceptual tools to frame it. How do we respond to suffering? Does suffering have some kind of existential or cosmic value? How can we escape suffering? Do we suffer alone?

One of my survey respondents, Jennifer, converted to Nichiren Buddhism, in part for the resources it gave her to navigate suffering after her prophylactic mastectomy because of a BRCA1 mutation. Jennifer knew another woman with cancer and was amazed at how calm she was through the experience. Jennifer discovered that this woman was a Nichiren Buddhist, so she decided to learn more about the faith and eventually ended up converting. She reports that the practice of chanting and reading sutras has been enormously helpful to her in navigating her health status, offering her practical tools to cultivate equanimity in the face of uncertainty and drastic change.

The book of Job, a biblical text that deals with the topic of suffering, appeared in the answers of two women in my survey—but they read the text in radically different ways.¹³ Jenn, the young Protestant evangelical, said that she found the message of Job hard to handle after her diagnosis. The book “made me feel like God uses his followers as pawns for his own edification/pleasure (during a time when I was struggling with trusting that God had my best intentions at heart),” she wrote. On the other hand, Laura (who identified as Christian) cited “the story of Job and his faithfulness in the Bible,” as well as prayer, devotional readings, and Christian music, as sources of religious inspiration after her prophylactic mastectomy and oophorectomy. These responses made me interested in how other people experiencing a health crisis engage this text’s multiple meanings.

One Christian respondent related her own experiences with BRCA to the central narrative in her religion. Jenna, an American Baptist, said: “The Holy Week story—Jesus’ suffering and the ways his friends betray him—comes to mind. I have had new friends come into my life and be amazingly generous. I have had people I love who have all but disappeared in fear at what I have learned. I’m grateful to have this sense of Jesus as close to my experience. Plus, I claim the mystery of resurrection—for the people I love who have died and, someday, for me. My fear of death is still palpable and real, but I do have resources as I consider it.” Jenna was scheduled for a preventative double mastectomy with reconstruction three days after she submitted her response to my survey.

For Jenna, Jesus is a cosmic role model for the suffering self, allowing her to interpret betrayal and suffering in a way that allows for hope. Her religion also offers her a “resource” on how to understand death. This aspect of religion—the ability to consider a life beyond this one—also has implications for end-of-life care.

Different Tales of Faith

Susan Sontag described illness as a foreign country.¹⁴ In the case of HBOC genetic mutations, it is a dynamic territory that has been little explored. As a result, I am compelled to say that this article is not a map; it is the hasty sketch of a hiker who intends to return to these woods and who hopes others will join me on the path.

Religion and spirituality help us to understand who we are and why we are. Our religious beliefs can turn a potentially catastrophic event into a minor setback in the narrative of our lives, something we can look back on with humor and perspective, marveling at what we have learned. But religion can also be a weight that pulls us down, that negatively colors our lives until we address the source of this pull and remedy it. A medical crisis can be a tale of faith that was tested and proven true, or it can be a tale of unutterable woe and loss that can never be redeemed. Religion can exacerbate inequality and provide a cover for bigotry and sexism, but it can also help women navigate their own authentic ways of being in the world. Whatever tale the sufferer tells, the role of religion must be addressed and understood.

Notes:

1. See Joi L. Morris and Ora K. Gordon, *Positive Results: Making the Best Decisions When You’re at High Risk for Breast or Ovarian Cancer* (Prometheus, 2010).
2. Jeannie V Pasacreta et al., “Genetic Testing for Breast and Ovarian Cancer Risk: The Psychosocial Issues,” *The American Journal of Nursing* 102, no. 12 (December, 2002): 44.
3. Henri Nouwen, *The Wounded Healer: Ministry in Contemporary Society* (Image Books, 1979), 88.
4. A *mikveh* is a Jewish ritual bath for various purification purposes.
5. Audre Lorde, *The Cancer Journals* (Aunt Lute Books, 1980), 9.
6. Genesis 1:28.

7. Robert Klitzman, *Am I My Genes? Confronting Fate and Family Secrets in the Age of Genetic Testing* (Oxford University Press, 2012), 124.
8. I am grateful for the support for my research project from Harvard's Institutional Review Board and administrators.
9. The Sephardim have long been contrasted with the Ashkenazim, another Jewish diaspora population of German and Western European heritage. Yet the ethnic make-up of Jewish communities the world over is remarkably complex. For example, Sephardim used to refer primarily to Iberian Jewry, but in Israel today, the term can be used more broadly. There are Jewish communities that never left the Middle East (sometimes called Mizrahi Jews), and other Jewish populations do not figure into these categories at all, such as the Cochin from India, the Maghrebi Jews from North Africa, and the Beta Israel Jews from Ethiopia.
10. Jeff Wheelwright, *The Wandering Gene and the Indian Princess: Race, Religion, and DNA* (W. W. Norton, 2012), 173.
11. Most of the families in the Southwest who discovered they have the mutation identify as Latino/Latina Roman Catholics.
12. Jessica Mozersky, *Risky Genes: Genetics, Breast Cancer, and Jewish Identity* (Routledge, 2014), 85.
13. In Job, Satan suggests to God that Job is only righteous because God has blessed him so much, and God gives Satan permission to inflict a variety of losses and suffering on Job. Job grieves his losses with quiet patience, and when at last he rails against God for allowing him to suffer so, God appears in a whirlwind and reminds Job not to question divine provenance. God then restores all that Job has lost.
14. Susan Sontag, *Illness as Metaphor* (Farrar, Straus and Giroux, 1978), 3.

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