To write about the disease of breast cancer from both scientific and spiritual perspectives is to reflect upon our genetic and spiritual ancestry. Our mothers, aunts, and grandmothers either currently have or have had breast cancer. Approximately one in eight women will be diagnosed with breast cancer, and it is the second leading cause of death for women (http://www.mayoclinic.com/health/breast-cancer/DS00328).

For women who are diagnosed and treated for breast cancer, a journey unfolds for each individual marking the intersection of spirituality, medicine, and biotechnology. Both of us have accompanied family members and friends on this journey, as witnesses to their stories. According to Donna

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Haraway, a feminist philosopher of science, witnessing is “a collective, limited practice that depends on the constructed and never finished credibility of those who do it, all of whom are mortal, fallible, and fraught with the consequences of unconscious and disowned desires and fears” (Haraway 1997, 267). Being a modest witness requires an aversion to abstractions, for they can be mistaken as the real thing. And to be a modest witness is to be engaged in practice: “The point is to make a difference in the world, to cast our lot for some ways of life and not others. To do that, one must be in the action, be finite and dirty, not transcendent and clean” (Haraway 1997, 36).

We also have read the memoirs of women’s experiences with breast cancer. Although the details may diverge, the stories all relate their bodily journeys through disease and healing. The authors include women from Jewish, Mormon, Christian, and other spiritual traditions. Masha Gessen in Blood Matters (2008) explores the ways that genetic and spiritual identities are bound together. Terry Tempest Williams in Refuge (1991) links family, history, and the landscape of Mormon Utah. Some women claim no spiritual tradition at all.

We want to examine the issues involved in breast cancer at the intersections of spirituality, technology, and science, using the fundamental thing we know about being human: our bodies. Our goal in this essay is to offer close readings of women’s spiritual and bodily journeys through the disease of breast cancer. As noted, we have interviewed and accompanied family and friends and read the memoirs of others. We also both work and study at the intersection of religion and medical science. Ann Pederson teaches theology, religion and science at Augustana College and has an appointment with the Section for Ethics and Humanities at the Sanford School of Medicine. Megan Eide completed an undergraduate honors religion major that included two internships in pastoral care and ethics at Sanford Hospital and advanced coursework at the Sanford School of Medicine.

What we have discovered is that both illness and health come within the stories of specific people and particular disciplines. To learn more about breast cancer, both scientific and spiritual aspects, one must be attentive to such particularities. Medicine and religion are bodily experiences. And being a body-self is what it means to be human.

Both of us are shaped by the Christian faith and the Lutheran tradition in particular. The narratives that grow out of our own experience of body engage the incarnational story of God in the world. Although this is our particular spiritual and religious background, we reflect on the many questions that the human spirit faces between life and death, health and illness. We focus on how women’s stories of both illness and health provide the interpretive framework of their life story, how they come to terms with their situation, reflect on their bodies, and find transcendence in the course of their journey. We believe that in a sense we are all living a kind of trauma/
illness and that we seek healing—whether explicitly and consciously or at a subterranean, under-the-radar level of our daily living. We need healing stories or personal mythologies to lead us from illness to health, from death to life.

To accomplish this, we will read, analyze, and systematize the insights we gain about the following questions: What are the cultural expectations of how women should deal with breast cancer? How do women relate to and with their bodies? What new awareness and insights develop when one is diagnosed with a disease? Does the disease bring new spiritual lessons, or are the lessons learned throughout life just affirmed and deepened as one copes with the illness? When do medical science and biotechnologies enhance life, making the world the wholesome place in which God intends for us to live fully? When do they destroy or lead us away from the ways in which we can most fully live for God? Where is God or an ultimate spirit/meaning in the midst of disease and healing?

**Cultural Stories of Body-Selves**

Our culture tends to view bodies as parts rather than a whole. This may be a result of our Cartesian/Enlightenment background, but it also is a result of our consumerist culture. We view the parts from commercial, sexual, medical, and spiritual perspectives. Women’s magazines advertise how to reduce flabby thighs and how to make decadent desserts. We receive mixed messages about being strong, independent women and yet are seduced by advertisements sexualizing every part of ourselves. This sexualization and commercialization surely influences the world of health care. The way breast cancer is evaluated, experienced, and treated mirrors our cultural values.

For many women, modern medical science approaches their bodies mechanistically and reductionistically. A common approach of cutting out the diseased parts and dealing with the patient from a detached perspective is a theme that runs through many memoirs. One patient recalls a physician coming into the room after a radiation treatment and simply asking “May I see your breast?” No greeting, no “Hi, how are you,” simply a request to see “the part.” After examination, the physician left the room. While this hopefully is an exception to the rule of care, we find many more examples of women being treated as parts and not as whole persons. Some feel as if they are in a garage being treated by a mechanic. Gessen reflects:

> American medicine takes essentially an instrumental view of the body: the body as a car. These things need regular checkups. Doctors are mechanics whose primary goal is to ensure that the functions are preformed properly. The primary function of the body is reproduction—hence the ease with which a woman’s reproductive organs are discarded once the function has been performed. (2008, 103)

Women feel like numbers and functions. Body parts can seem to be tied solely to their function and not to their relationship to the whole of the
body-self. Particular dilemmas arise when the breast is the part that is diseased and diagnosed. In a culture in which bodies are sexualized, women already struggle with their bodily image.

We know that medical education is changing in many arenas, but many health-care professionals, physicians in particular, still see the body as a mechanical unit that should be running smoothly. The shadows of William Paley’s watchmaker and Isaac Newton’s machinelike universe still linger in the scientific world. A local hospital used to advertise that they could help the body “function like a well-oiled machine.” Some women feel that the labyrinth of health care is very like a great machine—and they are the cogs moved from one doctor to another where no one ever seems to have all of the relevant information. (There are exceptions; some women speak of physicians who “get it”—that is, care for them as persons, and not just parts in the machinery of the universe.)

Therefore, when it comes to treatment, surgery of some sort is usually the first suggestion.

It came to make sense to me that the frontier of genetic medicine was, in fact, surgical. The simple and decisive nature of surgery is seductive. It is a one-shot deal. Being able mentally to reduce one’s own body to a collection of parts creates a powerful sense of control. Cancer, particularly hereditary cancer, makes this feeling of control especially desirable. Cancer is one’s own cells gone awry. Cutting out the potentially offending organ before it has a chance to betray you shows the body who is boss. The greater one’s fear of cancer, the greater temptation to cut. (Gessen 2008, 106)

However, in the last thirty years, the shift from assuming that one would have a radical mastectomy to consideration of a simpler lumpectomy has changed the treatment of breast cancer.

Breast cancer is not just a disease of a part; it is a journey that involves the whole self, physical and spiritual. If we have learned anything, we can testify to disease as process, as journey. The same is true with healing. To be human is to be whole. When we treat people as objects, as parts to be treated or studied, we take away their humanity. Many women describe the experiences as dehumanizing when they are treated as a part that is diseased instead of a person with an illness. No matter how nice the treatment by medical professionals, patients still experience many of the technological interventions as dehumanizing. This can heighten the sense of shame and fear: “Cancer becomes a disease of shame, one that encourages secrets and lies, to protect as well as to conceal” (Williams 1991, 43).

In our culture, breasts and hair are obsessions. “We are almost as obsessed with our hair as we are with our breasts in this country—ask any guy who’s bald” (Lewis 2008, 152). Women write about the connection of sexuality and reproduction with their breasts. The loss of hair during chemotherapy also diminishes their sexuality. For some women, the loss of the breast is less traumatic than the loss of all their hair. Many women recall
the horror of having clumps of hair fall from their head. We hide the illness with hats and scarves. We are not comfortable with visible signs of vulnerability. If women do expose their baldness to the world, they receive the “I know you have cancer” stare from others.

Technological treatments, for many women, feel like a strange combination of having an invasion from outside that takes place inside the body. The boundaries of inner and outer no longer seem to make sense; boundaries fade between what is “natural” and what is “technological.”

I was strangely eager to have my stereotactic biopsy, mostly because the machine fascinated me. It is, in essence, a robot. You lie facedown on a table with your boob protruding through a trap door. The breast gets clamped tight, uncomfortably so, inside an X-ray device, exactly like for a mammogram. Once you’re positioned properly, with your neck craned unnaturally and your kneecaps balanced against a sharp edge, a metal probe is inserted into your breast. Guided by the mammogram picture, this probe is a robotic arm. From it, little razor-sharp knives core slivers of flesh for diagnosis. It sounds like a torture device, but the process was surprisingly entertaining. (Norton 2008, 29)

Women see their breasts from the inside while watching the images projected on the outside whether in ultrasounds or x-rays. Probes surgically remove tissue from the inside of the breast, and every effort is made by the patient to keep a calm “exterior.”

This experience of body-self as inner and outer is consistently and often humorously noted during the experience of radiation. The science is an odd contrast of technological precision and old-fashioned tools:

Now, before you even can begin radiation, there is a lot of pre-treatment work to be done. Technicians and doctors have to map out exactly where to aim their rays. This is the simulation phase, and it includes such sophisticated high-tech techniques as taking a felt-tip pen and marking up your breast into sections that look like “choice cuts” until you resemble a steer on the butcher shop chart. (Lewis 2008, 163)

The radiation map becomes a kind of in-house joke among many women as their body looks like an odd tattoo of dots and lines to guide the technicians.

Everyone tries so hard to be nice, to be compassionate through the whole experience of diagnosis and treatment. Most women speak of receiving such care. Yet during the procedures of radiation,

The technicians are nice; they make small talk as they carefully adjust your body on the table, move your gown farther away from your breast, place your arm where it won’t be in your way. But the experience itself, in which you are lying there, alone, breast exposed, is dehumanizing, no matter how much the staff tries to connect with you. (Lewis 2008, 169)

Compassionate health-care providers can help to alter an experience that for many women still feels like simply being exposed. Some women who have experienced sexual abuse find such treatments even more traumatic.
Women have not always had choices about their bodies and the care they receive. Whether it was during the forced sterilization of “undesirable” women in the 1920s eugenics movement or in today’s culture of Roe v. Wade, women struggle with having too few options presented or being told what to do by a health-care professional. Paternalism (or maternalism) and autonomy still conflict in the ethical landscape of cancer treatment. Women hope for the best possible treatment and want to know what options are available. This is a difficult path to walk for physician, nurse, and patient. Nurses often play the most positive and significant role in communicating with the patient at both the medical and personal level.

Women feel dehumanized and demeaned when they are given inadequate or unhelpful information or when the information comes too late. Upon being told that her ovaries were rendered sterile from the chemotherapy, Meredith Norton reacts:

Yes, I suppose my dead ovaries were equally useless as suppressed ones, but what about harvesting and freezing my eggs before you pickle them in drugs? What about telling me or asking me and giving me a goddamned choice? Nobody, under any circumstances, has the right to take away my ability to reproduce without at least giving me a heads-up. (Norton 2008, 54)

Freedom is not simply a matter of choice; freedom is also being treated with respect. Women need to define their own notions of health and well-being. What works for one woman may not for another. Autonomy is not simply self-rule but also self-respect and receiving respect from others. In current bioethical discussions, autonomy is defined as self-rule—that is, always respecting the choice of the patient. But, as anyone who has been in the midst of a personal and medical crisis can attest, true autonomy does not exist. Relationships of physician, nurse, patient, family, and significant others come together in the patient’s personal crisis. Williams points out: “An individual does not get cancer, a family does” (1991, 214). Such a statement highlights the understanding that cancer/illness, like life, is muddled. Lines blur and we must make decisions amidst the ambiguity. And to be respected by and with others involves trusting those around—that is true autonomy.

Many women talk about how they “know” in their bodies, deep within, that something is wrong. Not just in breast cancer patients but in our lives as well, we often know when something is going on in our bodies. This was precisely the case for Megan’s mother. She recalls finding a lump during a self-breast examination and knowing that it was cancer. “Something inside of me just knew.” The biopsy confirmed what she already knew. Likewise, Williams’s mother speaks of knowing that something is wrong before the doctors ever confirm it. “Something is terribly wrong” . . . “I know my body” (Williams 1991, 166). Williams refers to this sense or way of knowing things internally as a “holy intuition,” which she says is the gift of the “Mother” (1991, 241).
We may not be able to express it consciously, but something feels different. For many, the experience of cancer is at the cellular level. We experience cancer deeply in our bodies and can relive that experience in our cells. The needles brought her right back to her traumatic cancer experience. . . . Her body had a cellular memory of those events that continued to wreak havoc with her psyche long after the experience had passed. Cellular memory is a phenomenon where certain experiences can evoke a genuine physical response. For instance, patients have shared with me that as they approach a facility where they once received chemotherapy, nausea will again overwhelm them. It is a true visceral response. (Du Pree 2006, 102)

As well, healing begins at the cellular level. Some women express connections to their mothers and grandmothers at some kind of cellular and genetic level. They “know” what their mothers endured. This knowing is not theoretical, but a kind of physical connection that resides deep within the body. The body-self defines our humanity—from cells to consciousness, from genes to religious impulses.

**GENES AND GENEALOGY**

This is the age of the gene. Several authors struggle with how the new genetic information we receive changes the way we perceive who we are. Medical science and biotechnology need to be reductionistic at certain levels for research to be successful. The danger arises when we treat those basic, fundamental levels as if they were literal statements of human identity. We treat our genes’ function as some kind of new sacred text that reveals who we are as human beings. We chart and map our genetic future, often hoping to predict the future of human identity. Like the characters in the movie *Gattaca*, we hope to live into “the not-so-distant future.”

The fears and hopes about genetics come across strongly in both *Blood Matters* (Gessen 2008) and *Pretty Is What Changes* (Queller 2008). This shows up more with families who carry the BRAC gene. Gessen:

I belong to a generation that grew up believing we were shaped by love, care, or lack of it—or perhaps the number of books on our parents’ bookshelves. But we will go to our graves believing that it is a combination of letters in our genetic code that determines how we get there, and when. Our concept of the stuff we are made of will have undergone fundamental changes. I got a glimpse of that when I was looking around that room at my fellow mutants, and again and again in the process of writing this book, as I looked at myself, my biological daughter and my adopted son. I was transported to a new era, a future that will rest on a different understanding not only of what causes things to go wrong in human beings but of what makes a human being in the first place, and what connects any one of us to any other. (2008, 29)

Genes are our genealogy, but there is more. Family history can be interpreted in new ways. Gessen sees her life story revealed by her genes and a reshaping of the human body as well. “What drove her was not even so
much a fear of death as a fear of cancer as a way of life—her family’s way of life” (2008, 112).

Williams writes about her genealogy in different ways. She draws on this ancestry for healing through its rituals and spiritual connections (1991, 10). Her maternal narratives empowered her to face the fears of cancer. “We spoke of rage. Of women and landscape. How our bodies and the bodies of the earth have been mined” (1991, 10). This ancestry is also deeply connected to her relationship to the land. For Williams, the health and illness of women and the land are linked. Families bear in their cells the trauma of the landscape around them.

**SPIRITUAL STORIES**

Genetic history is spiritually tied to geography and environment. Williams traces her maternal cancers to radiation testing in Utah during the 1940s and 1950s. The shadows of the research at Los Alamos were close to Utah.

I belong to a Clan of One-Breasted Women. My mother, my grandmothers, and six aunts have all had mastectomies. Seven are dead. The two who survive have just completed rounds of chemotherapy and radiation. . . . This is my family history. Most statistics tell us breast cancer is genetic, hereditary, with rising percentages attached to fatty diets, childlessness or becoming pregnant after thirty. What they don’t say is living in Utah may be the greatest hazard of all. (1991, 281)

How wonderful it would be for the future of breast cancer research if we paid more attention to this connection of environment and family history.

The disease of cancer brings the issues of fear and control to the forefront of patients’ and their family’s lives. To cut out the offending organ is an attempt to control the body. To get tested genetically is a way to control the future. But many things cannot be predicted, and the same issues of fear and control rear their heads. Cancer seems uncontrollable and foreign. Williams likens this to the creative processes of evolution.

How can we rethink cancer? It begins slowly and is largely hidden. One cell divides into two; two cells divide into four . . . normal cells are consumed by abnormal ones. Over time, they congeal, consolidate, make themselves known. Call it a mass, call it a tumor. It surfaces and demands our attention. We can surgically remove it. We can shrink it with radiation. We can poison it with drugs. Whatever we choose, though, our own creation. The creation we fear. The cancer process is not unlike the creative process. Ideas emerge slowly, quietly, invisibly at first. They are most often abnormal thoughts, thoughts that disrupt the quotidian, the accustomed. (1991, 42–43)

Williams’s mother, diagnosed with both breast and ovarian cancer, reaches a turning point in her life when she is able to see her cancer as something natural and internal, a product or creation of her own body-self. “It feels good to finally be able to embrace my cancer. . . . For the first time, I feel like moving with it and not resisting what is ahead. Before, I always knew
I had more time, that the disease was outside of myself. This time, I don’t feel that way. The cancer is very much a part of me” (1991, 156). By embracing her cancer, she allows herself to peacefully live within the moment, to love life. “You learn to relinquish. . . . You learn to be an open vessel and let life flow through you. . . . It’s not that I’m giving up . . . I am just going with it. It’s as if I am moving into another channel of life that lets everything in. Suddenly, there is nothing more to fight” (1991, 165).

The uncertainty of illness creates a kind of spiritual angst that is, however, rooted in bodily processes. Williams: “Nothing is familiar to me any more. I just returned home from the hospital, having had a small cyst removed from my right breast. Second time. It was benign. But I suffered the uncertainty of not knowing for days. My scars portend my lineage. I look at Mother and I see myself. Is cancer my path, too?” (1991, 97) Even if the statistics bear out that most breast cancer is not genetically inherited, women fear mammograms and wonder what their future holds. The regularity of health is shattered by a diagnosis of cancer. One is never prepared. Change becomes reality.

This statement rings true for both of us. Meg’s grandmother was recently diagnosed with breast cancer and her mother’s aunt a few months ago. Ann’s mother has finished radiation and started hormonal treatments for breast cancer. We feel a bit ashamed to admit that we cry not just for our mothers and grandmothers but also for ourselves. At some points, we honestly have felt as if we were the ones who had been diagnosed. Considering our family history and genealogy, we can expect to one day be diagnosed with breast cancer. The story of our mother’s, grandmother’s, and great-aunt’s cancer is also our story. We wonder if it’s all in the genes. And yet we know better. Aging, not genes, poses the greatest risk for being diagnosed with breast cancer. So, although Ann’s mother knows that breast cancer runs on the maternal side of the family, her doctors have told her that her age was most likely her greatest risk factor. We are our genes, but we are more than our genes. Our body-selves are not just parts but are whole selves living in a process of relationships. We have realized again and again that cancer, like life itself, is a process of transition and change. We cannot control our future, and that is fearful but also a message of grace. We live in the moment, each day.

A physician friend of ours notes that the way we die is the way we live. Spiritually, the way we handle our cancer is the way we handle crises before cancer.

The first question isn’t, “Why do I have this problem?” it’s “How do I solve this problem?” And the answer is, you’ll solve it the way you solve all of the challenges you confront. You bring a lifetime of experience, skills, and wisdom to breast cancer. Cancer didn’t teach me lessons that changed my life; my life taught me lessons that changed my cancer experience. (Lewis 2008, 5)
Cancer does not define a person. If it does, one’s life before cancer seems unimportant.

We found little in the memoirs that blamed God for the disease. Most women concluded that breast cancer, like many things in life, just happens. Many authors rejected the notion that God was afoot in the world causing illness in people. For some women, particular religious traditions provided sustenance and support. Williams found the most sustenance from her religious inheritance and particularly from the wisdom her mothers had passed on to her.

Healing is an experience of wholeness. This relates to how sexuality and gender are reconstructed in light of breast cancer. If one’s gender and sexuality are tied solely to one’s reproductive organs, the experience of breast cancer can be devastating. From some authors the experience is such. For others, breast cancer gives them an opportunity to reflect on the way sexuality is much more about relationships than body parts. Lewis explains: “Although I never thought about it much until I had a lumpectomy, I realize now that I’m not one of those women who considers her breasts to be the home office of her Womanhood. My femininity doesn’t reside in any one place; it is me, the whole me-ness of me, and can’t be sliced off in pieces” (2008, 98). Healing is wholeness that is knitted together through relationships of self, body, and other. Gender and sexuality are constructed through relationships; they are not objects to be owned. Our gender is constituted not by individual body parts but instead by how we as particular people relate to others and the world around us. This being so, a woman’s femininity need not be lost by a lumpectomy or mastectomy.

Healing comes through communities and through love. Telling stories helps healing. Often healing means a return to the “normal” world out of the tunnel of cancer. Stories also help to demystify the disease and to name fears. In his address “Care and the Elderly” Henri Nouwen speaks about the act of listening to others as a form of compassion: “To listen remains one of our most precious and rewarding forms of ministry. To listen is to become a student of your parishioner. Just as teachers learn their material best by preparing it for presentation to their students, so too troubled parishioners start understanding best their own story when they have to tell it to a receptive listener” (Nouwen 1975, 8). Healing according to Nouwen is bearing witness—listening to and with the pain of others. For what often happens in the treatment phase of breast cancer is that when people bear witness the patient is more receptive to healing. We understand ourselves spiritually through the stories we live and share with others.

Nouwen goes on to say: “Isn’t the interested listener who really wants to know our story one of the greatest gifts in life? When we have a chance to tell our story to someone who cares, we are blessed. Because it is in the listener that we discover that we have a story to tell in the first place” (1975, 8). When we tell our own unique story we contribute to the “mo-
sac of human existence,” highlighting the understanding that cancer is more than a diseased body part. Cancer weaves into our whole life story. When we share it with others we are connected to something larger than ourselves, and we can experience healing and wholeness in the process. As Nouwen notes, listening is more than a sympathetic nodding of the head; rather it is a “very active awareness of the coming together of two lives” (1975, 9). Listening can involve words, gestures, laughter, tears, and touch and is therefore a form of care. When a story is told and received, two lives come together in a healing way.

The way to understand and interpret the disease of cancer, according to Williams, is to see and listen to all the characters involved. The stage upon which Williams sets her story is the land and history of her ancestors. The reader cannot understand the nature of her mother’s ovarian and breast cancer apart from the suffering and dying of the birds at the refuge. Suffering and death as well as joy and life bring the human and nonhuman together in the narrative world. “I think of my family stories—Mother’s in particular—how much I need them now, how much I will need them later. It has been said when an individual dies, whole worlds die with them. The same could be said of each passing whale” (Williams 1991, 175). Williams’s attention to the slow death of the bird refuge is as poignant as the reflection on her mother’s death. The stories need each other. Without each other, the stories make no sense. “I am slowly, painfully discovering that my refuge is not found in my mother, my grandmother, or even the birds of Bear River. My refuge exists in my capacity to love. If I can learn to love death then I can begin to find refuge in change” (1991, 178). The capacity to love and even to love death as a process of life itself is the key that unlocks the heart of Williams’ story.

These memoirs about breast cancer weave a complex tale of science and spirit, life and death, culture and genes. Most of the women learned that this crazy complex mess is precisely where healing and wholeness are found. The disease of breast cancer reveals how our culture, both scientifically and spiritually, can reduce the complex to the simple, the whole to the part. But we have found that there is always more to the story.

CONCLUSION

When sacred texts are interpreted literally they lose their power to function imaginatively in religious communities. When diseases are interpreted literally they lose their power to function as imaginative metaphors that reveal the stories of what it means to be human. As we listen to and read women’s stories of breast cancer, we learn again and again the power of the human story, which is interlocked in, with, and under the intersections of the spiritual and scientific worlds. We realize that disease is about particular people—researchers, health-care providers, spiritual leaders, and, above
all, the individual patients whose lives are changed forever. To fully understand both illness and health we must listen carefully to our body-selves—wholly, from tip to toe. The danger in becoming obsessed with only part of the story, whether that is the diseased part or the cure we seek, is that we lose the person in the mix. Science and religion never were about abstractions as such but always have been about the people who live the disciplines through specific practices.

Breast cancer affects one in eight women. We may be one of them; we may not be. But we will never again take for granted the amazing lives of the women who move boldly and graciously into and through their disease as both a medical and spiritual journey.

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