In the early 1980s, when a woman was diagnosed with breast cancer it felt like a death sentence. At least that was the way I felt, as a 10-year-old, when my mother told me that she had breast cancer. I immediately thought, “My mom is going to die.” After the shock of the initial diagnosis, my mother discussed treatment. She would have a mastectomy, and all of her lymph nodes would be removed. The results of her surgery would set the course for additional treatment.

At the time, hospitals did not allow children in hospital rooms. After the trauma of having her breast removed and recovering from a bad reaction to anesthesia, the only way that my mother could see me, her only child, was to come down to the public lobby in a wheelchair. As I look back now, I am impressed by my mother’s strength, and saddened by the healthcare provider’s lack of understanding. Fortunately, with new developments like family-centered care, a situation like the one my mother faced has become a rarity in today’s hospitals. Now, children are allowed to visit their mothers in their rooms, and we involve families in the care and decisions that are made.

Over the past 20 years, enormous strides have been made in the treatment of breast cancer. Not only is breast cancer no longer a death sentence, but many women are able to have lumpectomies or less radical surgeries. Reconstructive surgeries have improved, and the overall understanding of the physical impact of breast cancer has grown. However, despite these strides, a diagnosis of...
breast cancer still carries with it huge emotional, spiritual, mental, and physical issues. The legal community is now beginning to understand the complexity of these issues, including the legal issues that breast cancer patients face. Because the impact of a breast cancer diagnosis is so personal, the best way to get a glimpse of the issues facing breast cancer patients is to speak to them and hear their stories.

With the background of my personal experience with breast cancer, I decided to interview breast cancer patients to identify three or four recurring themes related to their care and treatment. I anticipated that the patients would face a number of emotional and other issues that they may not realize could have legal implications. Of course, these issues are not isolated to only breast cancer patients, but with my mother’s experience, I felt most familiar with their experiences and am emotionally vested in this specific topic. However, I was not prepared for the wide range of experiences I learned about, and I quickly realized that while there are many common themes for the patients, each individual’s breast cancer journey is unique.

While the patients initially denied having legal issues, when we began to ask more probing questions about their stories we quickly learned that many patients did have issues, but they did not recognize those issues as legal ones. Over the course of several months, we interviewed 29 breast cancer survivors. We ultimately decided to include 13 of the stories we gathered in this article. We feel that the stories we included are representative of a group and we hope that their stories will contribute to legal practitioners’ awareness of the myriad issues that breast cancer patients may face.

If you, as the reader, take nothing else from this article, then I hope you take away this point: The most important gift that you can give breast cancer patients is to truly listen to them. As you will learn from the stories, the mental, financial, emotional, physical and spiritual toll that a diagnosis of breast cancer takes on a person can impact cognitive ability and the ability to apply reason. It can make even the most outspoken and strong individual feel weak and powerless.

As a legal practitioner, the most important thing you can do is listen to the patient’s story. As the story unfolds, you may likely identify problems of which the patient is unaware. The experiences of the patients we interviewed are the best evidence of this.

**The Stories**

**Changing/Ending Careers**
Debra

Debra was a healthy 59-year-old woman. Her biggest worry when she was diagnosed with breast cancer was that it appeared as if her healthcare providers were in no hurry to help her. Debra faced some challenges with her cancer and scheduling her mastectomy because the treating hospital would not schedule her surgery until she talked to a plastic surgeon about breast reconstruction, even though she had emphasized she had no interest in undergoing reconstruction. Also, the side effects of her treatment, especially the effects on memory, caused her to stop working. She felt she could no longer perform at the high level of effort she had prior to her diagnosis because of her lack of energy and the forgetfulness caused by her treatment.

Hannah

Hannah was diagnosed at age 38. One year before her diagnosis, she experienced a separate health issue that caused her to take time off from work. After her diagnosis and treatment for breast cancer, she continued to work, hiding the extent to which the chemotherapy affected her. In fact, she hid the devastating effects of her treatment so well that her employer was unaware of the physically and emotionally taxing nature of her recovery. She ultimately did not discuss taking Family and Medical Leave Act (FMLA) Leave with Human Resources because she felt guilty for taking a leave of absence the previous year. And, although she loved her work and co-workers, she resigned from her position a few months after her treatment ended. Looking back, she often feels that she should have given this decision more consideration.

Susan

Susan was diagnosed with cancer when she was 42. She was unprepared for the significant physical toll that breast cancer took on her body. She took an aggressive approach to her cancer treatment by having a double mastectomy, hysterectomy, and full doses of chemotherapy and radiation. Although she intended to take temporary leave, she left the workplace given the demands of her recovery. Her desire to support her family and reach out to others diagnosed with breast cancer directed her to new working endeavors, blogging and bravely sharing her ongoing journey.

Payment Issues and Navigating Health Insurance

Jane
Janewas diagnosed when she was 67. She faced some issues with health insurance as the treating hospital was unable to bill Medicare as a secondary payor. This delayed treatment and required her to pay out of pocket for treatment that should have been covered by her insurance. Ultimately, it took Jane five years to resolve her health insurance payment issues.

Anna

Anna was diagnosed with breast cancer after an ultrasound was performed due to a lesion found in her routine mammogram. She underwent surgery for a unilateral mastectomy, chemotherapy and radiation and wondered if the cyst found a year earlier during her annual mammogram was misdiagnosed. This led to thoughts of malpractice, but those thoughts evaporated quickly as the physical demands of treatment took precedence in her life. To complicate matters, prior to her diagnosis she had been laid off from her position of 32 years and had purchased insurance through a new healthcare plan. Dealing with the new healthcare plan for her treatments was tedious and costly. Anna was also required to get preauthorizations from her primary care physician prior to having most tests done or getting referrals prior to seeing any specialists. Many tests were not covered by her new insurance at all, quite a change from her employer’s more generous plan. She received unemployment benefits for a period of time and then applied for and received temporary disability. She was then informed that she had exhausted all of her temporary disability benefits and would have to apply for permanent disability, only to learn that her condition is considered temporary¹ and she does not qualify.

Nancy

One of Nancy’s biggest concerns after receiving a breast cancer diagnosis was caring for her teenage daughters. She found it difficult to navigate the health insurance system on top of dealing with such a life-altering health issue. She remembers struggling to understand the distinction between preapproval versus precertification.² Nancy also had concerns about taking FMLA leave and worried whether her employer would really be supportive or if she would be terminated for taking it. Nancy was frustrated when she was denied Social Security benefits for her daughters, who should have been eligible because they were under eighteen and their mother was disabled. With the help of an attorney, Nancy obtained the benefits for her daughters.³

Michelle
Michelle was 62 when she was diagnosed with breast cancer in February 2013. In August 2012 she found a drop of blood in her bra that came from her nipple. She went to her doctor who said it was probably an infection, but to be safe referred her to a surgeon. She underwent an ultrasound and diagnostic mammogram that came back with clean results. In October she found another drop of blood and headed back to the surgeon who proceeded to order an MRI. After a long period of waiting, Michelle finally called back to see when the MRI had been scheduled. She discovered that her insurance had denied coverage for the test. The surgeon appealed and she was finally able to have the MRI in mid-December. The MRI showed benign papilloma. Both attempts at a needle aspiration of the nipple and sonogram guided biopsy failed. She was finally scheduled for a lumpectomy on January 28. After four surgeries and a recurrence, she switched hospitals as she felt she was not being provided the best care possible.

Making the Best of a Tough Situation

Elizabeth

Elizabeth was diagnosed at the age 62. She has always led a very active lifestyle and generally did not allow her diagnosis or treatment to interrupt her way of living. She worried more once the cancer treatment had stopped, as she felt that it ended the proactive approach to fighting cancer. She began making various lifestyle changes to ensure the best chance at having the cancer never return. Although it has been over five years since her treatment ended, she still worries about the cancer returning. On the legal front, she focused on making sure that her estate planning was up to date and all documents (i.e. power of attorney, healthcare power of attorney, etc.) were in order.

Abigail

Abigail survived Hodgkin’s Disease nearly 20 years before receiving a breast cancer diagnosis at age 39. The single mother of two daughters in high school, Abigail felt she had to stay positive for her girls. Abigail had a double mastectomy and was out of work for five weeks after her surgery. Fortunately, the school where she teaches has been extremely supportive, instructing her to remain home if she does not feel well. Abigail was also protected by health insurance coverage of most of her expenses.

Linda
When an individual is diagnosed with breast cancer, even the best made plans are often abruptly derailed. Linda was living in a large city in the south when she was diagnosed. However, because her father had cancer and was declining quickly, she moved to be closer to him. Along with the move came the burden of changing her doctors, moving her chemotherapy treatments, and scheduling surgery at a new hospital. Linda was more concerned with her father and his care and didn’t really have time to think about herself. It was not until her father died that the reality of her own diagnosis hit her. Linda had come to realize that being alone was difficult, but admitting it was even more difficult for someone that is so independent. She reached out for help and was quickly surrounded by an incredible support group. Linda began to shift her focus onto her own treatment, and after a few setbacks due to surgical complications, she made it to recovery.

Becca

In winter 2012, Becca received a call from her primary care doctor with the news of her diagnosis. She was shocked because she did not carry any of the risk factors for cancer: she had no family history of cancer, she does not drink, she does not smoke, she exercises frequently, and she even eats organically. For Becca, the turning point in her medical care came when she found out she did not have the cancer gene. Once she determined that she did not carry the gene, her decision to have a lumpectomy rather than a mastectomy was easier. However, after the surgery, Becca felt pressured by her first oncologist surgeon to undergo chemotherapy. Becca worried that the cognitive side effects of chemotherapy, which include memory loss, could adversely affect her career as an attorney and her relationship with her significant other. After pressing her healthcare provider about whether the chemotherapy was a statistically-supported treatment in cases like hers, the surgeon responded, “oh right, you’re an attorney.” Becca found a new oncologist who reviewed the same test results and did not believe that chemotherapy was necessary. With the assistance of her new doctor and the support of her significant other, Becca decided to have radiation instead of undergoing chemotherapy.

Pamela

Pamela was diagnosed with breast cancer when she was 42. As a single woman, Pamela’s biggest fear was that she would die alone. Upon receiving her diagnosis, she had to quickly hire a lawyer to draft a will and healthcare power of attorney. After receiving chemotherapy, Pamela struggled with symptoms of
chemo brain for three years. Moreover, because she lived alone, Pamela does not remember how she paid her bills during some months of her treatment because her memory problems were so severe.

Not for Women Only

Mike

One of the more unique stories does not come from a woman at all. Rather, it came from a man who was diagnosed with breast cancer at the age of 43. Mike visited his physician three years prior to his diagnosis due to a lump he found. A sonogram suggested it was nothing to worry over. Years later, during a separate medical issue, he asked the lump to be checked again. While he was originally told not to worry because breast cancer does not affect men at nearly the same rate that it affects women, a subsequent mammogram revealed that Mike had stage 1 cancer.

After shopping around for specialists in male breast cancer, Mike decided to stay local for his treatment. He underwent a mastectomy and chemotherapy. In an attempt to have reconstructive surgery, he became infected with methicillin-resistant staphylococcus aureus (MRSA) and endured another reconstruction attempt. Mike had a positive support group surrounding him at work and home. His employer was incredibly supportive of his care, and he was able to maintain a healthy work schedule that facilitated his recovery. However, he found that the majority of breast cancer services and volunteers are aimed primarily toward women. Consequently, Mike felt isolated because it was very difficult to locate peers that could relate to his experience. While Mike didn’t have many legal concerns – he had a power of attorney and a will and was able to take off work as needed – he did bring to light a unique perspective. Mike became very vocal about male as well as female breast cancer, hoping to be an example and help men become more comfortable with the subject.

The Takeaways

Rather than focus on the laws that may affect clients with breast cancer, this article is intended to explore the lives of several individuals with breast cancer to enable attorneys to best serve clients by understanding where they might be coming from, physically, emotionally, and mentally. There were many common themes in the stories: the patients wanted to be heard and to discuss the effects of chemotherapy, and often didn’t recognize
the legal issues that they were facing. However, each story is distinctive. It is only by recognizing that every person with breast cancer is unique and has an individual story to share that attorneys may begin to effectively counsel clients with breast cancer. We hope that by sharing the stories of these breast cancer patients, we will encourage attorneys to think about the ways they can better interact with clients who have been touched by this terrible disease.

**We learned that legal issues are diverse**

A few legal concerns to consider are:

- Health Insurance Coverage and Paying Medical Bills
- Employment/Leave of Absence Issues
- Malpractice
- End of Life Care
- Financial Planning
- Comorbidities
- Disability/Americans with Disability Act (ADA) Rights

**We learned what helped patients be successful**

From the stories we gathered, we learned that the people who were most successful at enduring and battling breast cancer had strong support systems, whether through their families, workplaces, churches, or other community support.

Those with children particularly emphasized a desire to fight the disease for their children’s benefit. As attorneys, we must recognize the value of networks and support systems for our clients who have been touched by breast cancer, and we should encourage or suggest ways for clients who do not currently have support systems to find and cultivate them. Further, we should be aware that clients with breast cancer who are parents (or caregiver to another, such as their own parent) may minimize their own needs because of their perceived notions of the needs of others.

On the other hand, the people who seemed to struggle the most during their battle with breast cancer were those who did not have strong support networks. Those who were single, or were the sole providers for their families and had to continue working throughout their treatment, or even those who wanted to continue working during their treatment but could not because of their diagnosis, had the toughest time during treatment. Some of them were fearful to tell their employers about their diagnosis or treatment. We must understand our clients’ fears and help them navigate those fears when we educate them about their legal
We should be slow to accept a client’s denial of having any legal, employment, or personal issues as a result of a breast cancer diagnosis. It may be that the client is belittling his or her own needs or is unaware of underlying legal needs. For instance, a few interviewees did not comprehend their own legal needs until we asked about their leave of absence from work or if they had prepared end of life documents, such as a will or power of attorney. Many did not realize their legal rights under the FMLA or ADA. We should ask probing questions to encourage clients to evaluate their needs so that we can best counsel them.

No matter how intelligent or in control patients may seem, they should consider having someone they trust with them at all doctors’ appointments to take notes. Some patients we interviewed found it impossible to absorb all of the information provided during appointments while simultaneously dealing with the emotional and physical toll of their diagnosis. This holds true for those with large support groups as well as those with only a few close confidants.

Attorneys counseling clients with breast cancer should also be aware of the phenomenon known as “chemo brain.” Radiation and chemotherapy have been linked to a mental fog that can affect patients before, during and after treatment.¹ These mental changes can last for a short time, or may affect patients for years, but regardless of their duration, they can be debilitating and affect patients’ abilities to return to school, work, or previously-enjoyed social activities.² Chemo brain may affect not only how your client communicates with you, but also his/her employer and others during the recovery process.

**We learned the importance of psychological well-being**

Attorneys should be particularly aware of their clients’ psychological well-being when counseling clients, especially males who have been diagnosed with breast cancer. “Because most people think of breast cancer as something that only affects women, men who are diagnosed may feel embarrassed or isolated.”³ Even though it is rare, male breast cancer exists, so it is important to keep an open mind when dealing with any client, male or female. Mike’s story demonstrates that lawyers should avoid stereotyping and must recognize that everyone’s story is individual and unique.

**We learned about the concerns of male breast cancer patients**
Approximately one percent of all breast cancer in the United States occurs in men. In 2017, the American Cancer Society estimates that there will be approximately 2,470 new cases of invasive breast cancer in men and that about 460 men will die from the disease. On average, men are about 68 years old when diagnosed with breast cancer.

We learned about the concerns of breast cancer in older adults

Across gender lines, old age is the most common risk factor for breast cancer. Thus, attorneys counseling clients with breast cancer should remember to ask their clients about legal issues that commonly impact older adults, including end of life planning and related issues.

We learned that there is no “one size fits all” in patient needs

The most important thing we have learned about counseling clients with breast cancer is that nothing in their experience is “one size fits all,” as the clients’ legal needs may be as diverse as their healthcare needs. Of course, some breast cancer patients have few or no legal issues because they have excellent health insurance, a supportive and understanding employer, and a strong network that assists them. For those patients, often typical legal issues that a patient might face have either never arisen or have already been addressed. However, others have numerous and compounding issues, like those who are unable to continue employment and lose their health insurance.

As one of our interviewees, Michelle, suggested, the legal profession could further support breast cancer patients by providing information about their rights and how to access low-cost legal services. Michelle feels that there should be a pamphlet given to every new patient in oncology centers that provides information, phone numbers, website addresses, etc. about how to access legal services (especially low cost services). The pamphlet should include information on the Health Insurance Portability and Accountability Act (HIPAA); patient’s rights, such as what constitutes Protected Health Information (PHI) and what a patient’s rights are in relation to their PHI; the ADA; guardianship and custody; separation and divorce; wills; trusts; and bankruptcy. It should also address how to obtain Social Security Disability benefits; a temporary handicap placard; healthcare directives; powers of attorney (including healthcare); and insurance advocates and assistance. I couldn’t agree with her more.
Some hospitals, such as Wake Forest University Baptist Medical Center currently offer notary services to patients who need important documents authorized. Other hospitals and healthcare providers should consider offering similar services to breast cancer patients who need them.

**What else can attorneys do to support breast cancer patients?**

As a breast cancer diagnosis is a life-altering event, attorneys who are counseling clients with breast cancer need to do more than provide legal advice. They should listen closely to their clients’ stories, taking care to: (1) be open while remaining sensitive; (2) treat them as a person rather than a cancer patient; (3) do not make it seem like the cancer and the recovery is the only thing that defines the client; and (4) get to know the client’s family and network if necessary. Attorneys should ask probing questions. Do not ignore their cancer diagnosis. Educate yourself about your client’s diagnosis, understand the client’s situation, express an interest in understanding and helping clients through their unique recovery process, and ask about their morale. Encourage your client to be an advocate for herself/himself with or without a support system. Also encourage them to enlist your assistance early in the process. This is especially important if a patient’s cognitive skills begin to decline and important decisions need to be addressed.

One interviewee advised that attorneys be sympathetic and consider providing a checklist to clients who have recently been diagnosed with breast cancer to make sure they are weighing the proper considerations. She recalls that while she dealt with the complexities of her healthcare, she did not think about planning for a will or other legal concerns.

The ABA Breast Cancer Initiatives Interest Group (IG) has been developed to provide legal advocacy training to lawyers, provide resources for lawyers and consumers dealing with breast cancer, and educating women, attorneys and policymakers on the range of legal issues impacting women’s health. Membership in the IG is free to all ABA Members. If you are interested in joining, please contact Carol Simmons, Associate Director, at carol.simmons@americanbar.org.

Finally, not only is each story different, but so may be each individual as he/she deals with breast cancer. The attorney should be prepared to effectively counsel a patient or survivor who acts wildly different on a day to day basis and understand that the erratic nature of his/her behavior is likely due to treatment and
recovery. Each patient or survivor will go through different emotional, physical, and spiritual challenges. It is our job as attorneys to recognize, understand, and adapt to those challenges to best serve our clients.

*Names have been changed to protect the privacy of interviewees.*

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1. *Program Operations Manual System*, Social Security Administration, https://secure.ssa.gov/poms.nsf/lnx/0423022910 (last visited July 25, 2017) (According to the Social Security Administration (SSA), an individual must have inoperable or unresectable breast cancer and have a poor prognosis to be considered for full disability benefits through the SSA. SSA does provide a caveat which allows for adjudicators discretion that states “Adjudicators may, at their discretion, use the Medical Evidence of Record or Listings suggested to evaluate the claim. However, the decision to allow or deny the claim rests with the adjudicator.”)

2. Jason Gillikin, *What is the Difference Between Preauthorization & Pre-Certification Insurance?*, eHow, http://www.ehow.com/about_6436782_difference-preauthorization-pre-certification-insurance_.html (last visited July 25, 2017). (“A pre-certification requirement means that a payer must review the medical necessity of a proposed service and provide a certification number before a claim will be
“paid.” Whereas, “a pre-authorization requirement means that the insurance company will not pay for a service unless the provider . . . gets permission to provide the service.”


5 Chemo Brain, supra note 4.

6 Ibid.


8 Ibid.


10 Ibid.

11 Breast Cancer, supra note 7.