

MEDICAL CONSUMER BEHAVIOR? THE BREAST CANCER STORY

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Angelina Jolie's revelation that she had undergone a preventive double mastectomy triggered a discussion between Ethan and his longtime friend Victoria. Ethan's wife, Teresa, had been told a year ago there was a good possibility she had breast cancer. After a month of tests and appointments, it was discovered that, in fact, Teresa did not have any type of cancer. Ethan and Victoria's conversation led to some comparisons between consumer's reactions to poor medical customer service compared to other situations. What started as research for curiosity's sake became less academic when Ethan and Victoria received the opportunity to bid on a customer service project for a regional hospital system. The case has medical ethics overtones, with emphasis on the marketing aspects of consumer behavior and customer service.

INTRODUCTION

"Honey, we need to talk." Teresa's voice was at the edge of tears. And to make matters worse, the call came in around midnight. As Ethan recalled that fateful exchange that took place a year ago, he remembered it as clearly as if it were yesterday. Ethan continued the story, "Calls this time of night are always bad news. My first thoughts were that something must be wrong with one of the children – but it wasn't the children."

Teresa had just received a letter from a clinic that performed her yearly breast exam. Her mammogram results showed some problems and a biopsy was scheduled immediately. Teresa worked for a local clinic which recently purchased a mammogram machine. They offered their employees the opportunity to have a free mammogram. While there was no one on-site to read the results, the clinic contracted with an outside lab which agreed to read all scans and report the results to the clinic. The clinic would then follow up with the patient.

Ethan continued, "I was 300 miles away, and there isn't a lot of comforting you can do over the phone. My heart was in my throat". "I'm sure it's just precautionary" I replied, trying to calm both of us. Teresa's voice quivered as she half-heartedly

agreed with Ethan. While he obviously could not see her, he knew that tears were streaming down her face.

Neither Ethan nor Teresa let on that they were both scared to death. The prospect of breast cancer was suddenly thrust upon them and this was a situation that neither of them had ever even thought about. Teresa was pushing 50 and had always taken pride in the way she cared for herself, never overweight or underdressed and always mindful of her health. While she never said it outright, Ethan knew she was concerned about what she viewed as disfigurement if she needed a mastectomy. However, the more imminent concern was cancer.

Teresa's aunt had a double mastectomy about four years earlier and it devastated her. Ethan's sister had a mastectomy some ten years ago and the treatments seemed more of a health hazard than the cancer itself. That night there were more emotional phone discussions of both these cases. Teresa had already scheduled a biopsy but the earliest appointment she could get was two weeks away. Ethan left the next morning heading for home and had seven hours in the car to determine how he should handle the situation.

As Ethan recalled, "All my careful planning was useless. I wanted her to know that the surgery wouldn't affect how I felt about her, so the first thing I told her was how unimportant her physical appearance was to me. Oops! It was the wrong thing to say – although I don't know that there was any right thing to say. First she blew up at me and then she withdrew and didn't want to talk to me at all."

The two weeks leading up to the biopsy were an emotional rollercoaster. Results came back with the need to follow up with another biopsy. Needless to say, Teresa was devastated. Waiting for the second set of results, the couple researched cancer specialists in area. They found a doctor that they trusted and had the scans sent to her. The earliest possible appointment available was more than a month away. During that time the couple reviewed every article and alternative they could find.

When the appointment time came, Ethan and Teresa naturally went together. The doctor told them that while there was some calcification in the breasts, there was no need for another biopsy. It was typical for there to be some calcification in a woman's breast at this age. In other words, there was nothing abnormal or unusual in her scan. While this was a great relief and wonderful news, the couple had a month of agony based on the independent lab readings. Questioning why and how this could happen, they discovered the independent contractor was sending every scan that showed any calcification back with the follow-up biopsy recommendation. They also learned this practice would remove any liability issues for the lab once they recommended a follow-up.

It was now late spring of 2013. Angelina Jolie had just announced that she had had a double mastectomy as she was at high risk for cancer. The public debate about the pros and cons of such surgery reminded Ethan of his wife's scare and he shared the story with his colleague, Victoria.

Victoria replied, "I'm so sorry for the experience you and your wife went through. I never faced this particular situation, but in coping with some eldercare issues a few years back, there were similar problems. Dad had Alzheimer's and there were waiting lists for so many things in his care, contradictory information on his care, expenses for procedures we had no knowledge he was getting, and what appeared to us to be borderline inhumane treatment. Since this was the first time we faced so many of the situations, we were always a bit off-balance trying to understand if this was normal and acceptable or what". She continued, "If we took the situation out of healthcare and put it in a different area, we'd react much differently."

Ethan responded, "Yeah, like if I take my car for an oil change and the attendant tells me there may be a serious problem with my car and refers me to a local mechanic. I call the mechanic and he says he'll look at it a month from now. I go find a different mechanic."

"Or if a storm does damage to your roof, you don't sit around a month hoping it doesn't rain because that's when your insurance recommended roofer can do it," Victoria offered.

Ethan and Victoria were both tenured business professors at mid-size, private university in the Mid-West. They both did industry consulting, with Ethan focusing on healthcare information technology and Victoria's area found in small business and marketing. They had collaborated on several projects in the past where their joint expertise was needed. They found that their respective strengths and weaknesses complemented each other and they were interested in finding additional joint projects. Although there wasn't a client involved, they decided that this was a problem they wished to examine. They decided to keep the focus narrow and concentrate on breast cancer.

BREAST CANCER

The Website www.breastcancer.org provided useful statistics on breast cancer in the United States:

- About 1 in 8 U.S. women (just under 12%) will develop invasive breast cancer over the course of her lifetime.
- In 2011, an estimated 230,480 new cases of invasive breast cancer were expected to be diagnosed in women in the U.S., along with 57,650 new cases of non-invasive (in situ) breast cancer.
- About 2,140 new cases of invasive breast cancer were expected to be diagnosed in men in 2011. A man's lifetime risk of breast cancer is about 1 in 1,000.
- From 1999 to 2005, breast cancer incidence rates in the U.S. decreased by about 2% per year. The decrease was seen only in women aged 50 and older. One theory is that this decrease was partially due to the reduced use of hormone replacement therapy (HRT) by women after the results of a large study called the Women's Health Initiative were published in 2002. These results suggested a connection between HRT and increased breast cancer risk.
- About 39,520 women in the U.S. were expected to die in 2011 from breast cancer, though death rates have been decreasing since 1990 — especially in women under 50. These decreases are thought to be the result of treatment advances, earlier detection through screening, and increased awareness.
- For women in the U.S., breast cancer death rates are higher than those for any other cancer, besides lung cancer.
- Besides skin cancer, breast cancer is the most commonly diagnosed cancer among American women. Just under 30% of cancers in women are breast cancers.
- White women are slightly more likely to develop breast cancer than African-American women. However, in women under 45, breast cancer is more common in African-American women than white women. Overall, African-American women are more likely to die of breast cancer. Asian, Hispanic, and Native-American women have a lower risk of developing and dying from breast cancer.
- In 2011, there were more than 2.6 million breast cancer survivors in the US.
- A woman's risk of breast cancer approximately doubles if she has a first-degree relative (mother, sister, daughter) who has been diagnosed with breast cancer. About 15% of women who get breast cancer have a family member diagnosed with it.
- About 5-10% of breast cancers can be linked to gene mutations (abnormal changes) inherited from one's mother or father. Mutations of the BRCA1 and BRCA2 genes are the most common. Women with these mutations have up to an 80% risk of developing breast cancer during their lifetime, and they

are more likely to be diagnosed at a younger age (before menopause). An increased ovarian cancer risk is also associated with these genetic mutations.

- In men, about 1 in 10 breast cancers are believed to be due to BRCA2 mutations, and even fewer cases to BRCA1 mutations.
- About 85% of breast cancers occur in women who have no family history of breast cancer. These occur due to genetic mutations that happen as a result of the aging process and life in general, rather than inherited mutations.
- The most significant risk factors for breast cancer are gender (being a woman) and age (growing older).
- As of Jan. 1, 2009, there were about 2,747,459 women alive in the United States with a history of breast cancer. This includes women being treated and women who are disease-free.

(http://www.breastcancer.org/symptoms/understand_bc/statistics)

OTHER BREAST CANCER PATIENTS' EXPERIENCES

Almost immediately, Ethan and Victoria discovered two Websites – www.breastcancer.org and www.healingwell.com – which had online forums for those dealing with breast cancer. The forums had moderators who eliminated any obscene, libelous or questionable postings, and referred people to places where their questions could be answered. This allowed breast cancer patients, survivors and families the opportunity to discuss any topics they wanted. The forums provided a good place for breast cancer patients to gain information, but also to vent. Many posts were along the line of “Is it normal . . .?” From scanning these posts, a number of recurring problems showed up:

Waiting: The entire process seemed full of waiting. A questionable mammogram was nearly always followed by a second, follow-up mammogram or ultrasound. (Teresa's case was unusual, that is, going from the first mammogram to a biopsy.) Getting this scheduled took three or four weeks – or more. Getting test results might take another two to three weeks. If the second test was still of concern, usually a biopsy needed to be done and this, again took about a month to schedule. Again, results might be two or more weeks away. An inconclusive biopsy might mean having to have another biopsy, or a different type of biopsy done. If biopsy results showed cancer, there was a visit to be scheduled with an oncologist and treatment options to be considered. Patients generally needed some time to sort through options, and make decisions both about the treatment and about who to tell and how to get necessary support systems in place.

After all of this, treatment will be scheduled. Chemotherapy and radiation regimes usually run three or four months and often require some preparation – patient

education, evaluation of other medical conditions, insertion of ports and other requirements. Chemotherapy and radiation are followed with an assessment – another wait to get tests done and then to get the results. If the assessment raised any concerns, a decision would be made to do another round or try something else. Surgery might take six weeks to schedule, but was often followed up with chemotherapy, radiation or both. However, if a cancer was considered aggressive or later stage, surgery was often in a matter of days.

Under “best” circumstances, from the time of getting the results of the first mammogram to the start of treatment is often four months. Additional biopsies and other testing may add to this time line. If a patient had additional health concerns, time could be lost getting them healthy enough for treatment. Many patients sought second opinions – and usually not simultaneously with the first processes as Ethan and Teresa did. Medical professionals do take vacations, get sick, and have babies or others events that take them from their jobs, delaying normal times as there is often no one to take over in their absence except for emergencies.

This was a major complaint on the forums. Breastcancer.org’s forum even had a “Waiting for results” forum with over 38,000 posts when Victoria and Ethan found it! Many of those responding urged their fellow patients to be more proactive and to call frequently rather than worry, but many of the posters were concerned about being a pest or rocking the boat.

Interestingly, some of the voices on the forums were from the United Kingdom, Canada and Australia as well. The surgery wait times are much longer unless the cancer is considered high risk. Three to six months waits were frequently reported and 2 to 5 years if the surgery is considered preventive (e.g., like Angelina Jolie’s).

Delayed responses: Results from various tests and procedures were often promised on a certain date, but frequently took longer than reported. People on the forums considered themselves lucky to find out results a day or two after they were promised and waits of up to a month past the promised date showed up over and over. A number of patients called in and comments from the medical offices ranged were varied:

- “You shouldn’t have been told that; we never have results that quickly.”
- “The results should have been here by now; I’ll have to see if I can find out where they are.” (This seemed to be rarely followed by a call back.)
- “Yes, the reports have been back for a week, but the doctor hasn’t had time to look at them.”
- “The doctor is out and he/she’s the only one who can talk to you about them.” (It seemed that medical staff would bend this rule if the doctor

was going to be out several days and the results were good. Patients were told, “I’m not the doctor, but to me the results look okay.”)

- “The doctor would prefer to discuss the results in person. I was going to call you today to schedule a follow-up appointment.”

These reported delays were partially supported by research:

One of the most surprising findings, researchers said, was how long many women had to wait before receiving their results. While the average wait time was 2.5 days, many women had to wait five days or longer. By the fifth day, 37 women learned their biopsy was benign, 16 learned they had cancer and 73 still did not have a result, according to the report, which appeared in the medical journal *Radiology*. Most of the women who did not have a diagnosis had not received any information or explanation for the delay. (Parker-Pope, *New York Times*, 2/25 <http://www.medicalnewstoday.com/releases/140350.php>).

Additionally, research also shows the stress that women experience with these delays:

Harvard researchers tracked 126 women who were undergoing breast biopsy, monitoring their levels of the stress hormone cortisol while they waited. Women who were still uncertain about their diagnosis had abnormal cortisol levels that were “essentially indistinguishable” from the cortisol profiles of the women who were told they had cancer. And women without a diagnosis had significantly worse cortisol profiles compared to women who had received benign test results. (Parker-Pope, *New York Times*, 2/25 <http://www.medicalnewstoday.com/releases/140350.php>).

Internal delays: Waiting times in doctors’ offices for mammograms and ultrasounds and for chemotherapy and radiation treatments were problematic for many patients. Not only did patients have to wait sometimes up to three or four hours to get past the front desk, but patients now had to wait on: nurse, the doctor, after undressing, and then finally waiting for the actual mammogram. Patients reported extensive stays in a recovery room after surgery as there were no rooms available.

Procedural difficulties: Waiting rooms, treatment centers, doctor’s offices, mammography rooms, and other areas were often cooled to uncomfortable temperatures, particularly considering that patients are often partially clothed for many procedures. Patients might also have to wait in hallways or other semi-public areas.

Procedures were not always fully explained. For example, a patient would not be warned about claustrophobia in an MRI. They would not know the time some procedures would take or what pain to expect. They would not know of certain things they could do in advance to alleviate pain or other side effects. If they felt discomfort or even intense pain, they assumed it was normal and would not notify the staff.

Doctors: Comments on the forums showed that patients either loved or hated their doctors. However, for every report of a hated doctor there were dozens of reports of great doctors. The characteristics of the preferred doctors (and other medical staff) included being patient, treating them as a person and not a diagnosis, giving them options and the information to make an informed decision, taking time with them, common courtesies (such as not assuming a first name relationship), simplifying medical jargon and making sure they were understood. One of the top characteristics was treating the whole patient and not just the breast cancer. In this last case, information was clear concerning support groups, family assistance, day-to-day living assistance, coping with the emotional toll of breast cancer, and options post-surgery such as reconstruction.

The “hated” doctors tended to be in a hurry, curt or even rude, talked way above the patient’s knowledge, and presented “treatment ultimatums” without options. Any questions for more information were brushed off with a pamphlet to take home or less. For these sorts of postings, the more experienced breast cancer patients or the survivors would suggest changing doctors, although the original posters would express reluctance to do so. The forums did not discuss the most egregious types of problems, probably for slander/libel reasons although there were “contact me privately” messages. There were a few references to “seriously unprofessional behavior,” but no specifics. In these cases, patients either had or were in the process of changing doctors and considering further action.

Treating breast cancer like any other disease: While many of the above complaints may be common to many diagnoses, breast cancer seemed to have a psychological effect that was different from other diseases. Breasts are associated with femininity. Some women ignore self-examinations, forego mammograms, and delay treatments when breast cancer is found because of fears of losing their femininity.

Heart disease is still the number one killer of women. Yet, when asked, many women will tell you that developing breast cancer scares them more. Why? Part of it is emotional. Part of it is physical. Women's breasts are more than just a part of their bodies. Breasts are a symbol of sexuality,

motherhood and femininity to women. (<http://voices.yahoo.com/things-help-prevent-breast-cancer-91175.html?cat=5>)

There are several recent newspaper articles, academic papers, and other work examining some of these issues. Campaigns such as the Susan G. Komen's pink ribbon received some of the blame since pink equals girl/women and appears to tie breast cancer and femininity together. Another major organization criticized was the Savethetatas organization with their myriad of products sporting slogans such as "I love boobies," "Grope for a cause," "Save a life, grope your wife," "If you don't check them, I will," "Feel your boobies," and, of course, "Save the tatas." Many ads tended to objectify women (think models in bikinis) and the focus was on saving a body part and not a life.

Women having received mastectomies, however, reported that any fears of less femininity were mostly unfounded. Yes, some had husbands or boyfriends that felt differently, but the majority found that it was not as important as they had felt it might be. Regardless, this was an obstacle that was not always considered by medical professionals, with some doctors who tended to regard a mastectomy as not much different than the removal of a bad appendix.

RIGHT PLACE, RIGHT TIME?

As Victoria and Ethan continued their research, the local newspaper reported that patient satisfaction scores at a regional hospital group were dropping. Ethan had scheduled a meeting to see if this might be a good consulting project for them. "I know that we've been looking at only breast cancer, but I suspect their other patients are seeing some of these same problems. I think we can put together a bang-up presentation and get a chance at helping them out."

"I'd sure like to have an opportunity to work with them," Victoria replied, "but we still have some work to do before we present. We've gathered a lot of facts, but we have to understand what they mean. Why do breast cancer 'customers' feel the way they do about the whole process? How do they react to these customer service failures and why? If we can answer these and use this information in our presentation, we might have a real chance of getting this contract."