

Changes in Patients' and Caregivers' Lives, Pre- and Post-Treatment

You've probably picked up this essay because cancer affects you in some way. You're either a patient, a survivor, a caregiver, or a researcher. I'll begin with this: I'm no scientist or expert on cancer. I'm someone who has also been affected by it.

When I was 15, my mother was diagnosed with cancer. When she first told me, I had no idea what that meant or entailed. I did not realize that meant surgeries, therapies, hundreds of doctor appointments, changing her diet, changing her exercise and daily schedule, and more. I only understood the basic biology from my 8th grade biology class: this meant that there is an abnormal growth of a tumor resulting from the uncontrolled division of abnormal cells in her body.

After my mother told me about her cancer, I was affected and so was my brother. We were constantly worried and anxious, we were not as social, we felt lonely and like no one understood us. I then realized that cancer had a psychological impact on me, but questioned why. I was not the patient, I was not directly affected by this cancer – it was not inside of me killing me. So, I can't complain, right? Wrong. Everyone is affected by cancer. Not only would my mother be affected emotionally, but so would my father, my grandmother, and me and my brother. Thus, I wanted to research the psychological side of cancer.

From the many resources I've used and researched, I found that there are critical stages that specifically represent a timeline of when something specifically will affect us. This paper will describe what the psychological side of cancer generally is, as well as the stages of diagnosis, treatment, coping, post-treatment, and then how family and friends are affected. The research articles and studies that I cite in this paper look at the psychological impact on the patient specifically, but I also wanted to focus on family and friends because they are affected as well.

When people first hear the news of their diagnosis or their loved one's diagnosis, they are completely overwhelmed, scared, and uncertain. They question their life, how they will make it through and fight off cancer, and if it is even worth it to do so. Every way of coping is unique, because every individual and patient has unique characteristics when dealing with adversity. Their personality and sets of beliefs and values shape the way people view the world and motivate themselves to fight adversity. There are two major aspects of the human side of cancer: the psychological effect on people and families, and emotions and behaviors that may influence the cancer journey. The "human side" of cancer encapsulates the psychological, social, existential, and spiritual aspects of an individual.

My mother waited to tell me about her diagnosis about a month after she found out because she wanted to protect me and my brother from the psychological effect because we were in school. She found out in November, and told us on December 22nd after we had finished our finals and my brother finished applying to colleges. When she first told me, I immediately thought back to all of the images I had seen in the media -- lots of doctors appointments, loss of hair, and eventually death. I thought cancer is a death sentence. She immediately told me not to look anything up because Google will unnecessarily scare me, so that is what I made sure not to do. I had to be by myself for a bit and completely register that my mother has cancer, and she would need surgery and possibly further treatment, and that I may not even have her by my side

in the next few months. I realized that I had just turned 15, and she may not even be around for my next birthday.

The diagnosis of cancer generally represents the moment of transformation from certainty of your life to uncertainty about the future. Patients and families must grow accustomed to the idea that they cannot have an expectation of continued life and health. Some patients who have experienced their own loved one have cancer see warning signs in themselves and delay going to the doctor because they think the problem will go away; this problem is very dangerous because the problem could rapidly worsen by avoiding addressing the issue. After my mother was finished with her treatment, she confided in me and told me that she also regretted having to go through the cancer treatments because her quality of life after surgery wished she hadn't gone through the treatment because her quality of life after the surgery was worse than before. She also regretted having to go through the cancer treatments because her cancer ended up being benign. Some patients think that the period after diagnosis and before the start of treatment is the most anxious and worse time of the illness because individuals are faced with the bad news and with anxiety but have not yet planned to fight the disease and are constantly thinking that they might die. After being diagnosed, patients wonder if cancer even exists in their body because they don't feel it, they blame the system and wonder if the doctor mixed up their results with another patient's, and they begin to question why they got the cancer. There are ultimately three phases after being diagnosed. First, there is denial and disbelief to the point where the patient cannot believe that this is happening and someone must have mixed up the results. Second, there is the turmoil phase where the patient no longer can deny the cancer and feel restlessness, fearfulness, hopelessness, and helplessness. During this phase, the patient is expected to make treatment decisions, which is very difficult as they are still coping. The third stage begins when treatment does, and the patient finally feels some motivation for doing something about the cancer and fighting. Research indicates that this stage is when people differ in handling the adversity, but those who fight it head-on through researching and finding the best doctor and treatment for themselves is best. The key through the diagnosis phase is to not let the patient become paralyzed into inaction and inability to seek treatment to the point where their condition deteriorates.

A study in the psychooncology journal examined levels of depression and anxiety in diagnosed patients and their adult relatives. The researchers also identified other variables that could affect depression and anxiety as family functioning and the illness' characteristics. The results indicated that families who acted upon and expressed their feelings openly meant that the patient and relatives had lower levels of depression. The illness' characteristics only influenced the patient's depression and anxiety but their not relatives'. Thus, the environment around the patient is essentially crucial for both the patient and the family. If there is a supportive environment, then there are lower levels of depression and anxiety after the diagnosis. This result can apply to the real world and illustrate to doctors that when they diagnose patients they should emphasize to the patient and caregiver that the environment needs to be family-focused.

When my mother finally started her treatment with her 14 hour surgery, I definitely felt relieved. As I was young, I did not understand or comprehend the risk factors of a 14-hour surgery and that they may not get all of the cancer, but I didn't care. I was very optimistic, thinking that once she goes through the surgery, she will be fine and everything will be back to normal. I also knew that if the cancer had been malignant, then the sooner she fought it, the more it would be contained, and the more chances of survival. So, her waiting three months after her

diagnosis to even start surgery really bothered me and scared me. In terms of coping, my positivity towards the situation and support for anything my mother needed was as much as I could do as a 15-year old and definitely helped as much as it could towards adjusting to my mother having cancer.

Scientific studies have shown that relief comes when treatment begins as the patient feels like they are doing everything in their power to fight the cancer. Before treatment begins, patients feel lost and like they are driving through a dark tunnel with a blindfold on. Not only are they scared because they are scared of the unknown, but all the information that they do have scares them even more – like horror stories they have heard from other treatments. There are certain aspects that make coping easier – being optimistic, not feeling helpless, facing challenges head-on, not becoming overly stressed and anxious when faced with challenges. Besides the internal state of mind of patients, having a caring, supportive medical team as well as support from family and friends is crucial; also, knowing all the information about treatments and all options. In contrast, characteristics that hinder coping would be patients feeling pessimistic, nervous, distressed, reluctant to face the situation, feeling hopeless and lost, and not having a supportive environment. No matter what type of personality patients have, because everyone is unique, those who have characteristics that tend to hinder the coping process should be provided with special attention in terms of support to compensate and motivate these individuals to fight their cancer. Ultimately, a mindset that has been shown to be helpful across many individuals is taking everything one day at a time so the patient does not get completely overwhelmed, making it harder and even more difficult to deal with the illness.

There are many myths to cancer that affect the coping process, and the book: *The Human Side of Cancer* by Jimmie Holland, a psychiatrist who has specialized in cancer patients, outlines these very well. She recommends to not believe that cancer ultimately is a death sentence, that you brought the cancer upon yourself, suffer in silence, or feel too embarrassed and weak to ask for help or extra counseling. She emphasizes to do the following: rely on coping measures that help you solve everyday crises, cope one day at a time, seek control over your fears, and find healthcare professionals that respect you as individuals and spend as much time as necessary answering your questions.

A scientific study from the *Journal of Human Stress* found that patients who make use of strategies to cope with cancer feel less distress, have less symptoms of depression, OCD, and overall distress during treatment. In contrast, patients who did not use coping measures were actually found to have increased levels of distress.

After my mother's surgery, I did not realize to what extent her body had changed. She had a double mastectomy, and as she tried telling me as little as possible because she did not want to scare me, I did not realize how much coping she must have gone through and is still going through today. I clearly remember the month after her surgery how hard it was for her to do basic functions like even walking. My grandmother stayed for a few months, and for the month after her surgery had to clean or switch a drain out everyday. She helped my mother shower, eat, walk, sit, and more. Little did I realize that my mother felt like she was missing out in her old life of waking up early, driving me to school, going to work or cleaning the house, and cooking dinner for us. I didn't realize that she was thinking the entire time whether or not she would be better to even make it to my brother's graduation and sit through that ceremony. I also did not realize that my mother was waiting on finding out if she needed more chemotherapy or radiation until I found her crying one day. For two whole weeks after her surgery, she was just

waiting on more results: did she beat the cancer or would she have to fight even harder and withstand strong treatment that may not even be for fighting off the cancer because it may have spread to other parts of her body?

Ultimately, there are many side effects of treatments, and changes in emotions and mood are part of that. The patients can also feel like they are not themselves anymore because they may be losing hair, or have lost a body part.

The side effects of surgery are scary – patients are literally putting their life into another person's hands. Before the surgery, the patient can be filled with anticipation. Some patients are scared of anesthesia and being put to sleep because they will not be aware of what is going on in their body or they are scared that they never will wake up. Some fear the operation in and of itself because they may lose normal body parts or functions. After the surgery, many patients suffer from PTSD because of these painful memories. Some may be scared of the pain they will experience after surgery and fear they may not be able to handle it. It's a huge transition to go home after the surgery is over and the patient is cleared to do so without being under constant observation, and that can be a relief or scary. Those that are scared may feel bothered because their family will witness a new side of them – someone who needs help, support, and constant care.

Chemotherapy has many side effects as well, and many psychological effects because of its bad reputation from earlier days. Because of this bad reputation, many patients who must seek chemotherapy fear the side effects themselves. With today's medicine, chemotherapy has rapidly evolved and there is medication that can often help minimize those side effects. Others have trouble wrapping their minds around the fact that the therapy is killing cancer cells but also harms the healthy and normal cells. Medically speaking, there are some worrisome side effects, like the lowering white or red blood cell count that can lead to infections or anemia respectively. Mood swings can occur as a side effect of chemotherapy, and patients have trouble with this because they are not in control over their own emotions, and have unexpected highs and lows of emotions. Patients can feel wired all the time, being more frustrated and annoyed than usual. They also often have difficulty concentrating and remembering things, meaning that patients are taken away from their daily lives of working. Being away from their normal lives and being unable to even do what they could before is psychologically taxing on the patient. Patients also can be fatigued because of the drugs, and some find it difficult to think positively and be optimistic.

A scientific study from the Journal of Pain and Symptom Management found ways that were proven to be effective in reducing distress from chemotherapy and have had a positive influence. Coping preparation before chemotherapy, behavioral relaxation, and distractions like being able to use the computer for entertainment while receiving chemotherapy have all shown to relax the patient and reduce distress during chemotherapy infusion.

Finally, radiation side effects are similar to chemotherapy. As soon as patients hear that they need radiation treatment, they immediately are fearful because radiation historically was used as a palliative treatment, meaning that it would not destroy the cancer completely, but it aimed to delay the growth of the tumor so the patient would have more time. Thus, there is a stigma that when needing radiation, the patient may feel that their cancer will not be cured. Generally, radiation therapy is given in enclosed spaces, so those who are claustrophobic have trouble. Patients tend to become fatigued or depressed as well.

After my mother found out that she did not need any further treatment after her surgery, we were all relieved. Four years ago, she was deemed “cancer-free.” But what does that mean? Sometimes we forget that she had cancer because she is back to most of her functioning. We sometimes forget that at one point we were all scared that we were going to lose her. So that begs the question, when the patient is deemed “cancer-free,” does that mean that they did have cancer or they still have cancer? Are they still fighting cancer? Are they still a cancer patient? Or are they a survivor? If they are a survivor, then doesn't that imply the cancer won't come back? So will the cancer come back? These questions run through my head on a day-to-day basis, and it also does in other people, including the patients. They are “survivors,” but now what?

The problem is that the threat of death can constantly be looming over cancer patients, because cancer and its impacts never completely goes away. Many people define being a cancer survivor differently, some even refuse to use that term because it implies different things. Some people say a survivor is a person who has completed treatment 5 years prior and has no sign of cancer, others say that survival begins the day the patient is diagnosed, and then they survive the treatment, and then they survive returning to normal life, and finally they survive adjusting in the long-term. Problematically, even if a patient “survived” cancer biologically as there is no sign of it, physically, psychologically, socially, and sexually, they are still fighting every day. With new trends of people surviving after cancer because treatment has improved, there is low quality of life post treatment. Some treatments produce long-term, physical side-effects and take a toll on functioning normally. Furthermore, many patients constantly think about the statistics – anything less than a 100% survival can cause an individual to have a constant fear, and the problem is that no doctor knows for sure what the exact number is nor can they promise anything. Thus, the survival rate or amount of time left to live for certain people may differ because those numbers are averages. Ultimately, a strong predictor of long-term survival is general health, supportive family and friends, philosophical and spiritual resources, financial stability, and a satisfactory life outside of cancer.

One interesting problem is returning to work after treatment. The cancer follows the patients to the work environment as many people treat them differently, or feel like they are not considered to be able to perform normally. About 10-38% of cancer patients do not return to the place they were working at before being diagnosed and treated or shift from full-time to part-time. The fact that some employers do not feel that the patient can fully function as an employee opens doors to many reports of job discrimination of being fired, laid off, pressured to leave, demoted, given less desirable work, denied a promotion, or having trouble finding a new job because of having cancer. I've seen this firsthand with my mother. She has had trouble finding a new job that is accommodating for her needs because of her cancer, and just found a job a full four years after her treatment. The myths that contribute to this type of job discrimination is that cancer ultimately means death and that survivors are unable to work as much as they could because of absences, less strength, and less ability.

Lastly, after cancer, survivors have trouble seeing themselves as sexually attractive or desirable. As a result, some survivors tend to shun intimate relationships. Sometimes treatment can also make the patient infertile. But, feeling this way is completely normal after the first few months of treatment. For coping, though, it is important to get back to having sex with your significant other eventually.

A scientific study from ScienceDirect focused on quality of life post-cancer treatment found that patients witness the psychological and social consequences of cancer one to three

months after treatment, and they find it difficult to find someone who understands and listens to their worries. Compared to the control group, overall quality of life is never reaches the control group's numbers for the cancer patients, meaning that cancer survivors' quality of life statistically is not at the same level as individuals who do not have cancer.

Throughout my mother's journey with cancer, I went on that journey with her, and did whatever I could to help her in the best way I could. I felt that all she needed was love and support from my end, and my worrying or crying or feeling scared would only make her feel worse, so I hid that from her. But, I accepted that she had cancer and that I may lose her. In contrast, my brother was in denial. He refused to accept that my mother had cancer, and continued on with his life. Instead of dealing with the cancer head on, he hid from it. When my mother came back after her surgery, he stayed out of the house as much as possible because I believe he could not bare to see firsthand what the cancer had done to my mother's body. He says he regrets that now. There are so many different ways family members cope, and my brother and I are just two.

Generally, one-third of caregivers have significant anxiety and distress when their loved one has cancer. They continually feel anxious, depressed, and constantly dread that the treatment will be needed again. But, in order to remain strong and help the patient with making decisions which is something patients need, they outwardly show empathy and support but inwardly feel heartbroken, in pain and in despair. Besides emotional support, caregivers also help with scheduling appointments, paying medical bills, handling insurance issues, keeping track of medications taken, and keeping family and friends informed of the status of the patient and their treatment. In my case, I tried offering as much emotional support as possible, while my grandmother helped with physical coping of helping my mother do her day-to-day activities, and my father kept us informed with what the doctors said and helped schedule appointments, keep track of bills, and handle insurance. Some caregivers have to also be an advocate for the patient. As the patient is seriously ill, and may be completely preoccupied with coping with the disease growing inside of their body, they may not be in the mental state to advocate to doctors of what type of treatment they want or what care they want, and caregivers may have to step in.

Caregivers have huge responsibilities of maintaining stability of the home and family, ensuring that there is still an income for the rest of the family, and tolerate the emotional toil of going to appointments with the patient and remaining strong.

There is extensive research on how cancer can affect marriages, but ultimately it is very simple: good marriages tend to get stronger, but marriages that were already poor are not likely to get any better once cancer invades the family. Divorce rates are no higher in marriages where there is cancer compared to a healthy population, but when a cancer patient goes through a divorce, that is even more emotionally tolling and adds to the coping. In terms of other relationships, one-third of survivors claim that they've created deeper, emotional relationships with friends; however, over time, family and friends who were completely devoted during treatment tend to become increasingly less supportive over time.

I will describe two studies that I found relevant to the family and friends section of this paper. First, a study from the psychological bulletin looks at the distress on the cancer patient versus the caregiver. The study found that the level of distress was actually more related to the gender of the person rather than the person being the patient versus the patient's partner. More specifically, women essentially had higher levels of distress compared to men regardless of

whether they were the cancer patient or wife. This has implications on studying the psychological effect of cancer on caregivers because this can be applied to those studies and illustrates that caregivers can be just as, or even more affected, by cancer than the cancer patient, psychologically. Second, a study in the Journal of Social Sciences and Medicine, found critical characteristics that affect the survival rate of cancer patients. The number of supportive friends and persons, whether the patient (woman, in this case, as the study looked at breast cancer patients who were women), worked, whether she was unmarried, and the extent of contact with friends and social network were all effects on survival. This study illustrates how social support is crucial for survival, and that one can have all the medical resources, but if they do not have a strong support base then they can still not beat the cancer.

The point of this paper is to touch upon an untapped area of research and that is the human side of cancer. I think there is significant medical research, which is what people focus on because they care about beating the cancer and getting it out of people's bodies so they do not die. However, sometimes people forget to think about the aftermath of those actions. What would the treatment do to these patients' bodies? How is the quality of life after treatment? How are these patients psychologically affected through the process of getting treated for cancer and after possibly beating it? And finally, are friends and families as affected since they are immersed in an environment of cancer as well? Everyone is impacted differently when they go through life changing illnesses like cancer, whether they are the one with the illness or the loved one caring for the patient. It is normal to have different emotional responses and feelings, and I want everyone to know that it is normal and it is okay.

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