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Language of Medicine

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### The Singularity of Narratives

In an ideal world, cancer diagnoses are not given, patients do not die at the hands of a clinician, and families do not have to witness their loved ones in pain. However, these are all aspects of medicine, and doctors are not just knowledgeable of anatomy and treatment options, but they also know how to accommodate patients and their families in these more emotionally vulnerable situations previously mentioned. For decades, doctors were encouraged to hide any sign of emotional weakness when delivering medical news. This included becoming emotionally attached to patients and their families; moreover, in order to remain “professional”, doctors must remain strong and stoic in their practice. This concept stemmed from the assumption that being emotional makes one weak and incompetent. More recently introduced, narrative medicine aims to reduce the fear of being emotionally vulnerable in medical practice. This concept includes educating clinicians of mediums in which they can be more present and supportive for their patients. Rita Charon discusses this concept in *The Principles and Practice of Narrative Medicine* by saying “in narrative medicine we seek to establish that feelings are part and parcel of our intellectual work and to allow and invite them into the room, recognizing the role emotion plays in relationships and relatedness” (Charon 42). Being affective is important, especially in the situation of a patient-clinician relationship. Rather than having a hierarchical exchange of information filled with mistrust, a patient and their clinician should work as an alliance. In order to form a balanced relationship, like Charon said, there must be emotionally supported trust.

Keeping narrative medicine in mind, I want to compare two specific narratives of people who have been in vulnerable positions throughout their time as cancer patients.

The first narrative is more personal, that being my dad's experience of receiving the diagnosis of stage four Mantle Cell Lymphoma: a rare form of non-hodgkins lymphoma in which one case is recorded per 200,000 people per year. After going to the doctor for his annual blood work up, he woke up one morning to five missed calls from the practice. He was informed that his white blood cell counts were dangerously high, and he should go to the nearest hospital. From there, he stayed for about four days, having numerous blood tests, a CT scan, and a bone marrow biopsy. During his time at the hospital, doctors had warned him it could be leukemia, chronic lymphocytic leukemia, etc. It wasn't until he was out of the hospital and the doctors had gotten the results of his genetic markers that they were able to tell him it was Mantle Cell Lymphoma, the same cancer his best friend was diagnosed with eight years ago. Later on, I will mention his own words and perception while hearing the news. But for me, the news came from my dad over the phone. I had watched his best friend struggle through chemotherapy and relapse after several years in remission. The thought of watching my dad go through the same was terrifying, and I couldn't imagine what he was thinking and how his clinicians were going to help him and my family through this.

Like my dad, there are millions of people in the United States who have their own narratives of a cancer diagnosis, but I want to compare my father's experience to one woman's story of her diagnosis and treatment of breast cancer at the age of forty-four. Barbara Ehrenreich notes that she ate healthy, drank sparingly, exercised regularly, etc., but could not escape the breast cancer that had been found only ten days after her first mammogram. She goes on to

discuss how her doctors' words affected her view of the cancer. After receiving the resulting slides from her mammogram, the doctor told Barbara "there is a cancer" (Ehrenreich 44).

Hearing the news, all she could think was "that the most heinous thing about that sentence is not the presence of cancer but the absence of me... I have been replaced by [the cancer], is the surgeon's implication. This is what I am now" (Ehrenreich 44). The diction which the doctor used had a lasting effect on her throughout her recovery process. She felt that her identity had been replaced with her illness. This was how people would see her now. Additionally in her article, *Welcome to Cancerland*, she focused on the environment created by the breast cancer community. The hyperfeminine symbols and cheerful narratives were extremely frustrating in her journey through treatment. She felt that having breast cancer was almost romanticized, and very few people told the honest truth of how difficult it was. In relation to narrative medicine, Ehrenreich highlights many instances in which the way people spoke and acted around her affected her mindset during this difficult time.

As I look at both of these narratives, I have to consider the effects of reading with the narrative in comparison to reading about the narrative. In terms of narrative medicine, this concept of recognizing how a reader is interacting with the text is important. Arthur Frank discusses these interactions throughout his analysis of pain and medical practice. Reading about a narrative has been the more prevalent approach used in medicine. When reading about a narrative, the story itself is a stable object and the reader is an outsider simply analyzing the text. There is no personal connection and the reader must assume that there is one true meaning or lesson that can be taken from the person's narrative. On the other hand, reading with a narrative requires an acceptance of cocreation. This approach acknowledges that there are an infinite number of perspectives and interpretations of meaning that can be drawn from one's text. Each

reader is a cocreator of the story; moreover, the medium of translating text into significance is when a reader joins the writing process. Frank doesn't argue for one approach or another but recognizes that deeper understandings can be taken from narratives in either form. In terms of my narratives, I found it difficult to read about them. Especially because my father's diagnosis had occurred quite recently, adding my own experience and relative interpretations was almost inevitable. I began to question how I would act in their situations, or how I might want to be treated after a cancer diagnosis. I thought about Ehrenreich's experience, and I wondered whether I would have responded in the same way. Like Frank stated, "Thinking with stories involves taking one's own place in that process, in which all participants will continue telling stories" (Frank 209), and that is exactly what I found myself doing. I am sure that if someone else were to read with my dad's narrative, they would come to an entirely different understanding. My own personal connection and emotional concerns might be the cause, but in any situation, the reader's past experiences infiltrate the narrative when reading with it. For example, I read with *Welcome to Cancerland* rather than about it. I first read Barbara's narrative prior to my dad's diagnosis this spring, and still asked what kinds of messages I would want to hear from the breast cancer community if I had been going through treatment. It is interesting reading her narrative now, after my dad's diagnosis, and gaining a whole new perspective, having a new emotional attachment to her story. Because I now had a personal connection to someone with cancer, I felt more empathetic with Barbara and her struggles.

With academia, it can be hard to experience empathy like I had with Barbara's story. This is why reading about a narratives can be easier depending on the context and the reader's own influences. However, when reading others' personal narratives, I found that reading with it created a deeper connection and community feeling. When you share or read with others' work,

it creates a larger community where we don't feel alone in our struggles. Personally, I found that when reading with *Welcome to Cancerland* not only did I absorb Barbara's narrative, but I gained a new perspective on what I was going through with my dad. I felt her story showed me that each cancer patient responds differently to various support systems, and to be mindful of how words, symbols, etc. might affect an outlook on one's cancer. It made me feel comforted knowing more about what I might be able to do to comfort him. Knowing there are people dealing with the same thoughts and conflicts gave me a reassurance of hope.

After recognizing that each patient is affected differently, I started to question what the best language in terms of receiving a diagnosis was. Some cancer patients found it comforting when their doctor shed a tear giving their diagnosis, others want a more emotionally distant conversation to maintain "professionalism". I thought of all of the times someone might be at the doctors, anxious about what their doctor could determine about their health. I know I have felt that anxiety about the uncertainty of my physical health. How would I want to receive bad news? These narratives make me question my preferences in this situation, and that is something every person can relate to. Barbara mentioned her doctor gave the diagnosis with the words "there is a cancer", and how that made her feel that her identity had been taken by the cancer. In contrast, my dad described his hematologist's language as such: "he showed that he cared, he was emotionally invested, but only because he truly wanted to make me better" (John Arena). Because the hematologist was so positive and confident in the treatment plan, my dad wasn't scared. He was sure his doctor cared about his well-being but was not negative or sad about it in any way. My dad felt that if a doctor had been sad about a diagnosis, it would terrify him because it would show he had a reason to be sad, it would make recovery seem impossible. The contrast in physician's diction created two different responses in patients.

In addition to the language used by doctors, the options are often a short list for cancer patients. This too can have an effect on one's outlook of their health. A concept called *therapeutic screens* is extremely prevalent with oncologists. After diagnosis, treatment plans are framed differently by each doctor, often including their own bias by leaving out unfavored options. As a patient, it is a difficult position to be in. Some have felt they lost control of their health. Barbara discusses how she felt she had lost control of her treatment plans after her breast cancer diagnosis:

I know women who followed up their diagnoses with weeks or months of self-study, mastering their options, interviewing doctor after doctor, assessing the damage to be expected from the available treatments. But I can tell from a few hours of investigation that the career of a breast-cancer patient has been pretty well mapped out in advance for me: You may get to negotiate the choice between lumpectomy and mastectomy, but... as it's less threateningly put—you're doomed to chemotherapy, meaning baldness, nausea, mouth sores, immunosuppression, and possible anemia. These interventions do not constitute a "cure" or anything close (Ehrenreich 44).

Ehrenreich goes on to explain how the women who have tried alternative options have not had great success beating the cancer. Because of the lack of success, you are "doomed to chemotherapy, meaning baldness, nausea, mouth sores, immunosuppression, and possible anemia"; your health is nothing like it used to be. Chemotherapy kills both cancer and healthy cells, draining any ability to have the energy for things you might have once enjoyed, let alone everyday tasks. Why is opting out of treatment not a common option? Barbara uses the word "doomed" to illustrate how she has no choice. Those side effects are inevitable, even though

they might keep her from doing activities and spending time with her loved ones. I am not saying that cancer treatment is not helpful, because it can be, and medications are evolving each day, getting more and more advanced; however, patients aren't always given all of their options. Doctors often value a successful patient as one who lives longer, rather than having the abilities to participate in their life longer. Their well-being is not considered. This priority is seen especially with cancer patients.

In addition to these termanistic screens that force the patient in one direction, there are various metaphors used in the medical community, specifically with cancer patients, that cause a similar feeling of pressure to make certain treatment decisions. Phrases like medicine as war, cancer survivors, battling cancer, etc. all force one agenda on a patient. Cancer patients who don't "fight" their disease are cowards or weak. However, those who beat cancer are "survivors". The diction used in these commonly seen phrases create an environment where people who chose to forego treatment or are unable to withstand the treatment and beat cancer are considered weak. When talking to my dad about his experience so far, he mentioned this idea of "battling cancer" and how not only does it affect the doctor's perception of you, but also changes the way family and friends look at you. Although he chose to go through with immunotherapy treatment, he feels that he is now labeled as battling cancer, and "often feels pity from other people" (John Arena). This is discouraging for him in that he wants to be treated in the same way as someone without cancer. These words can create an environment that makes him feel weaker and someone who is defined by their illness. Both termanistic screens and metaphors are present in my dad's and Barbara's narrative. Hearing their real-life experiences with these issues in medicine redefines my perspective on cancer patients. There are so many aspects to their illness that I had never considered, and still am not fully able to understand.

Having a deeper understanding of the cancer community and those who deal with it daily is significant in not only my life, but many others too. According to the CDC, there are currently 23.3 million living adults who have ever been diagnosed with cancer. Chances are, if you have not been directly affected by cancer in your family, you know a family that has. Because of this, I think it's imperative to question where the medical field has gone wrong. I view the issues of medicine as points of growth for our doctors. After seeing my dad and what he has gone through in the past three months, I am now more motivated to hear other patients' narratives so that I can gain more perspectives on how such a prevalent disease is affecting both the physical and mental health of our community. There are limitations to what I can know in terms of what it means to be a cancer patient, and I am grateful for that. There are also limitations to what I can understand from a doctor's perspective; however, my interest in becoming a Physician Assistant has caused me to take special interest in medical training in these situations. For those who do not know, Physician Assistants are able to prescribe, treat, and diagnose. One day, I might be the one having a tough conversation with a patient about their cancer diagnosis. Although scary, I am more motivated after hearing these two narratives in how I can improve the quality of care for those who have to deal with cancer. There is no correct answer but exposing myself to as many narratives and experiences as I can will help me to be prepared. I recently heard a quote that was comforting for someone who wanted a future in medicine. It was from Audre Lorde, a poet who eventually passed from breast cancer. She said, "what I leave behind has a life of its own" (Lorde). As I read these narratives, and critique each doctor and what they said, I have to remember that there comes a certain point where the patient reads "with" what I have to say. They cocreate their own meaning. Certain patients will respond differently to the same phrase depending on their own history and perspective on their life and the cancer. There is an invisible



boundary between trying to give the best medical care possible and understanding that your words will “have a life of its own”. From the narratives I have read, it seems impossible to always say the individualized right thing as a clinician.

Although it’s unattainable to speak and act the right way in every consultation, learning from individuals’ stories can help to improve the narrative medical practice. We gain knowledge through our own and others’ experiences. Narratives are a mode of sharing this knowledge. After reading them, many are able to gain a new perspective on their own life. However, narratives have limitations. I asked my dad what it meant to be a patient. He said “I have been a patient hundreds of times, but I never truly understood what it meant until now. I can now empathize with all of those other cancer patients. I felt that pain they have felt, and when you’re the one in it, you have a totally different perspective. I had to reevaluate what was important in life, and I saw the small day to day challenges in a completely different light” (John Arena). Narratives like this, especially ones with a personal connection can have a lasting impact on your outlook. I think what my dad said was really truthful though, even if I read thousands of narratives like his, I will never truly understand what he or any cancer patient went through. In actuality, we are only able gain the most genuine perspectives after we have experienced these things ourselves. In connection to Lorde’s quote, this is why narrative writing is so important. The people writing narratives are the ones who whole-heartedly understand what it’s like. After they are printed, their narratives have a life of their own. The narrator’s exact interpretation will never be able to be translated to someone else. I find that reading with a narrative is almost inevitable. Because there is a limitation to what you can connect with, you co-create by adding in your own interpretation and stories. Each narrative has its own singularity, which adds a sense

of value to everyone's interpretations. This is what creates a stream of unique narratives that give us access to thousands of significant perspectives to learn from.

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