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Permalink

<https://escholarship.org/uc/item/61t3b57k>

Journal

Teaching and Learning Anthropology, 4(2)

Author

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Publication Date

2021

DOI

10.5070/T30054359

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STUDENT SHOWCASE

To Be Told You Have Cancer

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Abstract

This paper functions as a narrative examining the firsthand account of a family encountering the mother's diagnosis of ovarian and lung cancer. This experience and its relationship with society is explored through concepts such as the perception of time, family roles, biomedical culture, and conceptions of normality. While explicitly delineating the connections between theoretical lenses like those of Arthur Kleinman and Ruth Benedict and the story at hand, the main purpose of the paper is to highlight the complexity of illness. This is completed by examining only the very first moments of diagnosis and its profound, permanent effects on patients and their loved ones.

Keywords: cancer; family; diagnosis; illness narrative

"The doctors say, 'You have cancer.' Literally", my mother explained to me over the phone, discussing her journey battling cancer. She is 53 years old and a mother of five biological children plus at least a few more "strays," as she lovingly calls them – friends of her own children who lacked support systems at home. When I called my mom, she didn't quite understand why I wanted to talk to her about this, and especially not why I chose her to be the subject of an assignment at my Ivy League school. She felt as though she is unremarkable, and when asked about her experiences fighting cancer, she simply responded, "What else are you going to do?"

She started telling her story from the beginning, October 22nd, 2018, when my father brought her to the local emergency room for stomach pains and she expected to be diagnosed with something akin to diverticulitis, from which her sister-in-law had died less than a year prior. They left for the hospital, tearfully instructing me to watch my siblings and keep a phone nearby. I slept with my phone on top of my face that night so I could hear the ring once they called. Around one in the morning, the phone rang. "Hannah, honey, I'm okay. I have a mass on my right ovary, and it's big. They don't know if its cancer. I love you. I'll be home soon. I love you." The report from the ER that night records a "large 21.5-21.5 x 16.5 cm multiseptated cystic mass which appears to originate from the right adnexa. This is likely of ovarian origin." Later, upon collecting information for this paper, I

received an email from my father containing said medical records. The email read as follows:

Hey Sweetie!

There are 16 reports (sorry no images). I labeled them by date and a short description. Those that impacted us the most were the first one from the Villages ER and the Holloway visit on 5-23-19. I hope this helps

Love you,

Dad

This first report from the night of the ER visit (October 2018) impacted my family the most. While time continued on for many people, it stood still for my family until the removal surgery on November 5th, 2018, an experience felt especially by my mother. She doesn't recall the two weeks between that late-night ER visit and waking up from the anesthesia. She claims feeling "numb" for that entire time. To some relief, the surgery was successful and she could begin her routine visits every three months in order to count her cancer cell levels and weigh the need for any further treatments.

This strange phenomenon of time being frozen yet still continuing on during that dreadful waiting period before my mother's surgery is akin to the experiences described throughout *The Year of Magical Thinking* (2006) by Joan Didion. In the book, Didion contrasts the ordinary events of life to the earth-shattering death of her husband, expressing the perplexing feelings one gets when major events occur in life: "It was in fact the ordinary nature of everything preceding the event that prevented me from truly believing it had happened" (Didion 2006, 4). In making sense of this cancer discovery, I found myself going over the details in my head: I came bounding into my parents' room, excited to announce that I finished my college applications, to find my mother in tears and my father packing a bag for the emergency room. My siblings were still reading, packing for the next day's sports and afterschool activities, or finishing their homework, as if this were a normal Monday night. The juxtaposition between ordinary life as we knew it and this looming, emotionally cumbersome disease didn't make sense to us, so time stood still.

The other side of the phenomenon, where time and responsibilities continue despite the perceptions of the ill and their social network, is illustrated in Arthur Kleinman's 1988 *The Illness Narratives: Suffering, Healing, and the Human Condition*. In this work, Kleinman interviewed and chronicled the daily lives and struggles of some of his psychiatry patients that suffered from illness. Describing the case of his patient Alice Alcott, who experienced multiple complications from diabetes, Kleinman explains that, "Early in psychotherapy, our sessions centered on grief for her multiple losses. But as her spirits lifted, she returned to her characteristic denial. The last few times we met, she would discuss her children's problems, her parents' problems, anything but her own" (Kleinman 1988, 38). While the terror of an 11-pound tumor remained in the back of our minds, my siblings and I still needed a mother, my father a wife, and my mother her normal life. Illness didn't stop my mom from being who she was, it just added another thing to her plate. Thus, she carried

out her responsibilities, including walking me across my high school football field for my marching band Senior Night. What wasn't apparent to everyone on the outside was the fact that I supported my mother's weight during that walk, and my parents' adorable, matching "SENIOR PARENT" t-shirts were donned so that my mother had clothing that fit over her bulging, cancer-filled abdomen.



Figure 1. My parents and I at my marching band Senior Night.

In a sense, the dangers of a large tumor tested and proved the resilience of both my mother and her social support system. While the fear never left during those two weeks, my mother decided to nickname her ovarian tumor "Rocky," since she felt as though she was pregnant with a lithopedion – an extremely rare condition in which a fetus calcifies into rock whilst inside the womb (Medhi, Nath, and Mallick 2014). This act of naming, while on the exterior appeared to be a lighthearted joke, was actually a process of making something more real. By giving a name to the mysterious mass that shocked my mother, it made it tangible. The comparison to pregnancy, something my mother knew extremely well, helped make sense of the experience of having a foreign body within her own. The surgery would be an act of expulsion, a birth of sorts.

In the days leading up to my mother's surgery, the family plan was set: my parents would leave for the hospital and I would miss my classes, take my siblings to school, and then wait until they finished their classes to set off for Orlando on a two-hour drive to the hospital to visit my mom once the surgery was over. I remember, while discussing minor logistics with my brother in front of my mom, her ensuring us that we would be coming to visit the night after her surgery, "To make sure she was alive, and celebrate." At this point in my mom's journey with cancer, the illness was a side note. Her surgery was just another thing she had to do, written on the family calendar next to "Liam-soccer game-5 PM" and

“Band Parent Meeting-6:30,” among many other similar appointments. While this obligation happened to be a scary one, the family, while supportive and loving, collectively considered it to be a big day, akin to “Hannah-College Decisions Come Out” or “Derek-Military Leave Starts.”

This major illness was incorporated into the ordinary in order for my family to survive, especially because the illness affected an integral member of our family network. During our interview, almost a year and a half later, my mom described the experience as, “When you have it, you’re living it. So you’re just living in the now, because that’s all you can do.” My mother explained that collecting her medical records helped her realize everything that she had been through, because at the time, she didn’t, and more likely, she couldn’t, “see the whole picture.” This role-keeping resonates with the experiences of many people struggling with illness, including a man from Bolivia called Alejandro Mamani, who continued to tend fields and worry over his children’s affairs while straining under the stress of “spirit possession” (Reichline and Smith 1974). While this disease effectively changed my mother’s life, the period between the initial discovery and the tumor’s removal surgery was a pseudo-life for her. She went through motions and continued to be the foundation of our family all while feeling as though and fearing that it truly was only a hazy memory, soon to be forgotten.



Figure 2. My Mother’s Ovarian Cancer Tumor, through her Surgical Incision.

My mother had viewed her surgeon, Dr. Holloway, as someone who had saved her life. In fact, upon describing her care during our interview so many months later, my mother attributed her recoveries to be, “With God’s grace, and medical help.” The doctors themselves were assisting her divine figure, continuing to ensure that she was safe. So

when this doctor brought bad news, my mother took it as gospel. On her second follow-up appointment, on May 23rd, 2019, my mother was roughly six months post-ovarian cancer. The cancer-cell count determined that she had No Evidence of Disease (NED) for ovarian cancer for the second time. As the relief washed over my parents in their examination room, the head oncologist's voice was heard from outside the door, questioning why a chest CT scan was included in the report. Then, as if this were a nightmare, the voice confusedly said, "Wait a minute, that looks like lung cancer." There were the characteristic two raps on the door, followed by the entrance of the surgeon my mother trusted so deeply. Another mass had accidentally been found, in my mother's left lung, at the very same post-op visit that had cleared her of ovarian cancer.

My mom described the feeling of shock and horror all over again. The doctor alone was in disbelief, and my mom argued that the hazy cloud appearing in the images were simply old scars from a bout of pneumonia she had as a child. She later told me that after that fateful visit, she had stood in the shower, thinking "this is it"; since one major cancer is detrimental enough, my mother couldn't conceptualize how fatal another occurrence would be. To add insult to injury, when lung cancer is suspected, standard procedure calls for scanning of the brain for "mets," or small cancerous masses. My mom confessed in our interview that one night after the discovery, after her children were safely in bed, she had told my father that if the cancer had truly spread, that if she had mets on her brain, she didn't think that she would make it. This trust that my mother felt with Dr. Holloway is not uncommon in the American medical system. Within the culture of biomedicine, doctors are given prestige and respect, and thus authority over the general public (Kleinman 1995). For my mother, Holloway fulfilled this role.

Despite the struggle to yet again conceptualize a dangerous tumor in her body, my mother found another set of difficulties in the differences between the reactions to her second cancer diagnosis compared to her first. With the ovarian cancer, people expressed a great deal of concern. I remember people cooking and bringing meals for my siblings and me and visiting our house to help us clean and decorate for her return from the hospital. Some of my teachers offered to come help me with my responsibilities, such as folding the family's laundry, understanding that being the oldest daughter placed quite a bit of pressure on me. This resounding community support fell silent when the discovery of lung cancer came to light. When my mother told anyone the news, the first response was typically the question, "Did you smoke?" One bout of cancer was seen as unfortunate, while this second round was abnormal, and people fell back on their prejudices to explain it away.

The question about smoking has heavy implications. My mother took the question to mean that if the answer was yes – and it was, my mother had quit smoking a decade before the tumor discovery – then she somehow deserved to have cancer. Regardless of interpretation, the shift from genuine concern for one's wellbeing and seeking justification for misfortune is obvious. The first time my mother had a cancer diagnosis, it was of a

female sex organ and her first time having an altercation with cancer. Upon discussing surgery, people expressed concern for my mother's identity and the serious struggles faced by women after complete hysterectomies due to the perceived loss of their femininity. By the time the lung cancer was found, my mother had seemingly already worn out the community's sympathies by "getting" another cancer, and she also happened to be unlucky enough for this second round to be a type of cancer that is strongly associated with societal abnormality (Benedict 1959). My mom's abnormal cancer was being classified as a sort of consequence for her abnormal habits in the past: smoking and addiction.

This social classification as abnormal had a profound effect on my mother. I remember that the family decided not to tell people that she had lung cancer, simply because we had to constantly defend my mother, a person facing a serious illness, from judgmental inquiry. When the doctors discovered that the lung cancer was not related either to smoking or to my mom's previous ovarian cancer, the doctors were even more confused. Even the medical professionals wanted to define this perceived abnormality in terms of blame on my mother, in some manner. When this prescription of guilt or abnormality fell short, the doctors had to dig deeper, and my mother had a foothold in her defense. Despite the facts that saved her from condemnation, my mother is still defensive about her lung cancer to this day, reciting facts about cases of lung cancer in nonsmokers and even repeatedly remarking, "Nobody deserves to get cancer," despite their history of smoking. However, smoking as a cultural abnormality is still present in her views, as she later remarked in our interview, "you could argue that they're [smokers are] an idiot" with a laugh.

The discoveries of cancer in my mother were extremely challenging for many reasons. The fear of cancer is indescribable, and my mother has experienced it multiple times over the past year and a half. When I asked about the social side of her experiences, specifically her experiences in the family, she expressed extreme gratitude for having a family that remained by her side during her illness. Whenever the "bomb" was dropped and a new tumor was found, my mom tearfully recounted that the first thing she thought of was all her children as infants, all at once. Her instinctual fear was centered around protecting her children, being a mother. Even in times of the most distress, my mother grappled for her role in normal life.

"That's what it's like to be told you have cancer," she concluded during the first few minutes of our hour-long interview, before beginning to discuss the rest of her story.



Figure 3. My Mother and I, Taking High School Graduation Pictures.

Acknowledgments

I'd like to thank the teaching staff of Medical Anthropology at Princeton University, Onur Günay, Ipsita Dey, Nikhil Pandhi, and João Biehl. This story also wouldn't exist without my wonderful family, especially my amazing mother, who at the time of publication is in remission.

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