Abstract

Drawing on the disciplines of psycholinguistics, medicine, and medical anthropology, this thesis evaluates the suggestion to rename breast Ductal Carcinoma In Situ (DCIS) to remove the reference to cancer. Chapter 1 focuses on the evolution of medical and social understanding of cancer and how the language used to describe and treat the disease reflected that understanding. Chapter 2 describes the war metaphor applied to cancer and stigma it causes. Chapter 3 explains Dr. Laura Esserman's proposal to rename DCIS to Indolent Lesion of Epithelial Origin (IDLE). Chapter 4 discusses the recent precision medicine movement and a change in the taxonomical categorization of cancer within that framework. I argue that the language used to describe cancer has diverged from the science and should once more be realigned to benefit both patients and doctors. A new taxonomy should be informed by science, metaphors, and lived experience from patients and doctors. Finally, I conclude that such taxonomy should be developed within the near future, as we know enough scientifically about the disease to reclassify many of its heterogeneous types.

Cancer by Another Name:
The Quest for a Better Linguistic Taxonomy

Julia Storella Karron

Advisors:
Professor Lynn Morgan
Professor Francine Deutsch

Committee:
Professor Kyle Johnson
Professor Mara Breen
President Lynn Pasquerella

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Preface

JULIET
O Romeo, Romeo! Wherefore art thou Romeo?
Deny thy father and refuse thy name;
Or, if thou wilt not, be but sworn my love,
And I'll no longer be a Capulet.
ROMEO
[Aside] Shall I hear more, or shall I speak at this?
JULIET
'Tis but thy name that is my enemy;
Thou art thyself, though not a Montague.
What's Montague? It is nor hand, nor foot,
Nor arm, nor face, nor any other part
Belonging to a man. O, be some other name!
What's in a name? That which we call a rose
By any other name would smell as sweet;
So Romeo would, were he not Romeo call'd,
Retain that dear perfection which he owes
Without that title. Romeo, doff thy name,
And for that name which is no part of thee
Take all myself.
Romeo and Juliet, William Shakespeare, Act II, Scene II (MIT Shakespeare Website, 2015)

Introduction: The Necessity of Change

As of 2011, the leading cause of death among women, second to only heart disease, is cancer (CDC report, 2011). Among those cancers, breast cancer is the most common (CDC Breast Cancer Page, 2014). With such high prevalence, more steps should be taken to address this disease. Some such steps, for example more coherent biological research and regular screenings, have aided in this process. However, one facet of cancer, which has yet to be reshaped, is the taxonomical definitions of types of breast cancers. This paper addresses the need to change, or to at least consider reform of the taxonomical definition of Ductal Carcinoma In Situ (DCIS) as the science and language of cancer no longer align. To accomplish this, I consider the scientific and linguistic histories of cancer, explore the war metaphor, long used to describe cancer and its treatment, explain Doctor Laura Esserman's work on renaming DCIS entirely, and, finally, consider the future of "precision medicine" and how it can inform the discussion and treatment of breast cancer.

A newspaper article given to me by my mother, a radiologist, the summer before my senior year sparked my decision to research why the language and science of cancer are not aligned. I was intrigued that a doctor wanted to change the name of a disease whose taxonomy had not been rewritten since the 1800s. And so I asked myself: why have the language and science not kept up with each other? When did they diverge? How can we bring them together again and what would it take to do so?

As I began exploring this problem, I realized very quickly that this was a multifaceted problem that could have many different solutions. DCIS was not the only

case where the language did not agree with the science of disease: that was the case for many other cancers. Yet the taxonomy currently used is in place for a reason. Changing the language alone would have broad implications.

This problem has been discussed explicitly for some time. Both researchers and doctors have recognized the problem, but they have not been able to reach a definitive solution as to what could be done. Some argue that changing the name could lead to underdiagnosis; others believed it is too soon to create such a change.

Moreover, the fact that the name makes a huge difference from a patient's perspective was never fully considered. Patients should have the right to truthful information so they can make informed decisions. How these competing considerations should be appropriately balanced is a dilemma. But the word "cancer" terrifies people and can make it hard for them to evaluate treatment options rationally.

In the next four chapters, I ask and answer questions about how the language of cancer can and should change. My perspective is an interdisciplinary psycholinguistic and medical one. My self-designed major in psycholinguistics provides me the tools to understand why we use and understand language on a deeper level. The use of metaphors and historical linguistic background of a word inform my understanding of how the taxonomy and language of cancer evolved, with particular emphasis in the second and third chapters. At the same time, understanding the language of cancer requires a basic understanding of a biological background. My review of relevant biology and medical literature and my experience as an Emergency Medical Technician informs the first and third parts of my thesis with regards to the medical background of cancer and how it has

evolved over time, as well as why there is pushback against change from a medical perspective.

The four chapters each addresses a separate element of the argument I make, and as a whole, they complement each other. In the first chapter, I draw upon current and past medical and linguistic knowledge to understand how "cancer" evolved, both in terminology and in biology. Starting in Ancient Egypt and advancing to our current knowledge, I draw upon both facets to more deeply explain why DCIS is called a cancer. In the second chapter, I argue that the metaphor of war to describe cancer, as used by both doctors and patients, has stymied the advancement of both the linguistic and biological treatments of cancer. With the use of different metaphors implemented by both patients and doctors, I move from Nixon's "War on Cancer" to today's stigmatic labeling of cancer metaphors as an explanation for lack of change. In the third chapter, I present Dr. Laura Esserman's argument for the renaming of DCIS to IDLE and the pushback it has received within the medical community. Understanding the motives for changing a name and why in the medical field is important when moving forward and suggesting a name that informs both the medical and patient community. In the fourth and final chapter, I discuss the concept of "precision medicine" and how it will effect a potential change in the cancer taxonomy and classification system. As medicine progresses and becomes more individualized and precise, the linguistics should reflect such a trend.

Contra Shakespeare, as Juliet wants to deny but actually recognizes, there's a lot in a name. With this recognition that names matter, cancer's name comes under pressure when the science and name do not align.

Chapter 1: Linguistic and Biological Intersections: A Brief History of Cancer

We tend to think of cancer as a "modern" illness because its metaphors are so modern…Cancer, far from being a "modern" disease, is one of the oldest diseases ever seen in a human specimen – quite possibly the *oldest…Where was cancer "born"? How old is cancer? Who was the first to record it as an illness?*

Siddhartha Mukherjee, *The Emperor of All Maladies: A Biography of Cancer*

Evolving Scientific Understanding of Cancer

Classical Medicine

The history of cancer begins in ancient Egypt, around 3000-2600 BC. Imhotep, a physician, describes in the Edwin Smith Papyrus scrolls (American Cancer Society, 2015) a case that by today's standards would be breast cancer. In his classifications and descriptions, Imhotep states, "bulging tumors of the breast mean the existence of swellings on the breast, large, spreading, and hard." (Mukherjee, 2010: 40) When asked what is the treatment for such a tumor, he writes, "There is none." (Mukherjee, 41: 2010). Imhotep also identifies this disease with the descriptive label tumor as the Ancient Egyptians had not devised a word to encompass the symptoms Imhotep described.

In 1500 BC, the first discussion of possible treatments is presented in the Ebers Papyrus: "The Egyptians attempted to treat tumors and cancers with cautery, knives, and salts, and introduced arsenic paste that remained in use as 'Egyptian ointment' until the 19th century." (Hajdu, 2011: 1097) Sadly, these remedies did not work.

The bulging tumor and the symptoms Imhotep mention do not appear in texts again until 440 BC. Herodotus, a Greek historian, details the story of Persian queen Atossa. During her reign, she suddenly took ill to a "bleeding lump in her breast that may have arisen from a particularly malevolent form of breast cancer labeled inflammatory."

(Mukherjee, 2010: 41). Eventually, after a self-imposed quarantine, she allowed the tumor to be removed. There is still no mention of a distinct name for this ailment.

While historical texts have provided some context to the discovery of cancer, archaeological digs have provided more concrete evidence of cancer's ancient roots. At a Chiribaya dig site in Peru, the remains of a roughly thirty-year-old woman contain "a hard 'bulbous mass' in her left upper arm…this, without question, was a malignant bone tumor, an osteosarcoma, a thousand-year-old cancer preserved inside of a mummy." (Mukherjee, 2010: 43). But remains of this kind were not only found in Peru; returning to Egypt, a preserved "abdominal cancer from Dakhleh…from about four hundred AD" (Mukherjee, 2010: 43) was also discovered. Cancer, therefore, was not limited by geographic boundaries; it existed throughout the ancient world in a variety of places and presented itself in many ways. It would not be until one man's description in ancient Greece of a tumor that the formal name for these varying diseases emerged.

Hippocrates, a Greek physician considered the father of western medicine, is the first to name the tumorous masses he encountered during treatments. He used "cancer", derived from the word karkinos, meaning crab, because "a tumor looked like a 'crab'…in that there is a central body to a tumor and the tumor extension appeared as the legs of the 'crab'" (SEER, 2015). In 400 BC, it makes its first appearance in medical textbooks, and the name was fitting for many reasons:

> The tumor, with its clutch of swollen blood vessels around it, reminded Hippocrates of a crab dug in the sand with its legs spread in a circle…for some, the hardened, marred surface of the tumor was reminiscent of the tough carapace of a crab's body. Others felt a crab moving under the flesh as the disease spread stealthily throughout the body. For yet others, the sudden stab of pain produced by the disease was like being caught in the grip of a crab's pincers. (Mukherjee, 2010: 47)

With a new name, the disjointed diagnoses of different tumors and masses were now united. By receiving an identifier, something the common man could name, physicians could now explain to patients in understandable terms what was happening to their bodies. This nomenclature reflected the science at the time used to diagnose cancer. The Ancient Greeks did not have microscopes; so an understanding of the biological processes on a deeper level would not be attained for some time. The difference between a benign and malignant tumor was unknown; and those tumors that were recognized were huge masses that were quite visible.

Another word that emerged referenced the pain and hardship patients were under. *Onkos* is the root word for the modern term for the study of cancer: oncology. In Ancient Greek, it was defined differently depending on the circumstance:

> *Onkos* was the Greek term for a mass or a load, or more commonly, a burden; cancer was imagined as a burden carried by the body. In Greek theater, the same word, *onkos,* would be used to denote a tragic mask that was often "burdened" with an unwieldy conical weight on its head to denote the psychic load carried by its wearer. (Mukherjee, 2010: 47)

In both circumstances, the burden endured by cancer patients was visible and hidden. Tumors at the time were only those that could be easily identified, but that burden that was visible was coupled with an invisible burden that cancer would be associated with from ancient times until today: depression.

In Hippocrates' era, these two diseases were manifested through bodily fluids known as "humors." Hippocrates identified four different cardinal liquids within the body, which were thought to be the cause of all diseases: "blood, black bile, yellow bile, and phlegm. Each of these fluids had a unique color (red, black, yellow, and white), viscosity, and essential character. In the normal body, these four fluids were held in

perfect…balance. In illness, this balance was upset by the excess of one fluid" (Mukherjee, 2010: 48). For both cancer and depression, black bile was believed to be the source of the physical and mental manifestation of illness. But black bile was a mysterious entity, its roots unknown, and its presence minor in a healthy body. No one knew what black bile looked like, and this contributed to its mystery: "uncritical acceptance of Galen's views over this period resulted in the same long period of unproductive medical thinking" (van den Tweel and Taylor, 2010: 4). Further research would be necessary to unveil the source of black bile.

Aulus Celsus, a Roman physician, contributed his own treatments and remedies for the insidious black bile. Discerning the distinctions between aggressive tumors and more superficial cancers, Celsus described two methods of treatment: "Celsus treated superficial carcinomas with a topical application of boiled cabbage and a salted mixture of honey and egg white. For cancers, he recommended aggressive surgical treatment" (Hajdu, 2011: 1097). These therapies, like those of the ancient Egyptians, could not successfully treat cancer, and the black bile theory continued.

Claudius Galen, a contemporary of Hippocrates and a Greek doctor and writer who practiced with the Romans, would accomplish the research and writing Celsus could not. Through Hippocrates' assumption of the four humors, Galen studied black bile closely, and presumed that cancer was merely "'trapped' black bile – static bile unable to escape from a site and thus congealed into a matted mass" (Mukherjee, 2010: 48). It was this overproduction of black bile that Galen believed to be the source of both cancer and depression. Even depression's original name, *melancholia*, reflects this connection: "from the Greek *melas*, 'black' and *khole,* 'bile'" (Mukherjee, 2010: 48). While cancer was the

physical manifestation of overproduction, depression was the psychological manifestation. These two would remain intertwined throughout the course of medical and linguistic history, as depression is still a common side effect of cancer treatment and diagnosis today (NCI Depression Statistics, 2014).

Both Galen's and Hippocrates' theories on black bile spread throughout the eastern world as the possible source of cancer. Rhazes of Baghdad, in concurrence with Celsus, championed "surgery and introduced new operative techniques and instruments" (Hajdu, 2011: 1099), but quickly cautioned that for cancer surgeries and operations "no surgery should be attempted unless the cancer can be excised completely" (Hajdu, 2011: 1099). With the continuation of surgical procedures as the only true method of disrupting the black bile collections, the black bile theory would persist through the Middle Ages and into the Renaissance. Removing tumors, even with some successes, was considered a generally hopeless endeavor, as doctors still believed the assumptions of Hippocrates and Galen that the source of the black bile could not be identified. However, these theories would eventually face scrutiny by doctors who questioned the standing of such assumptions.

Vesalius and the Anatomists

While studying medicine in Brussels in the 1500's, Andreas Vesalius began to challenge the assumption of black bile that had persisted through his teachings in Galenic anatomy. Vesalius took matters into his own hands, unsatisfied with the lack of clarity, and created his own anatomical map. While creating his own maps of the veins and arteries, Vesalius could not find the elusive black bile Galen preached about. His next

assumption was that black bile was only produced by the tumors the body produced. Such bile should therefore have been found in excised tumors of cancer patients.

Under this new assumption, Matthew Baillie, an anatomist, researched this concept at the end of the 1700's. To accomplish this, Baillie created his own anatomy: one of a diseased body. Baillie recorded findings on all types of cancers, but could not find the black bile Galen had spoke of, even within tumors: "Black bile may not have existed discernably in normal tissue, but tumors should have been chock-full of it. But none was to be found…he could not find the channels of bile anywhere" (Mukherjee, 2010: 53).

The Emergence of Cell Biology

As the search for the humors remained elusive, anatomists and physicians were making novel observations with the use of new devices. Zacharias Jansen, A Dutch spectacle maker, built and mass-produced the first compound microscope in the early 1600's (Royal-Woods, 2012). Scientists from all parts of Europe wanted to understand the world around them, and the compound microscope gave scientists that opportunity. Jansen's invention is critically important: "it was the invention of the microscope that revealed the cancer cell itself" (SEER, 2015).

A Dutch biologist, Antony Van Leeuwenhook, built his own in 1688 (UCMP Van Leeuwenhook, 2015) and studied anything that could be placed under it. In analyzing the plaque from his own teeth (UCMP Van Leeuwenhook, 2015), he discovered bacteria, or as he called them, "animalcules, because they looked like little animals" (Royal-Woods, 2012). Upon this discovery, he contacted a colleague in England, Robert Hooke, who

analyzed pieces of cork under his own compound microscope. The small chambers he found in the cork gave rise to the term "cell" in 1678 (UCMP, Hooke, 2015): "The little chambers he saw reminded him of 'cells': or, the rooms monks slept in in their monasteries" (Royal-Woods, 2012). For all his hard work, Hooke's studies were not truly appreciated in its time. Hooke's scientific theories contradicted those of the most famous scientists of that era. It would take until the 1800's for Hooke's work to resurface and inspire a new generation of scientists (Royal-Hook, 2012).

In 1838 in Germany, Matthias Schleiden and Theodore Schwann worked on plant and animal cells, respectively. Both recognized a surprising commonality: that every plant and animal they studied was composed of cells. Their collaboration and subsequent work by Rudolph Virchow in the 1850's produced what are now commonly referred to as the tenets of Cell Theory:

1. All living things are made up of cells
2. The cell is the basic component of life
3. New cells are created from preexisting living cells (Mazzarello, 1999: e14).

This theory governed future discoveries in oncology.

Of interest, Virchow's contributions grew out of his study of childhood leukemia, or *weisses Blut* for the white blood cells that permeated his patient's blood. Virchow's studies in leukemia drew him to a startling conclusion:

> If cells only arose from other cells, then growth could occur in only two ways: either by increasing cell numbers or by increasing cell size. Virchow called these two modes hyperplasia and hypertrophy. In hypertrophy, the *number* of cells did not change; instead, each individual cell merely grew in size – like a balloon being blown up. Hyper*plasia,* in contrast, was growth by virtue of cells increasing in *number*…cells becoming cells becoming more cells, *omnis cellula e cellula e cellula*…Conversely, and importantly for this story, Virchow soon stumbled upon

> the quintessential disease of pathological hyperplasia – cancer. (Mukherjee, 2010: 15)

The humors were a thing of the past.

But Virchow did not understand the fundamental mechanics of why these cells replicated uncontrollably. This jump was made during this same period, when Austrian monk and biologist Gregor Mendel studied plant reproduction by planting different combinations of purebred plants with one another and focused on their outcomes. In one instance, he combined a "purebred yellow seeded plant with a purebred green seeded plant, and he got only yellow seeds" (Jimenez Diaz, 2013). From the visual representations these pea plants provided, Mendel concluded that there was some way this information was being passed from one generation to the next: "inherited traits…are transmitted in discrete, indivisible packets. Biological organisms transmit 'instructions' from one cell to its progeny by transferring these packets of information" (Mukherjee, 2010: 343). But on a microscopic level, Mendel did not understand why these results occurred.

Theodor Boveri, a student of Virchow's, uncovered Mendel's work on pea plants in the 1900's. Through the study of cytology via sea urchin egg fertilization under a microscope, Boveri discovered meiosis:

> Male sperm nuclei and female egg nuclei were equivalent in the amount of hereditary information. They each had a half set (haploid number) of chromosomes. As long as there was a set of both (diploid number of chromosomes), there was fairly normal development of the sea urchin larvae. Any more or any less and there was abnormal development. (DNA Learning Center, 2011)

By focusing on the chromosome staining work that Walter Flemming pioneered (DNA Learning Center, 2011), Boveri connected Mendel and his predecessor's work to cancer:

that a cancer cell's mutation comes from the chromosomal make up in the DNA of a cell. These conclusions informed cancer research from the 1900's on based on a bold theory: "Since cancer cells possessed striking aberrations in chromosomes, Boveri argued that these chromosomal abnormalities might be the cause of the pathological growth characteristic of cancer" (Mukherjee, 2010: 341-342). The inner mechanisms of cancer were finally exposed, and the 1900's surged with more investigative work on how cancer operated on a molecular level.

History of Cancer Surgery

John Hunter, a Scottish surgeon, began practicing the difficult task of removing cancerous tumors and lesions in the 1760's. Upon removal, Hunter would dissect and study these tumors, and began classifying tumors by mobility: "*Movable* tumors were typically early-stage, local cancers. *Immovable* tumors were advanced, invasive, and even metastatic. Hunter concluded that only movable cancers were worth removing surgically" (Mukherjee, 2010: 55 & American Cancer Society, 2015). He also suggested that lymph was the core antagonist: "of all the fluids, the most important were blood and lymph…Hunter…agreed that tumors grow from lymph constantly thrown out by the blood" (American Cancer Society, 2015). With the advent of surgical removal of tumors and a new fluid as the source of cancer, surgeons became more brazen in their attempts to remove cancer from people's bodies moving into the 1800's.

Motivated by these results, surgeons like Theodor Billroth and Joseph Lister started taking bigger risks in the operating room. With the inventions of anesthesia and antisepsis in the 1840's playing pivotal roles in patient comfort and safety (Mukherjee,

2010: 58), surgery was no longer the supposed "fool's errand" once considered a waste of effort and energy. Instead, it became the standard for cancerous tumor removal, and still stands as one of the foremost methods of cancer treatment.

But even with more modern surgical techniques many tumors grew back or metastasized to other body parts. And so the questions that would push surgery, and cancer treatments, into a new era of discovery were asked:

> What if the whole of cancer could be uprooted at its earliest stage using the most definitive surgery conceivable? What if cancer, incurable by means of conventional local surgery, could be cured by a radical, aggressive operation that would dig out its roots so completely, so exhaustively, that no possible trace was left behind? (Mukherjee, 2010: 59)

William Halsted, the Baltimore surgeon, believed he had an answer to one of these questions. While studying surgery abroad in Europe, Halsted formulated an idea about how to stop the more persistent cancers that kept growing even after surgery:

> If breast cancer relapsed due to the inadequacy of the original surgical excisions, then even more breast tissue should be removed during the initial operation. Since the *margins* of the extirpation were the problem, then why not extend the margins...Halstead called this procedure the "radical mastectomy," using the word *radical* in the original Latin sense to mean "root"; he was uprooting cancer from its very source. (Mukherjee, 2010: 64-65)

By cutting into the pectoral muscles, Halsted's widening surgical margins worked for some; recurrence rates dropped. But there were still some for which even this radical surgery did not work. Halsted could not discern *why* this surgery worked for some but not others. Frustrated, Halstead extended his margins to cut into even more tissue, disbelieving the idea that a cancer's metastasis was due to travel through the blood stream: "he believed that adequate local removal of the cancer would cure it – if the cancer later appeared elsewhere, it was a new process" (American Cancer Society, 2015).

This surgery left many women permanently disfigured, but the results compared to other methods and treatments were unparalleled: "His mastectomy had outperformed every other surgeon's operation in terms of local recurrence. Just as Halsted had promised, he had seemingly exterminated cancer at its roots" (Mukherjee, 2010: 67-68). This method catapulted the theory of "radical" surgeries forward.

After observing Halsted's method for some time, surgeons realized that, while effective in many breast cancer cases, radical mastectomies did have their limits. Critics of Halsted's approach noted the problem that stymied Halsted's thinking: "The ultimate survival from breast cancer, in short, had little to do with how extensively a surgeon operated on the breast; it depended on how extensively the cancer had spread before the surgery…more surgery had just not translated into more effective therapy" (Mukherjee, 2010: 68-69).

The term "radical" evolved from Halsted's original intention of "root" to mean something more drastic and aggressive:

> "Radicalism" became a psychological obsession, burrowing its way deeply into cancer surgery... Halsted had used it in the Latin sense of "root" because his operation was meant to dig out the buried, subterranean roots of cancer. But *radical* also meant "aggressive," "innovative," and "brazen," and it was this meaning that left its mark on the imaginations of patients. (Mukherjee, 2010: 69)

This language has still stuck to cancer treatments, surgical or pharmaceutical. Evolving with cancer's other descriptors, "radical" became a standard of the lexicon.

Non-Surgical Treatment of Cancer

Two of these new "radical" treatments were the advancement of X-rays and the development of chemotherapy. Their growth throughout the 1800's and 1900's paralleled

each other and their containment of cancer, coupled with surgery, gave patients the best chance at survival. Both methods are still used today.

Wilhelm Röntgen discovered the X-ray in 1895 when he discharged an electron tube at his wife's arm with a photogenic plate behind it. This produced a black and white image that showed the bones within his wife's arm (Mukherjee, 2010: 73). After Röntgen presented his work with X-rays in 1896, many soon realized the potential of this new technology: "within months, systems were being devised to use X-rays for diagnosis, and within 3 years, radiation was used to treat cancer" (American Cancer Society, 2015). But there was an unforeseen side effect from too many of these X-rays: tissue damage and cell death. By shooting these electron rays at cancers, doctors saw some improvement in treatment and containment. Emil Grubbe was one of the first doctors to accomplish this feat on a patient named Rose Lee in the 1900's: "He irradiated her cancer every night for eighteen consecutive days. The treatment was painful – but somewhat successful. The tumor in Lee's breast ulcerated, tightened, and shrank, producing the first documented local response in the history of X-ray therapy" (Mukherjee, 2010: 75-76). In combination with the discovery of Radium and the United States' surplus of the chemical, X-ray's produced a new therapy to shrink tumors and extend patient's lives.

But like Halsted's mistakes and assumptions before him, Emil Grubbe soon understood that the radiation used to control cancer only worked if the cancer had not already metastasized. There was still some deeper understanding of the biology of cancer that was missing, and Grubbe could not place it, since the science to understand the true roots of cancer still did not exist: "Like surgery, radiation medicine also struggled against its inherent limits…since X-rays could only be directed locally, radiation was of limited

use for cancers that had metastasized…indiscriminate irradiation left patients scarred, blinded, and scalded" (Mukherjee, 2010: 77).

Sidney Farber and Paul Ehrlich made the conceptual leap of treating the entire body systemically with drugs in their search for a cure for leukemia, a cancer of white blood cells. By testing dyes on animal cells in the late 1800's and early 1900's, Ehrlich had conceived the biological idea of a lock-and-key scenario for all toxins and anti-toxins within the body: "'Chemotherapy,' the use of specific chemicals to heal the diseased body, was conceptually born" (Mukherjee, 2010: 85). Through trial and error, Ehrlich developed his famous "'magic bullets – *bullets* for their capacity to kill and *magic* for their specificity" (Mukherjee, 2010: 86) for all sorts of diseases, but the hurdle he still could not surpass was cancer. It was in this arena that Farber would accomplish what Ehrlich had yet to accomplish: an almost cure for cancer.

Farber studied childhood leukemia in Boston in the 1950's in search of a cure by using Ehrlich's "magic bullet" idea of chemical compounds that would devastate the cancer. These trials included poisons such as mustard gas because the belief that the cancer cell was different from a bacteria cell meant that truly any chemical concoction could be a drug: "Cancer chemotherapy, consumed by its fiery obsession to obliterate the cancer cell, found its roots in the obverse logic: every poison might be a drug in disguise" (Mukherjee, 2010: 89). Some of these poisons-turned-drugs did work, if only for a limited time. With the creation of the National Cancer Institute, over which Farber presided as chairperson, more extensive research on the basic biology of cancer finally started to gain traction.

Molecular Biology and the Hallmarks of Cancer

From the research pioneered by Farber and his followers, the understanding of cancer on a biological basis has come a long way. Today, it is known that cancer is defined as "diseases in which abnormal cells divide without control and are able to invade other tissues" (National Cancer Institute, 2015). This typically happens due to a mutation or a fault in the cell DNA:

> The genetic material (DNA) of a cell can become damaged or changed, producing mutations that affect normal cell growth and division. When this happens, cells do not die when they should and new cells form when the body does not need them. The extra cells may form a mass of tissue called a tumor. (National Cancer Institute, 2015)

These divisions continue until the cells have replicated enough to become considered normal by the body (See Figure 1 in appendix for graphic).

Cells in normal tissues typically look organized and uniform. Any straying from that norm implies that cancerous mutations occurred. When pathologists examine cancer cells via biopsy under a microscope, they are looking for four specific characteristics that differentiate these cells from a normal cell:

- Cellular Proliferation: lots of extra cells piling up
- Intercellular Cohesion: cells get out of line and fall into disarray;
- Cytologic atypia: abnormal inside of cell (big bizarre nuclei, lots of nucleoli, clumped chromatin)
- Architectural atypia: bizarre overall architecture not ordered the way the organ normally orders itself. (Storella, 2014: 10)

There is also the matter of grading and staging of a tumor, two related but confusing concepts. "Grade of a cancer refers to how aggressive the cells look; Staging refers to other prognostic features like: tumor size, involved nodes, distant metastasis" (Storella, 2014: 12). It was originally assumed that these two concepts correlated highly with each other. However through visualization of many types of cancers, pathologists

have shown that cancers can vary highly: one could have a high staged tumor that has metastasized, but that cancer's cellular grade could be quite low.

The thinking that cancer is a simple mutation that multiplies in a single cell was challenged. In 2000 Hanahan and Weinberg articulated a unifying theory of cancer based on molecular biology called "The Hallmarks of Cancer." These hallmarks have been identified as characteristics that occur in all cancers. They are

1. self-sufficiency in growth signals
2. insensitivity to anti-growth signals
3. evading apoptosis
4. limitless replicative potential,
5. sustained angiogenesis
6. tissue invasion and metastasis (Hanahan and Weinberg, 2000: 58; see Figure 2 for reference).

These characteristics interact with each other to create a more insidious, challenging disease. It is important to understand how cancer manipulates these separate processes because normal cells use these capabilities to maintain their health. However, cancer's management of these qualities is purely for the need to survive and evade the body's defenses.

Self-sufficiency in growth signals occurs when the growth signals and cell communications in a cells microenvironment transform in three different ways:

> First, they can alter the level of growth signal itself…Second, the cancer cell can tweak the growth factor receptor itself, so that a larger-than-normal number of these receptors are present on the surface of the cancer cell…Finally, there are alterations further downstream of the signaling pathway, so that the requirement for growth factor and receptor are both bypassed. (Samarasinghe, Scientific American Part 1, 2014)

But these cells do not accomplish this by themselves. All of the cells are corrupted by the intent of a few.

The second hallmark is insensitivity to anti-growth signals. During a cell's four stages of growth, the cell depends on cyclin, cyclin dependent kinases (CDK's), and the retinoblastoma pathway to monitor its advancement in growth. Cancer cells evade this by creating "defects in the Retinoblastoma pathway…that are missing the services of a critical 'gatekeeper' of cell cycle progression; the absence of the Retinoblastoma gatekeeper permits persistent cell division" (Samarasinghe, Scientific American Part 2, 2014). By interacting with the self-sufficiency in growth signals, these two in combination produce mutated cells that multiply uncontrollably.

Evasion of apoptosis is the third hallmark. Apoptosis is the programmed death of a cell, when the regulatory machinery and signaling within and outside of the cell are corrupted, cells avoid apoptosis: "The most common method is the loss of the apoptosis gatekeeper, the protein P53" (Samarasinghe, Scientific American Part 3, 2014).

Limitless replicative potential, the fourth hallmark, is exactly what it sounds like. Normal cells stop replicating after a certain number of divisions, eventually undergoing apoptosis:

> How does a cell count its divisions? How does it 'know' when to stop? The answer is telomeres…(cancers) achieve this by destroying the cellular timekeeper, the telomere. Immortality comes at a price; the accumulation of damaging mutations only increases with time. (Samarasinghe, Scientific American Part 4, 2014)

Through the destruction of its telomeres, cancer cells can continue their replication without interference, each mutation more egregious than the next.

Sustained angiogenesis, or the ability to proliferate blood vessels in order to maintain growth, is the fifth hallmark of cancer. Typically, there is an on and off switch for angiogenesis, and it is normally used when we get a cut or wound. But cancer cells require constant sustenance, and have corrupted this process to continually keep angiogenesis "on": "The angiogenesis within the context of a tumor is a warped, twisted version of what it should be; the vessels are convoluted and excessively branched. They are distorted and enlarged, with erratic blood flow and leakage" (Samarasinghe, Scientific American Part 5, 2014). By maintaining its own blood supply a tumor need not rely on other methods of sustenance; it can create its own.

The final hallmark proposed by Hanahan and Weinberg is tissue invasion and metastasis. Cells are usually linked together at their epithelium, an outer skin, and in between these links is the extracellular matrix. When cells need to break apart, for example they need to respond to inflammation, these cells detach and are in a mesenchymal state. This is known as the Epitheleal to Mesenchymal Transition (EMT). The reverse of this can also happen (MET or Mesenchymal to Epitheleal transition) when the task of those cells is completed. Cancer cells use this pathway to detach themselves from a larger tumor, and can be carried throughout the blood stream to another location, known as metastasis:

> Cancer cells hijack this process, first to enable metastasis through activating the EMT program and then, once they reach their new home, to revert back to epithelial form by activating the MET program. Thus although the EMT-MET program has been known of in the context of embryonic development for many years, it is only recently that the significance of this EMT-MET program to cancer progression has been recognized. (Samarasinghe, Scientific American Part 6, 2014)

All of the aforementioned processes work together in a coordinated effort, making cancer a very complex disease. If one of these processes were stopped, cancers would not be able to thrive like they do. It is the ability of these corruptions to work in concert that makes cancer such an intriguing and deadly disease: it is a cell that can advance and survive past what is deemed necessary or possible.

In 2011, Hanahan and Weinberg revised their original research to include two additional hallmarks or "enabling characteristics" have been identified and contribute to the six already present in most tumors. The two new hallmarks are "deregulating cell energetics and avoiding immune destruction" (Hanahan and Weinberg, 2011: 658). Cells have certain regulating mechanisms that maintain their stability, and when these fail, the cell undergoes apoptosis. The avoidance of immune destruction occurs because the cells have coopted limited normal cells into helping the cancer sustain itself. These two together produce an even stronger cancer. The two enabling characteristics are "genome instability and mutation and tumor promoting inflammation" (Hanahan and Weinberg, 2011: 658). As the cell replicates, the genome it is composed of deteriorates or mutates to assist the cancer with its needs. By staying inflamed, the cancer can quickly retrieve a blood supply and enact the body's immune response to corrupt even more cells for its aid. Whether these are subcategories of the previous hallmarks or are their own entities is currently debated, but it is clear that these new methods of corruption aid in cancers' sustained life (see Figure 3).

Despite cancer's uncanny ability to maintain its survival, there are available treatment options, and more research has been accomplished to stop cancer's advance. The original methods of surgery, radiation, and chemotherapy are still the most common

and widely used, however newer theories are being assessed. Drugs for the BRCA1 and 2 mutations in breast cancer are becoming more readily available (Mukherjee, 2010). Other pharmaceuticals, such as Perjeta (pertuzumab generically), block the HER2 receptor in breast cancers that encourage the unbridled tumor growth (Pollack, 2014). Hanahan and Weinberg suggest that future cancer treatments and therapies will be derived from targeting the hallmarks they have discovered: "we can envisage that cotargeting of multiple core and emerging hallmark capabilities and enabling characteristics in mechanism-guided combinations will result in more effective and durable therapies for human cancer" (Hanahan and Weinberg, 2011: 668). A final emerging method is the idea of containing cancer or reprogramming the cells that have been coopted instead of destroying it. These immunotherapies are gaining traction: "immunotherapy coopts the body's immune system into attacking and eradicating the tumor…the emerging research on A.M.L suggests that at least some cancer cells might be redeemable" (Groopman, 2014: 47-49). With investment in these directions, more precise cancer treatments for this heterogeneous disease are developing.

Ductal Carcinoma In Situ (DCIS)

The specific cancer that I am focusing on in this study is Ductal Carcinoma In Situ of the breast (DCIS). This is a cancer of the milk ducts in a breast. A carcinoma is defined as "cancer that begins in the skin or in tissues that line or cover internal organs" (National Cancer Institute, 2015).

It is important to note here that cancer cells are currently recognized and classified by their microscopic appearance, using the histopathologic changes used in

cancer grading and staging. The existing taxonomy of cancer dates back to 1940's and 50's. It has always been based on "the location of the tumor in the body…and the morphology i.e., the appearance under a microscope " (Muir and Percy, 1991: 64). Subsequently, the WHO adopted a manual published by the American Cancer Society called The Manual of Tumor Nomenclature and Coding in the 1960's (SEER Historic Background, 2015). While there have been updates to this nomenclature, basic underlying principles have remained unchanged since the 1950's.

Specific classification and detection of DCIS has progressed through the use of biological markers (see Figure 4 for a complete breakdown). DCIS's categorization, like cancers generally, is heterogeneous and "the molecular categories of DCIS have not yet been finalized, nor have they gained clinical usage" (Trop et al, 2014: 1182). While a consensus has not yet been reached, scientists agree that Magnetic Resonance (MR) screenings are the best way to track and discover if a patient has DCIS: "Although not perfect, MR imaging offers the best method to predict pathologic complete response, a method superior to clinical evaluation, mammography, and US (Ultra Sound)" (Trop et al, 2014: 1190). Because this technology is the most advanced and is highly sensitive, more cases of DCIS are appearing on MR imaging that would not have been caught on older devices. "Incidentalomas," cases that on mammography and clinical evaluation would not appear, are more frequently appearing and being categorized as DCIS. This does not concur with the original step-wise process cancers are presumed to take; the malignant cells form and the ultimate steps are metastasis and invasion. DCIS is unique in that it may or may not follow this path.

This background is important when discussing a possible change in name when it comes to DCIS. Based on the current histopathologic classification system, DCIS meets the current definition of a carcinoma, including the smallest of lesions that appear on more accurate MR imaging. As has been addressed by Trop et al, DCIS is a heterogeneous subset itself; some of these lesions become invasive and metastasize, and some do not. Even with the current molecular understanding of cancer it is impossible to predict which case will progress to lethal invasive cancer and which will lie dormant. Therefore, the treatment has remained the same for all cases of DCIS: lumpectomy augmented with radiation (breast conserving therapy) or mastectomy. The contention comes when a specific case of DCIS does not progress, but the unnecessary treatment is implemented. With DCIS cases, the cancer becomes invasive or it stays benign; there is no gray area to define a state when the cancer simply *exists* (Esserman et al, 2013). The lack of language to describe this state in some DCIS situations is I believe, part of the reason of the continuation of treatment methods.

I argue in the next chapter that this treatment regimen of cutting and poisoning is exacerbated by the concepts and metaphor of war that are attached to cancer. When patients' conceptions of a disease coincide with the language of warfare, those patients are obligated to "fight" instead of observe. As we know, DCIS has the potential to not progress to the invasive stage. However, the strategy of "attack to defend" is so ingrained in cancer literature that not even DCIS can escape it. Furthermore, this language impacts the perception of the disease. Because there is no spectrum of classification for DCIS, it is important for both patients and doctors to consider alternate treatment possibilities without being clouded in their judgment by this metaphor. I argue President Nixon's

“War on Cancer” created a cancer culture where attacking is the only option doctors and patients have. Changing the perception and culture surrounding DCIS will require a different taxonomic system.

Chapter Two: The War on Cancer: When Reality Meets Metaphor

We cannot avoid metaphors, but we can become conscious of our metaphors – individual, professional, or socio-cultural – and critically assess them.

James F. Childress, *The War Metaphor in Public Policy: Some Moral Reflections*

The War Metaphor in Medicine

The war metaphor has been used as a trope in both literary works and public policy. Historically within politics and public policy, war metaphors have been used to equate a problem within public society to an entity that can be addressed through brute force. With a collectively agreed upon strategy, the problem is attacked and neutralized and society can progress. This metaphor permeates the language we use to describe even the most basic of concepts, and has warped our thinking of these entities while forgetting the nuance of what a war entails. For example, society has used metaphors such as the war on drugs, the war on AIDS, and others as language to combat problems. In this instance, murder becomes morally justifiable because the "enemy" is deviant.

Something as simple as an argument uses this type of language, and James F. Childress clarifies this. Within an argument, there are typically two different points of view. One person explains their idea, and then the second for refutes against that position. However, the typical terminology that describes such an event is equivalent to the language of warfare:

> Your claims are *indefensible…His criticisms were right on target*…It is important to see that we don't just *talk* about arguments in terms of war. We can actually win or lose arguments…It is in this sense that the ARGUMENT IS WAR metaphor is one that we live by in this culture; it structures the actions we perform in arguing. (Lakoff and Johnson, 1980: 4)

This bellicose language used to describe a simple event has been grafted onto our psyche and we cannot escape it. Imagine trying to describe the same argument scenario but free

from the metaphors that label it as an act of war. It would simply be two people having a discussion in which they fervently oppose views. However, this does not have the visual or visceral impact and drama that the war terminology brings to mind, and the subtle moral implications of warfare are lost when this language is used. An argument seems like a natural act as opposed to the intense discourse we visualize. This directly conflicts with the notion that war is a special instance of moral engagement because the moral goal justifies a means that is typically impermissible. This is where the metaphor contains its power: the ability to create a mental lens through which we see a world and describe such a world both expands our understanding of a subject, but conversely limits it to that specific lens.

Childress argues that the war metaphor began its use in public health and policy in the 1880's with the discovery of bacteria. These small cells that were contagious were believed to threaten the body and the body utilized its own "weapons," white blood cells of various types, to defend itself against a foreign body within by disposing of the intruder (Childress, 1992: 186). Having progressed from these early stages, we now understand bacteria as an integral part of our physiology, outnumbering even our own cells (NPR Bacteria Bonanza, 2010). But the metaphor continued in medicine through its usage in textbooks, studies, and descriptions of our immune system (see Figure 5). Today, doctors and patients alike accept the language of war as a descriptor of disease in hospitals.

Hospital vocabulary in particular depends on this metaphor. Within the medical language, this representation has integrated itself as the basis of description. We imagine the human body and the physician "battle against disease…develops a plan of

attack…treats aggressively, and expects compliance. Good patients are those who fight vigorously and refuse to give up. Victory is sought and defeat is feared" (Childress, 1992: 185). As with the previous example of an argument, it is difficult to separate the metaphor from the words to which it has attached itself. Anthropologists Scheper-Hughes and Lock argue that the biological illness itself is a coded metaphor, and that we can either use this language or instead subject ourselves to strict medical terminology:

> All of us can be open and responsive to the hidden language of pain and protest, rage and resistance, or we can silence it, cut it off by relegating our complaints to ever-expanding domains of medicine…once safely medicalized, however, the social issues are short-circuited, and the desperate message is lost in a bottle. (Scheper-Hughes and Lock, 1986: 138)

This ability to express our feelings about medicine is the benefit provided by the metaphor. The importance of metaphor lies in its ability to convey meaning to a foreign concept, particularly when the matter is complicated or nonsensical: "Metaphor provides the intellectual and linguistic tools for communication about senseless suffering, and yet also offers a plan for personal transformation in coping with illness" (Franks and Gibbs, 2002: 141). The metaphor makes itself relevant by opening a line of communication that is familiar in daily discourse, thereby permitting patients to express themselves in a way that seems natural. By permitting emotional expression, medicine is not strictly bound to its biological diseases but also to accommodating the expressions of those it seeks to help.

In accordance with the opinion that the medical conception of an illness is a metaphor, Donald Joralemon would stipulate that the actual characterization of a condition as a disease instead of referring to it as a natural process is a cultural phenomenon we've employed. Citing Peter Sedgwick, he claims that in nature, the

process of disease does not merit special recognition. However, through human naming and allegory, we give a natural development more weight and a new definition:

> Are there not fractures of bones, the fatal ruptures of tissues, the malignant multiplications of tumorous growths? Are not these, surely, events of nature? Yet these, as natural events, do not – prior to the human social meanings we attach to them – constitute sickness, illness, or disease (Sedgwick in Joralemon, 2006: 2-3)

This develops the usage of metaphors to describe an otherwise standard part of living. Humans are the only sentient group that distinguishes these categories as "bad" and imprinting names onto them creates the imagery of something that is not suitable for a human body. Additionally, it can narrow our vision of a disease in both treatment and procedure, and the war metaphor is particularly suited to that role. By narrowing the lens through which we see disease via the war metaphor, both doctors and patients become limited, not only in treatments and mentalities, but in the distribution of resources in medical care as well:

> When it comes to conquering the enemy, no price is too high. Surrender is unacceptable, either on the battlefield or in the hospital. Metaphorical frameworks such as these may make complex biological processes easier to understand, but they can also influence the organization and allocation of medical care and even limit our ability to conceive of alternative ways of caring for the sick. (Joralemon, 2006: 8)

Furthermore, the war metaphor is incorrect as it implies that fighting against oneself is logical: "There are conceptual weaknesses in the metaphor. There are no actual enemy invaders; the enemy is self…the weapons indiscriminately destroy the enemy (cancer cells) and the defenders (the immune system). And the battlefield is the patient's very body" (Reisfield and Wilson, 2004: 4025). It is through these limitations that society now considers how cancer should be dealt with, from diagnosis to treatment. To understand

why our culture views cancer this way, we must understand the origins of the metaphor in popular culture.

The Political War on Cancer

The initial lens through which we perceived cancer was one of shame and the inability to express that emotion. This view sis still prevalent as Susan Sontag explained that "for all the progress in treating cancer, many people still subscribe to Groddeck's equation: cancer = death" (Sontag, 1978: 19). While the statement was made in 1978, cancer remains a disease shrouded in mystery, and this mysteriousness, combined with Groddeck's equation, can lead to shame and humiliation of the patient: "the person dying of cancer is portrayed as robbed of all capacities of self-transcendence, humiliated by fear and agony…having a tumor generally arouses some feelings of shame" (Sontag, 1978: 17). However, with the establishment of a new metaphor and the "War on Cancer" lens to view cancer through, patients acquired the ability to speak about the disease to physicians without the feelings of shame and humiliation. This metaphor established itself during Nixon's presidency, while inadvertently illuminating a taboo disease.

The War on Cancer developed due to Sidney Farber and Mary Lasker's persistence to create a powerful platform that would urge the United States government to act on what they believed was *the* medical peril to solve in the 20th century. This cooperation was founded on Farber's work with childhood leukemia and Lasker's political sway. Farber, a scientist, and Lasker, a socialite, agreed on the ideology that cancer was an enemy. After meeting in the 1940's they soon partnered together to bring cancer to the forefront of American policy. It was this association that brought the

metaphor of crusade into the descriptions of cancer research and political jargon. Its use effectively persuaded congress and the nation that this was a fight the country should back:

> In the 1950's, Farber began to use the word *crusade* to describe their campaign against cancer. The word was deeply symbolic. For Sidney Farber, as for Mary Lasker, the cancer campaign was indeed turning into a "crusade," a scientific battle imbued with such fanatical intensity that only a religious metaphor could capture its essence. (Mukherjee, 2010: 115)

This persuasive metaphor, combining religious imagery with military ferocity, provided the language patients and doctors desired, while additionally convincing the president to act on behalf of those with the disease.

President Richard Nixon signed the National Cancer Act into law on December 23rd, 1971 due to mounting pressure from Farber and Lasker's union, as well as scientists seeking what Paul Ehrlich deemed a "magic bullet" cure (National Cancer Act, 1971). The act called for a complete overhaul of the way cancer was studied, as Congress believed cancer was a "leading cause of death in America" (National Cancer Act, 1971), when in fact heart disease was. The National Cancer Institute gained additional power to coordinate with President Nixon and a selected committee of oncologists and doctors to derive better treatment options for patients, while additionally researching how cancer functioned as a disease. This select group became known as the National Cancer Advisory Board (National Cancer Act, 1971). Concurrently, it was the board's duty not only to seek cures and treatment options, and to create prevention plans, but to also create facilities in which these goals could be met (National Cancer Act, 1971).

At the time of the bill's signing, Nixon was removing troops from Vietnam, and uniting the American people towards a common internal enemy appeared not only to be a

smart move politically, but also scientifically. Finding a cure for cancer would be the hallmark of Nixon's presidential career if accomplished, and while subduing the Viet Cong was not an attainable goal, cancer appeared to be a foe that could be conquered (Viewpoint BBC, 2013).

President Nixon's statement on the National Cancer Act called for complete coordination against the common enemy of cancer. He promised an "intensive campaign" by $100 million to the cause (Nixon, National Cancer Act Signing, 1971). While the text of his statement did not directly call this pursuit a "war", the statement uses the language of a call to arms:

> I should emphasize that a total national commitment means more than government. It means all the voluntary activities must also continue. We have to realize that only one-sixth of everything that is produced in America is produced by what government does. Five-sixths of what we do in America is produced by what people do in their voluntary and cooperative capacities. (Nixon, National Cancer Act Signing, 1971)

This call to action is a call to war for the entire nation. The rhetoric he uses signifies battle motifs: a call to war from citizens who truly understanding the meaning of what this means both from the individual standpoint, but also the military one. Nixon refers primarily to the medical pursuit as the "conquest of cancer" (Nixon, National Cancer Act Signing, 1971), evoking the visions of the crusades of King Arthur in the 11th century and even calling upon what many consider "the greatest generation," who fought in both World Wars and aided through voluntary efforts in the community, and knew what it meant to serve.

In the short term, the NCI developed serious chemical weapons that they believed would stop cancer from growing and, if they proved effective, exterminate the disease completely in the human body. Chemical combinations such as VAMP, ABVD, BEP, C-

MOPP, and others were the supposed "magic bullet" oncologists were searching for in their answer for a cure (Mukherjee, 2010: 207). However, this strategy failed over time, as many realized that chemical combinations not only destroyed the cancer, but the human body as well. For the drug cocktails, it was quite literally a fight for the right to live, because if the cancer did not kill you first, the potent drug combinations would do so even in the cancer's absence.

These drugs, in combination with Nixon's "conquest" that required the full cooperation of the American people, created the war terminology we use for cancer today. Until this point, cancer was typically a shameful secret among patients that was not discussed due to stigma. But with this new lexicon that used weapons, targets, and combative strategies instead of passivity, patients and doctors alike had a way to impart social understanding to a biological process. This provided a perception of malignant cells into an entity that could be beaten through the doctor's strategies and a patient's resilience, and this vocabulary usage of "the battle of cancer" and "war on cancer" spikes in documented literature after Nixon's declaration against the common enemy (see Figure 6).

Cancer and its Metaphor

For cancer, the war metaphor is tied directly to it. As discussed previously, cancer is a mutation of a cell that evolves into a hyperplastic state: the unbridled growth and consumption of normal tissues it create an environment in which the bodies' own immune system does not recognize it since the cells that compose cancer are that of the same human entity. The cancer then metastasizes until it reaches a level of growth that

cannot be controlled: the body is infected and cannot fight back. In nature, this would be deemed a simple biological process. However, due to the attachment of the war metaphor, the trope plays out in society's view as well as the persons own body, as a "fight" against an "invader" with medical "weapons" are used to "dispose of", "attack", and even "destroy" the cancer, the goal being to not damage the healthy cells and human surrounding it, leaving the person a "survivor". Typical treatments both historic and current try to starve out the cancer but in the process of doing so also destroy the human. In gaining survivorship from cancer, a person has survived a medical gauntlet of tests, therapies, and unquantifiable pain equivalent to that of being a war veteran. This, coupled with doctors' advice to attack and fight the disease instead of trying to contain it, amounts to not only a "war" on the disease, but on the person themselves.

However, this allegory does not capture the nuances of war that are presented in actual combat. Childress would argue that the morality of the war metaphor should be questioned. Are we not in this process accepting murder not only of the cancer, but of the person as well? Childress would claim that the War on Cancer would "require moral justification, and its justification must meet a heavy burden of proof. When killing is justified, the prima facie duty to not kill doesn't just evaporate – it continues to exert a moral pressure on our conduct and on our attitudes" (Childress, 1992: 182). However, this moral pressure Childress speaks of has evaporated, as the shortsighted goal of winning the War on Cancer has neglected the patients.

Here we must consider Sontag's argument that cancer has become its metaphor. If, as she claims "the illness is the culprit. But it is also the cancer patient who is made culpable…the disease itself becomes a metaphor. Then, in the name of the disease…that

horror is imposed on other things" (Sontag, 1978: 57-58), then this inseparability should be a cause for concern as Childress' comments on moral attitudes towards the disease come into direct conflict with the patient. The patient's body in Sontag and Childress' views becomes a battlefield, and the morality of saving the patient both mentally and physically is lost. This directly conflicts with the morals of war, as now the destruction of the patient is justified: the patient *is* their cancer.

While Sontag argues that stripping the metaphor from the disease and leaving only the biology behind is what is most sought after, this would abandon a language that is necessary to the mind-body connection of the patient. Without the use of metaphors to describe an illness, "we are without a language with which to address the mind-body-society interactions, and so are left hanging in mid-air, suspended in hyphens that testify to the radical disconnectedness of our thoughts" (Scheper-Hughes and Lock, 1986: 137). As aforementioned, the need for emotional expression of a biological entity is still present. But the lack of subtlety the war metaphor provides leaves patients without this ability.

While some patients agree with the war terminology, both scientists and patients alike have used other analogies to discuss cancer. Michael Overduin, a professor at Birmingham University, does create "warheads" that fit into cancer cells so normal cells don't deteriorate. However, he thinks of cancer more as an orchestra: "Cells work together like the players in an orchestra playing a symphony…But if a cell is malfunctioning it produces dissonance. The instrument may need to be retuned or the cell retrained" (Viewpoint, BBC, 2013). Another metaphor that is used by Jim Cotter, a poet and priest, is that "his cancerous bone marrow is like a garden that has become

overgrown with weeds. The weedkiller that takes out the weeds also damages the healthy plants. But with luck the good plants may re-grow" (Viewpoint, BBC, 2013). The symphony metaphor redirects the battle motif to a simple cellular malfunction, while the over grown garden allegory keeps the same language of killing and destruction. The importance lies in that it is the patient's decision about which metaphor they use to describe their illness. Instead of thrusting onto them a metaphor that is disagreeable, patients should have the choice in selecting which metaphor describes their cancer.

Cancer as a Label

One reason the proliferation of this metaphor has occurred is due to the stigmatization and labeling of the war metaphor and its attachment to cancer. The two in combination are what produce this stigma, as the war metaphor alone could be combined with any number of scenarios. This inability to detach the war metaphor from the cancer leads to the labeling and stigmatization of the patients it is trying to emotionally and verbally assist.

Labeling theory is a categorization of social deviance, or "otherness," of one group by emphasizing that group's difference. This "othering" occurs in two ways: The first is through the complex factors that initiate the labeling of a deviant group. The second is the reinforcement of those deviant behaviors as opposed to society's perceived "normal" behaviors (Oxford Reference). If we are to apply this theory to cancer and the war metaphor, then we must define what is "normal" and "deviant" behavior.

In this case, the deviance and labeling is two-fold. Cancer and malignant cells are deviant in that the body is mass-producing something that it should not be. As Joralemon

has argued, it is the application of deviance by society that is critical, not the malignant cells being present. Typical cell production is the norm, and doctors can document this norm in blood tests. Furthermore, a patient who does not "fight" within the boundaries of the war metaphor's parameters is considered deviant. A patient is expected to use this language as a "survivor" if they win the "war" and if they do not, they are considered weak. Whether or not a person uses such metaphors is highly variable: "Some people who have cancer find the language of battle useful - but not all of us. Some of us need new metaphors that come closer to our own experience" (Viewpoint, BBC). This double deviance on behalf of the patient – having a body that by society's standards is abnormal, coupled with the rejection of the war metaphor in favor of something less aggressive – puts the patient in a position of double stigmatization, not only from society, but also from their own doctor.

Stigma, like deviance, is a two-fold circumstance. Stigma has the characteristics of "the co-occurrence of its components – labeling, stereotype, separation, status loss, and discrimination – and further indicate that for stigmatization to occur, power must be exercised" (Link and Phelan, 2011: 363). Cancer itself is stigmatized as "ill-omened, abominable, repugnant to the senses" (Sontag, 1978: 9), even though today's medicines and treatments can control the disease for years. As a deviant form of the human condition, cancer separates its victim from society, fulfilling this definition. This stigma is compounded by the power of the doctors exercising their control to over-treat the illness. Because of the war metaphor, the inclination among physicians is to fight the cancer through any method necessary instead of considering all possible alternatives that could contain the cancer instead of obliterate it. The concept of a passive response to

cancer is one that deviates the patient from the typical war-like mentally, and this labels them as inactive, even if that option may be the better course of action. This is the reason patients should choose the metaphor that describes their cancer instead of being thrust into an analogy that is inconsistent with their personal approach to cancer.

This is not to say that the war metaphor for cancer is the most useful for some patients. Cancer is an invader that does multiply and invade healthy tissues, thereby threatening one's health. However, the metaphor for the *treatment* of cancer can evolve beyond that of the war metaphor. Lumpectomies, mastectomies, and aggressive chemotherapy are no longer the only methods for treatment. Genetic factors and switches can be manipulated, and new medications have been manufactured for a small number of cancers that have produced solid results. As medicine progresses towards new treatments of cancer, the war metaphor must evolve to accommodate the just and moral fight that Childress describes. If the metaphor does not account for this, a more sophisticated one may be preferable.

One possible route of evolution is for patients to use multiple metaphors once diagnosed with cancer, considering "no single metaphor alone is capable of capturing the complexity of the individual woman's thinking about cancer. Many metaphors are needed to make sense of the different aspects of learning about being ill, treatment, and healing" (Franks and Gibbs, 2002: 161). These metaphors included cancer and life as a journey, a gambling game, a bank account, and many others (see figure 7 for complete breakdown). The metaphor cited most frequently by the women interviewed in Franks and Gibbs' (2012) study was life as a journey, and it serves as a more benevolent one than that of war: "like the martial metaphor, the journey metaphor offers excellent cross-domain

mapping. It allows for discussions of goals, directions, and progress. Quieter than the military metaphor, it still has the depth, richness, and gravitas to be applicable to the cancer experience" (Reisfield and Wilson, 2004: 4026). Therefore, if patients should choose, inadvisably, a singular metaphor to describe their cancer experience, the journey metaphor provides a more accessible vision than the war metaphor.

Despite all of these analyses, the war metaphor within the cancer community has arguably changed little since Nixon's initiation of the idea. Do doctors drop the metaphor at some point when someone who really is "fighting" hard eventually succumbs? Does the metaphor determine understanding, or is it applied opportunistically? Does it shape cognition, or is it used by cognition working at a deeper level? These are the questions that must be addressed in future endeavors to describe cancer.

Of utmost importance is a doctor's recognition of this metaphor when treating a patient. In the following chapter, I will deconstruct Dr. Laura Esserman's research on the possibility of renaming DCIS as Indolent Lesion of Epithelial Origin (IDLE) and how this has affected the cancer community, both for better and worse. While I believe her solution is too simplistic, it is a necessary starting point for interactions among doctors, patients, and biomedical scientists. Because these groups remain separate in their solutions to this problem, no consensus has yet been reached. I propose that Esserman's work be considered across a variety of solutions to ensure a proper resolution for a potential taxonomic change.

Chapter 3: Ductal Carcinoma In Situ Versus Indolent Lesion of Epithelial Origin: Dr. Laura Esserman's "War"

The suggestion that cancer taxonomy be revised to reflect binary classification as either indolent or lethal constitutes casual oversimplification that is unsupported by the present molecular understanding of disease.

R. Brooks Robey, *Changing the Terminology of Cancer: To the Editor*

Dr. Laura Esserman and the Push for IDLE

Dr. Laura Esserman is a breast cancer surgeon and professor of Surgery at the University of California, San Francisco Medical Center where she has been the Director of the Carol Franc Buck Breast Care Center since 1996 (Beck, Wall Street Journal: 2014). She and her colleagues have suggested changing the name of DCIS to Indolent Lesion of Epithelial Origin (IDLE) (Esserman et al, Lancet Oncology, 2014: e234). They suggest this change to address the potential overdiagnosis and over treatment of breast cancers in women.

Esserman proposes a less-is-more approach. DCIS is considered "an abnormality that most specialists call 'stage zero' breast cancer — on a scale of 1 to 4. In many cases it doesn't ever progress to invasive cancer, the type that can be life-threatening" (Neighmond, NPR: 2013). While there is the potential that abnormal cells could further mutate into invasive cancer, only about 20% of DCIS cases will do so (Esserman et al, 2013: 1830). From this biological standpoint, Esserman counsels that there is no need to panic and rush into surgery. She advises keeping a watchful eye on the lesion and using hormone therapy as the first line treatment. While Esserman's proposed approach is being studied in clinical trials, it is different from the current standard of care. The current standard is lumpectomy and radiation (breast conserving therapy) or mastectomy is required to ensure that there is no possibility of the lesion metastasizing.

Esserman's proposal also is rooted in this belief that the term "cancer" scares patients and distorts treatment decisions. As discussed previously, "cancer" brings with it connotations of war and death. Esserman believes a change in the language based on more sophisticated biologic understanding could mitigate the effects the metaphor has on our thinking:

> The word 'cancer' often invokes the specter of an inexorably lethal process; however, cancers are heterogeneous and can follow multiple paths, not all of which progress to metastases and death, and include indolent disease that cause no harm during the patient's life time. Better biology alone can explain better outcomes. (Esserman, Thompson, and Reid, 2013: 797)

Both patients and doctors, she says, are guilty of assuming the worst when they hear the terminology: "when patients hear the word cancer, most assume they have a disease that will progress, metastasize, and cause death. Many physicians think so as well, and act or advise their patients accordingly" (Esserman et al, 2014: e234).

Esserman's belief is not just based on a hypothesis or anecdotal evidence. To evaluate whether the language used to describe DCIS matters in both treatment and surveillance, Esserman surveyed 394 healthy women who had no history of cancer. These women were then randomly told they had one of the following descriptions of DCIS: noninvasive breast cancer, breast lesion, or abnormal cells. They were not directly told they had DCIS. These patients then chose a treatment option for the disease description. These treatment options were surgery, medication, or surveillance (Esserman, et al, 2013: 1830). There were statistically significant difference in which treatment option patients elected depending on the description of DCIS. Those patients who were told they had a lesion or abnormal cells were more than 62-69% likely to elect a nonsurgical option than those who were told they had noninvasive breast cancer. When told they had noninvasive

breast cancer, patients were more than 53% likely to elect a nonsurgical option (Esserman, et al, 2013: 1830). While these two appear close in percentages, Esserman found significant differences in results: nearly 10% more women who were not given a diagnosis with the term "cancer" were likely to elect a nonsurgical option. Framing the disease differently led to alternate treatment outcomes (see Figure 8 for full statistical breakdown of the study). As I will show later, this supports a lighter version of the Sapir Whorf Hypothesis, that language controls thought, because language does appear to play a role in determining which course of treatment a patient will choose. It is up to doctors and patients to make a coordinated effort to educate them about this matter and to act accordingly.

Esserman and her colleagues list multiple potential remedies to the problem of potential panicking of patients with resulting overtreatment. She includes changing the basic terminology, creating registries for lesions so they can be classified correctly, and more education and precision on cancers and how to diagnose them (Esserman, 2013: 797-798). Typically, solutions such as these would split doctors into supporting a method they feel is best. However, all solutions listed by this group incorporate patients, doctors, and multiple sources of information that work together to come to a better terminology and solutions that could work. These are the minimal steps that Esserman and her colleagues are asking fellow practitioners to adopt in order to address the alleged overdiagnosis and overtreatment of precancerous lesions. It is hoped that these steps can be taken because “altering the semantics will reduce the anxiety brought about by one of these diagnoses” (Mulcahy, 2013: 3) This strategy, to reserve cancer as a term only for those lesions that are actually invasive or metastasizing, seeks to distinguish diseases

such as DCIS that may not progress into something more, thereby saving patients from potentially unnecessary treatment and expense.

This call for a change in terminology is not solely Esserman's idea. Dr. Otis Brawley, Chief Medical Officer for the American Cancer Society, describes the need for a change in the language surrounding DCIS:

> What we're trying to do is spare some people the harms associated with unnecessary treatment. And there's a lot of people who are demanding unnecessary treatment, there's a lot of doctors who don't understand that every cancer is not highly aggressive and there's a wide spectrum of cancers. Helping those doctors understand, helping the patients understand. (Martin, NPR: 2013)

One reason Esserman wishes to change the taxonomy is because of the psychological impacts. The Sapir-Whorf hypothesis, which suggests that language influences and structures our thoughts, is relevant here. Whorfianism suggests why changing the taxonomy is necessary as opposed to optional, as people's behaviors could change in response to a change to taxonomy.

Professor Edward Sapir and student Benjamin Lee Whorf formulated their hypothesis at Yale in the 1930's. Both studied the Hopi language, and this spawned a transformative idea: that the language one spoke directly controlled their thoughts (Deutscher, 2010: 130). This concept had intriguing implications: if one spoke a different language, their thoughts could not exceed the bounds that language created. For Sapir and Whorf, this was groundbreaking:

> The grammar of each language…is not merely a reproducing instrument for voicing ideas, but rather is itself the shaper of ideas, the program and guide for the individuals mental activity, for his analysis of impressions…we dissect nature along lines laid down by our native languages. (Whorf via Deutscher, 2010: 140)

This new concept of Linguistic Relativity sparked a debate amongst linguists for years to come.

Others who refined this concept included the anthropologist Franz Boas and linguist Roman Jakobson. Both believed that it wasn't thoughts that were confined by language. Rather, it was what was *mandatorily* expressed versus what *could* be expressed in any given language that mattered: "languages differ essentially in what they must convey and not in what they may convey" (Jakobson via Deutscher, 2010: 150). This was based on the concept that instead of languages confining the thoughts of people, any idea could be expressed in any language: it would simply be refined to what fit in that specific language.

The premise of Linguistic Relativism and the Boas-Jakobson Theory is quite appealing: certain languages require speakers to mandatorily convey certain aspects, therefore influencing their thought processes. Across languages, this implies that similar concepts must be processed differently. But does language truly constrain thought? According to John McWhorter, that is a false belief.

McWhorter believes that, while there is some truth to Linguistic Relativity, the impact it has across languages is so minor that there is no discernable difference. Many linguists today have tested these effects through countless studies, but McWhorter concludes their work shows how small these results are: "most would consider it a fair assessment that the work of this cohort, often termed the 'Neo-Whorfians,' has shown that languages' effect on thought is distinctly subtle, and overall, minor" (McWhorter 2014: xiv).

While across languages Sapir-Whorf has shown little evidence for language controlling thought, what about *within* a language? Esserman's study in changing the language she used for doctors and patients had significant results, which implies that the language is controlling the thought process. While the Sapir-Whorf hypothesis may be too strong for this particular case, the Boas-Jakobson Theory has some merit here, as Groddeck's Equation (cancer=death) is still in effect when patients hear the word "cancer." Esserman would not have significant results if the Sapir-Whorf Hypothesis were entirely false. It is important to consider this as a feasible explanation for her outcomes. Furthermore, if Esserman is suggesting that there is no middle ground between benign and malignant tumors, and that her solution of IDLE fits that gray area, then the language surrounding cancer is influencing how patients and doctors proceed.

These differences have real world implications given the nature of DCIS. For example, early detection and prevention methods have led to an abundance of early biopsies: "fuelled by fear of missing the chance for early detection, an aggressive strategy of undertaking biopsies has evolved" (Esserman et al, 2014: e237). But it turns out that DCIS is a tricky disease to grapple with and define. The assumed progression of any type of cancer is a linear progression: the cancer eventually metastasizes and kills a patient. However, more recent research has shown that cancer is not a homogenous disease and different cancers can develop (or not) in different ways over varying periods of time (See Figure 9). Some DCIS and similar lesions fall under indolent or regressive states, and the potential progression to a more invasive and deadly disease is less assured. It may be that most DCIS cases do not progress to an invasive state, and therefore patients avoid unnecessary treatments. This does not mean that early detection and prevention have not

worked in assisting both patients and doctors identify to cancers and save lives. However, it may also have led to more procedures than may be necessary.

Agree to Disagree: Oncologists' Opinions on Language Change

Many oncologists and others within the cancer community have resisted Esserman's proposal. The current language, they believe, has worked well, saved lives, and aided preventative measures for many cancers. They argue that some overdiagnosis is acceptable if it provides greater assurance of treating cancer that could progress and avoiding the complications and harm of that progression (Capurso and Robey, 2014).

Biologically, these medical professionals believe that DCIS remains consistent with traditional histopathologic definitions of cancer. Therefore, physicians believe it is better to assume DCIS is likely to progress to full-blown invasive cancer in order to protect patients. This is accomplished through vigilant screening and treatment with breast conserving therapy (lumpectomy and radiation) or mastectomy. For doctors, assuming the worst in a case protects against the possibility of an unfavorable outcome:

> "I am confident that somewhere between 10% and 30% of women with localized invasive breast cancer would be just fine if we just watched them," says Otis Brawley, chief medical officer of the American Cancer Society. "But I cannot look into a patient's eyes and say, 'You're one of the 10% to 30% that should not be treated.' (Beck, Wall Street Journal: 2014)

Without knowing which patient's cancers will metastasize, the current treatment assumes that all of these lesions will progress: more treatment is better, and there is less chance of further progression.

Medical professionals also disagree with Esserman's viewpoint from a psychological perspective. Cancer patients who had DCIS consider themselves to be

cancer survivors, and a new definition that rejects that status comes with consequences: "they do not consider the psychological consequences of changing a diagnosis for millions of people who already see themselves as cancer survivors…for better or worse, is no longer a diagnosis, it is an identity" (Capurso, 2014: 202). This would invalidate the experiences of many cancer patients, and their identity as patients would effectively be stripped and no longer considered in a conversation about both treatments and therapies. This could effectively do more harm than good, as these "survivors" deserve a voice if a change in lexicon is to take place. This will be addressed further in chapter 4.

Others agree that the taxonomy is potentially incorrect, but that Esserman and her colleagues' treatment of the issue is only a simplistic dichotomy, and does not allow for flexibility. There is the potential that merely changing the name of DCIS will not produce the results she is looking for, and instead will cause more confusion for patients and doctors alike. Robey (2014) disagrees that cancer is either lethal or indolent, and that there is no middle condition that could arise. But as we have seen with the classification of lethal and nonlethal cancers, there is a space that could be occupied by those cancers that move from indolent to aggressive but are not necessarily lethal. Esserman's solution is too simple in its approach, and does not provide enough depth or nuance:

> Although the need for terminology reform is urgent, I would caution Esserman and colleagues that they could be underestimating the challenges they will face when extending their reform efforts beyond examples of clear-cut misuse of malignant terminology (eg low grade ductal carcinoma in situ). (Foucar, 2014: e306)

It is this grey area where Esserman's argument for a binary definition and word change is questioned. More classification and understanding would be needed in order to change the taxonomy, and a consensus would be required.

Finally, an objection to Esserman's proposed name change is that doctors are using internationally accepted taxonomy and terminology upon which evidence-based treatment regimens have been formulated. Considering a name change implication, categorizing a potentially cancerous lesion as indolent too early could result in malpractice suits from patients who feel that their doctors have not met the standard of care by experiencing a poor outcome. Doctors are unwilling to take that chance with a disease as diverse as cancer. Management in the currently flawed system is the safest approach that doctors can currently take:

> Renaming a destructive and sometimes fatal disease – to make it sound harmless – is a disservice to our patients. Rather than suggesting a semantic change that is potentially harmful, it would be more constructive to start planning how to best manage the epidemic at hand. (Coldiron et al, 2014: e307)

Economic Consequences

The government also has a stake in a potential name change for cancer. At the current rate of growth, health care expenditures are projected to reach 34% of GDP by 2040 (The White House, 2009). The existing fee-for-service system creates a system whereby clinicians need to perform more procedures in order to meet hospital quotas, even if that procedure may not be medically necessary (Ramsey, 2015). In 2010, Congress passed the Affordable Care Act (U.S Department of Health and Human Services, 2010). A goal of the ACA was to improve quality of care while lowering costs,

frequently referred to as "bending the cost curve" by creating incentives for physicians to provide quality care without performing unnecessary tests (Leichleiter, Forbes, 2014).

If the definition of cancer changes, the government would recommend against treatments and procedures deemed "unnecessary" to save society the cost of overtreatment:

> Government will soon account for 66% of health spending and is aggressively seeking to limit health expenditures. Hence, the government may have a vested interest in definitions that err towards undertreatment, rather than overtreatment. We must remain vigilant against any attempts by the government to use language as a tool of covert rationing. (Hsieh, Forbes: 2013)

The government in this instance would be morally compromised because it would have financial incentives to change the name, as lower expenditures would be directly tied to the new language. Concurrently, patients may also be swayed to accept a name change if it means saving themselves money on unnecessary treatments. Patients and consumers should be cautious when considering this name change.

If the name changes, and DCIS is not cancer, then insurance companies could argue that there is no medical justification to pay for screening exams. Again, the financial incentive to do less might lead to the underdiagnosis that doctors want to avoid and presents ethical issues. While further research on the political and economic consequences of a name change is warranted, that is beyond the scope of this thesis.

Concurrently, while the taxonomy might be flawed, it could also be the case that the understanding of cancer biology is not far enough along to make a semantic leap quite yet. A taxonomy that allowed for biological change over time would be ideal. However, some argue (Capurso and Robey, 2014) that the basic understanding of cancer biology is not large enough to make such a big jump. Until such a point is reached, modifying the

taxonomy without the most accurate medical knowledge would be a waste. With these important arguments in mind, proceeding with a new definition of these indolent lesions requires the attention of all of voices.

Can a Solution be reached?

In order to reach a plausible solution for redefining DCIS, three factors must be addressed. First, the assumption that the current taxonomical definition of DCIS and other similar lesions is inadequate both on a semantic level and on a biological level must be true. By this, I mean that the current definition does not adequately represent the biology being used to describe DCIS. Second, a method for creating a new taxonomy would require the cooperative involvement of pathologists, doctors, patients, and all those who are affected by cancer. Through standpoint theory, which claims that those with different viewpoints should collaborate, as all standpoints are different (Oxford Reference), I will defend this notion. Finally, such taxonomy would need to be malleable over time by the NAS and NCI, the governing bodies: change is the only constant in science, and a new definition would need to allow for this.

With the advent of "precision medicine" – a more recognized term for "personalized medicine" – such a change in definition may become possible. As medicine becomes more tailored to individual patients, doctors need to be more accurate in their diagnoses. However, merely changing the name, like Esserman suggests, can only do so much. For example, in Brazil, practitioners have pushed to change the name of Leprosy to Hansen's Disease, as the former is too entrenched in stigma. Some patients of Hansen's Disease feel that "hanseníase was a euphemism, a fancy term used by doctors

to talk about leprosy to hide the truth from them" (White, 2005: 319). The goal of the new cancer taxonomy should not be to euphemize the disease for patients, but rather to elucidate a confusing concept so the description is more accurate. In the next chapter, we will analyze a proposed solution provided by the NCI to this name change and how it would affect precision medicine and future cancer patients.

Chapter 4: Moving Forward: How to Conceptualize a New Language for Cancer

Taxonomy is the practice and science of classification, typically considered in the context of biology…The Committee envisions a comprehensive disease taxonomy that brings the biomedical-research, public health, and health-care-delivery communities together around the related goals of advancing our understanding of disease pathogenesis and improving health.

Committee on a Framework for Developing a New Taxonomy of Disease

Persuasive Arguments From Dr. Esserman

Esserman does make a persuasive argument for *why* the language surrounding DCIS should change. The question moving forward now is not whether the taxonomy should change; it is evident that there is a discrepancy between the science and language. Rather, the new question is whether Esserman's approach is the best solution to this problem.

As discussed previously, Esserman's primary argument is that DCIS is the incorrect description for certain lesions of the breast ducts that have characteristics associated with the definition of cancer, and this terminology should be void of the term "carcinoma" entirely. The reasoning is that, biologically, these lesions do not have the invasive character of cancer yet, and the word "cancer" instills fear into patients and doctors, clouding their judgment before a true assessment can even begin. It is important to assess whether Esserman's biologically based argument is persuasive.

Esserman is correct in arguing that a change in taxonomy is warranted to reflect accurately the current scientific understanding of the nature and development of cancer. The current taxonomy used by oncologist's stems from an understanding of the disease that was informed only by microscopic study of tissues. More recently, scientists have

developed a better understanding of how cancer operates. With the advent of light microscopy and an understanding of the cell cycle, scientists have determined that the simple linearized track progression model of cancer is overly simplistic. Scientists now understand that cancer is a heterogeneous disease, and that evaluation of abnormal cells requires a more careful comparison and analysis of such cells with each other and with normal cells. Because the assumed step-wise progression of abnormal cells to cancer, which is reflected in the traditional taxonomy, is scientifically insufficient, Esserman is correct in stating that some forms of DCIS may not progress to the metastatic stage, so that characterizing all DCIS as "cancer" may imply adverse development that will never occur.

Furthermore, as much as we may not wish to admit it, Groddeck's Equation mentioned by Susan Sontag is still correct for many patients. Combined with the Boas-Jakobson claim that language subtly governs thought, cancer still bears weight as a psychologically damning word, whether in its earliest stages or on a patient's deathbed. If patients can be spared the psychological and economic burdens caused when practitioners use the word "cancer," then it would be desirable to implement a change that could avoid this. To the extent that precise, nuanced diagnosis and explanation can be provided, this could result in carefully tailored treatment recommendations, including close monitoring, so that patients would not be subjected to unnecessary harsh or disfiguring therapies. From this standpoint, Esserman's point is completely valid.

Esserman's Inaccuracies

However, Esserman's broad recommendation that DCIS should be renamed IDLE is an inadequate remedy for the problem she has identified. Mere modification of the name does not change the facts that some cases of DCIS will become metastatic or invasive and that medicine currently lacks tools to predict accurately which cases will (or won't) progress. Thus, many doctors disagree with Esserman's proposal because until the doctors have ability to predict which patients with DCIS will develop further disease and which ones will not, the proposed renaming would increase the risk for underdiagnosis of breast cancer. The evolution of radiological technology has enhanced physicians' ability to identify DCIS and other abnormalities at earlier stages, which increases the opportunity for treatment that can reduce morbidity and mortality from cancer. Doctors and patients who believe Groddeck's Equation, that cancer is equivalent to death, feel it is better to be cautious with cancer and confront it from the start rather than wait and see how it develops. A mere word change does not negate the possibility of this disease being deadly.

What Esserman has suggested is an undeveloped, incomplete fix for a terminology that needs massive reconstruction. Renaming all cancers as something other than "cancer" under the assumption that some or many of these lesions will not progress to a dangerous metastatic level will discard much of the progress doctors have achieved in enhanced cancer diagnosis and deprive some patients of the opportunity for successful treatment. Esserman's argument is based on the supposition that merely changing the name is the "ideal" way to address this issue. As an issue of distributive justice, ideal theory "concerns hypothetical institutional arrangements that are just, known to be just,

and whose requirements are largely complied with by those to whom they apply" (Emanuel and Millum, 2012: 9). In this instance, the ideal scenario is that changing DCIS to IDLE would work perfectly, and doctors could easily identify which patients had invasive cancers. However, we are in a "non-ideal" scenario: "non-ideal theory deals with the obligations that arise either when institutional arrangements are not just or when some of the individuals subject to the institutions do not comply with them" (Emanuel and Millum, 2012: 9). While Esserman's overhaul would be perfect in an ideal situation, one in which all cases of DCIS could be treated as IDLE's and none would become invasive, that simply does not exist. We still do not know which cases of DCIS will transform past the invasive stage. From this perspective, Esserman's argument is therefore invalid in that it does not address this non-ideal scenario. Another route must be taken to compensate for this.

NAS' Suggestions for a Better Taxonomy

What is now required is a more ambitious reform than Esserman's Band-Aid fix: that is, a new taxonomy for the disease now labeled "cancer" is required. The concept of developing a new taxonomy, not only for cancer, but also for all diseases, is not new. In 2011, the National Academy of Sciences coordinated with the National Research Council to create a committee to develop a new medical taxonomy for diseases. This committee was composed of scientists, pharmacologists and doctors spanning many fields, and together they outlined the potential for a new taxonomy of all diseases based upon current molecular biology, and then developed a framework through which this taxonomy could

be implemented. To this end, the committee constructed a report on the potential for taxonomic change. The committee report discussed three important aspects of a potential taxonomic change: why the taxonomy needs to change, what such taxonomy would look like, and how this taxonomic change would come to fruition (NAS, 2011: xi-xii).

This taxonomy is part of an emerging field of medicine known as "precision medicine." This term refers to the new desire for more "personalized" or "precise" medical care that focuses more on the individual patient and her particular biological characteristic than past approaches have done. "'Personalized' implies the prospect of devising a different treatment for each individual patient" (Katsnelson, 2013: 249). While this may be the ultimate future goal of medicine, we lack enough data on every person that could require medical care. Conversely, "precision" medicine attempts to classify those diseases that afflict patients with more accuracy influenced by the most recent medical science: "We are trying to convey a more precise classification of disease into subgroups that in the past have been lumped together because there wasn't a clear way to discriminate between them" (Katsnelson, 2013: 249). It is from this precision medicine standpoint that the Committee evaluates the need for a new taxonomy on disease.

In arguing for why the medical taxonomy needs to change, the Committee explains that our current language does not accurately reflect certain conditions. For example, Type II Diabetes is identified through certain signs and symptoms, and is also treated with metformin, a drug that has been used for over 50 years. There is little concrete molecular information that could help individual patients receive the most effective, precisely tailored treatment (NAS, 2011: 10). This leads to a lack of

information to both patients and doctors. By developing what they have deemed a "Knowledge Network" and "Information Commons," this could be easily addressed:

> The rise of data-intensive biology, advances in information technology, and changes in the way healthcare is delivered have created a compelling opportunity to improve the diagnosis and treatment of disease by developing a Knowledge Network, and associated New Taxonomy, that would integrate biological, patient, and outcomes data on a scale hitherto beyond our reach. (NAS, 2011: 21)

By integrating all facets of healthcare that are now available to us, a new taxonomy could reflect this in every patient, coinciding with the development of "precision medicine." This is where the second part of their review, what such taxonomy would accomplish, becomes important.

To start, the Knowledge Network would be created, and this database would catalog all medical conditions on a microbiological level, instead of only on the signs and symptoms we typically associate with such conditions. Through taking statistic biological samples from patients within a certain condition and developing biological and statistical analyses, the genetic and molecular biology affecting each individual disease can be better identified, studied, and understood. As far as DCIS/IDLE is concerned, this Knowledge Network could track which patients with certain genetic variations will develop metastatic cancers and which patients will not. The Committee believes that this would be accomplished in the following ways:

> They would drive development of a disease taxonomy that describes and defines diseases based on their intrinsic biology in addition to traditional physical "signs and symptoms"…They would go beyond description and be directly linked to a deeper understanding of disease mechanisms, pathogenesis, and treatments…They would be highly dynamic, continuously incorporating newly emerging disease information. (NAS, 2011: 21)

From here, how this technology develops and becomes available to doctors and patients is of utmost importance to the Committee. Should it be implemented, this would revolutionize how medical taxonomies for all disease function.

The Committee recognizes that developing a new taxonomy is challenging because the necessary tools to create the Knowledge Network required for a better taxonomy do not presently exist. However, they recommend three steps to establish a Knowledge Network:

> 1, Design of appropriate strategies to collect and integrate disease-relevant information…
> 2, Implementation of pilot studies to establish a practical framework to discover relationships between and among molecular and other patient-specific data, patient diagnoses, and clinical outcomes…
> 3, Gradual elimination of institutional, cultural, and regulatory barriers to widespread sharing of the molecular profiles and health histories of individuals, while still protecting patients' rights. (NAS, 2011: 60)

All of these strategies would require a coordinated effort across all fields: from oncology, to biology, to the doctors and patients. The patients would be required to submit their information to this Knowledge Network, doctors would be required to inform their patients about what this kind of Network would entail, biologists and oncologists would have to coordinate with one another on the molecular biology of all of the diseases and cancers and input this into the database. By coordinating all of their efforts, the Committee believes that a project of this magnitude could be executed and available to all those who need it.

While the NAS's suggestions are thorough, there is a critical voice they do not consider when making this taxonomy: patients. While they briefly mention patients' rights and that they must be protected, they do not state a position on patient input for the

new taxonomy. It is the patients who will be impacted the most by this decision, and neglecting their view would mean a new taxonomy is only from a scientific perspective, and may not benefit the people it is supposed to.

The reason why patients need to assist the creation of a new taxonomy can be explained through Standpoint Theory. Standpoint theory states access to a certain standpoint makes a person "epistemically privileged" (Saul, 2003: 240). This privilege allows for a systematic change due to the acceptance of multiple viewpoints. The theory originated in Marx's critique of capitalism because workers under this regime had a "social position (that) gave them access to a standpoint from which they would be able to perceive social reality better than capitalists could" (Saul, 2003: 241). From this perspective, the workers could criticize, but also improve, working conditions that benefitted both their bosses and themselves.

For the new taxonomy, patients offer a standpoint that scientist's lack: one for the common voice of sensibility. If we equate the patients to the workers in the Marxian example, they offer a valuable perspective because scientific jargon has failed patients by failing to account for their position and understanding. While one could suggest mere diversity in scientist's ranks could resolve this issue, it needs to be taken a step further:

> Scientists must do more than ensure diversity within their communities. They must find a way to listen to the insights of those outside the scientific community. They must also make sure…that the research they do involves effectively listening to and understanding those who are the subjects of the research, even when they may communicate in ways that are not familiar to scientists. (Saul, 2013: 252)

Without these considerations, creation of a new taxonomy would be a fruitless endeavor. It would not support the people who need it most. Therefore, scientists must respect input from patients if and when a new taxonomy is created

In the context of DCIS/IDLE, this recommendation should be taken quite seriously. From what has been considered and discussed, Esserman identifies the problem, but her solution is faulty. Merely removing a word, which in this case is still an accurate descriptive term based on the current definition of cancer, would not be enough. An entire revamping of how we define cancer would have to be implemented. And the Committee recognizes this need for a better medical taxonomy across all diseases:

> Everyone on the Committee agreed that a *better* taxonomy is needed and that we have a spectacular opportunity to create one. Moreover…developing and implementing Knowledge Network of Disease has the unique potential to go far beyond classification of disease to act as a catalyst that would help to revolutionize the way research is done and patients are treated. (NAS, 2011: 76)

The Committee is correct in this assumption, and for cancer, the process would be arduous. First, the molecular biological breakdown of a cancer cell would have to be developed. This would need to be applied to all varieties of cancers, and instead of naming cancers by location the molecular signature could serve as the taxonomic apparatus. From there, various molecular classifications of cancer could be observed through their progression (or not) in large swathes of patients. If it appears certain molecularly classified types of cancer develop in a stepwise process, that can be charted; and where that is not the case, that can also be noted and addressed. For DCIS/IDLE, this tracking could be used to achieve a more precise evaluation as to which types of lesions progress to metastatic cancers and which do not. IDLE and DCIS could be two different categories of cancer, with those that do not progress being labeled IDLE's and those that

do as DCIS. This would also produce better outcomes for patients, as over- and underdiagnosis may become negligible through comparing the biological factors this precision medicine offers.

Language as Malleable: Can the Language of Cancer Change?

In this endeavor, the Committee has recognized that change for a better taxonomy is required. But what is a realistic expectation of when such taxonomy could appear, particularly for cancer patients and doctors? This answer varies in the immediate future and in the long term. Both come to the same conclusion: the taxonomy and language surrounding cancer, highlighted by the move by Esserman to change DCIS to IDLE, must change. However, the short and long-term aims vary greatly.

In the short term, it is unlikely that we will see the required change. Oncologists, researchers, and biologists disagree with Esserman because of their belief that the biology necessary to completely revamp how cancer is defined and described is not yet readily available. The need to conduct more research on how cancer operates as a disease is what will drive that change. Once cancer is understood completely as a disease, only then would these researchers most likely recommend a taxonomic overhaul. At the current juncture, the lacking scientific understanding of cancer is the hindrance to immediate change. The Committee understands this, and all parties must be on board for the Information Commons previously mentioned in order for any form of change to occur.

Conversely, as more scientific information on cancer is acquired and discovered, the necessity to change the taxonomy will increase. The discrepancy noticed by Esserman leading to her proposal to rename DCIS to IDLE will become more apparent, not only for

this specified breast lesion, but also potentially for other cancers. As the misalignment of the language with the science increases, more gaps will be apparent, and the existing terminology will be less and less useful to patients and doctors. The larger the gap, the worse this gets. Waiting too long to change the taxonomy will result in an overhaul that may come too late for many patients.

The key to both of these approaches would be to find the balance between the right time and the correct amount of information. With too little information, the taxonomy revisions will be incomplete and will fail to inform patients and doctors of the most appropriate treatments. But if too much time elapses, and the data collection and analysis and taxonomic development processes never start, the gap between the existing scientific knowledge and the language used to describe cancer and other medical conditions may widen past a point that may be readily corrected. In this instance, it would be advisable to take the Committee's recommendations and at least try to start cataloguing diseases based on their molecular biology. From there, a better taxonomy could develop for DCIS, as well as for all cancers. As the new taxonomy develops, the language surrounding cancer would also alter, thereby creating new metaphors and potentially from there, treatments and options for patients. This would have a profound impact not only on patients and doctors, but on society at large in determining how this disease is spoken about, described, treated, and understood.

This change in taxonomy could be aided by revolutionizing the way we approach treating cancer; by this I mean the language could evolve from new treatments. As of this year, research at the Mayo Clinic in Minnesota and other laboratories across the US has suggested that mutated viruses that are reprogrammed to target cancer cells could be the

new frontier of cancer remediation (Vice Special Report: 2015). Although the studies are in their infancy, the results on animals have been astounding, and a 90% human response rate could make the enduring radiation and surgical options obsolete in the future (Vice Special Report: 2015). Should this solution prove to be a valid one, the language addressing patient treatment could drastically change. Cancer may not be seen as "undefeatable" or something that must be "conquered." Groddeck's Equation would no longer hold any validity, and potentially, a restructuring of the taxonomy could develop.

Based on the Committee's guidelines and emerging cancer treatments, the clearest option ahead would be to implement this Information Commons and revamp an outmoded taxonomy. Neglecting such a task puts patients at risk of overtreatment, and also misinforms doctors who wish to do well by their patients. A coordinated effort from all fronts would be required to tackle such a problem, but the Committee recognizes this and has set forth guidelines it believes could be accomplished (see Figure 10 for the Committee's outline).

Conclusion: Strike While the Iron is Hot

In the evolving world of medicine, the definitions and treatments for cancer are constantly changing. The language used to describe diseases, particularly cancer, matters immensely to patients, doctors, and even society at large. Cancer as a word carries much more weight than some wish to acknowledge, and due to this, our ability to clarify the language around it can have massive repercussions.

We have noted biologically that the language has not fulfilled its duty to adequately convey correct information. This inaccuracy has encouraged patients and doctors to resort to the language of war to describe their situation, instead of critically assessing the situation and working towards a favorable outcome. Esserman suggested a name change specifically to DCIS in order to change it to IDLE, but has met considerable resistance from colleagues. Finally, we discussed the idea of precision medicine, and how a new taxonomy for cancer would fit into a medical world based on a more thorough understanding of the molecular biology of the disease. Together, these forces direct us to overhaul a flawed taxonomy, ideally within the near future.

While the Committee's recommendations were constructed in 2011, such action has not yet been taken to even attempt to reformat the language we use around cancer, let alone create an Information Commons. However, if we do not start now, in 2015, when will we finally take the initiative to complete such a project? 10 years later? 15? The more the project is delayed, the bigger the gaps become, and the harder this problem is to solve. Why wait when the opportunity has presented itself and guidelines have been outlined? To delay a task would be a waste of precious time that could be used to implement a system that has the potential to affect millions of lives.

This is not to say it is a task that will happen instantaneously. Human nature desires quick, easy fixes. There is no doubt that this would be a Herculean task. This project would require immense coordination, cooperation, and communication among doctors, patients, oncologists, microbiologists, and the public. It would also be required to update information regularly, with attention to detail and precision. But a problem has been identified in the linguistic description of a cancer, and to merely create a Band-Aid for a problem that requires surgery seems unsatisfying. That is why I believe that a dedicated group should undertake this project to construct a taxonomic overhaul in the language of cancer. As this thesis has shown, the language we use to describe disease matters, from the actual term to the metaphors that extend beyond. Medicine is a field that constantly updates and revolutionizes: the language surrounding one of the deadliest diseases known to mankind should reflect that ideology, and it is up to us to implement that transformation.

Appendix

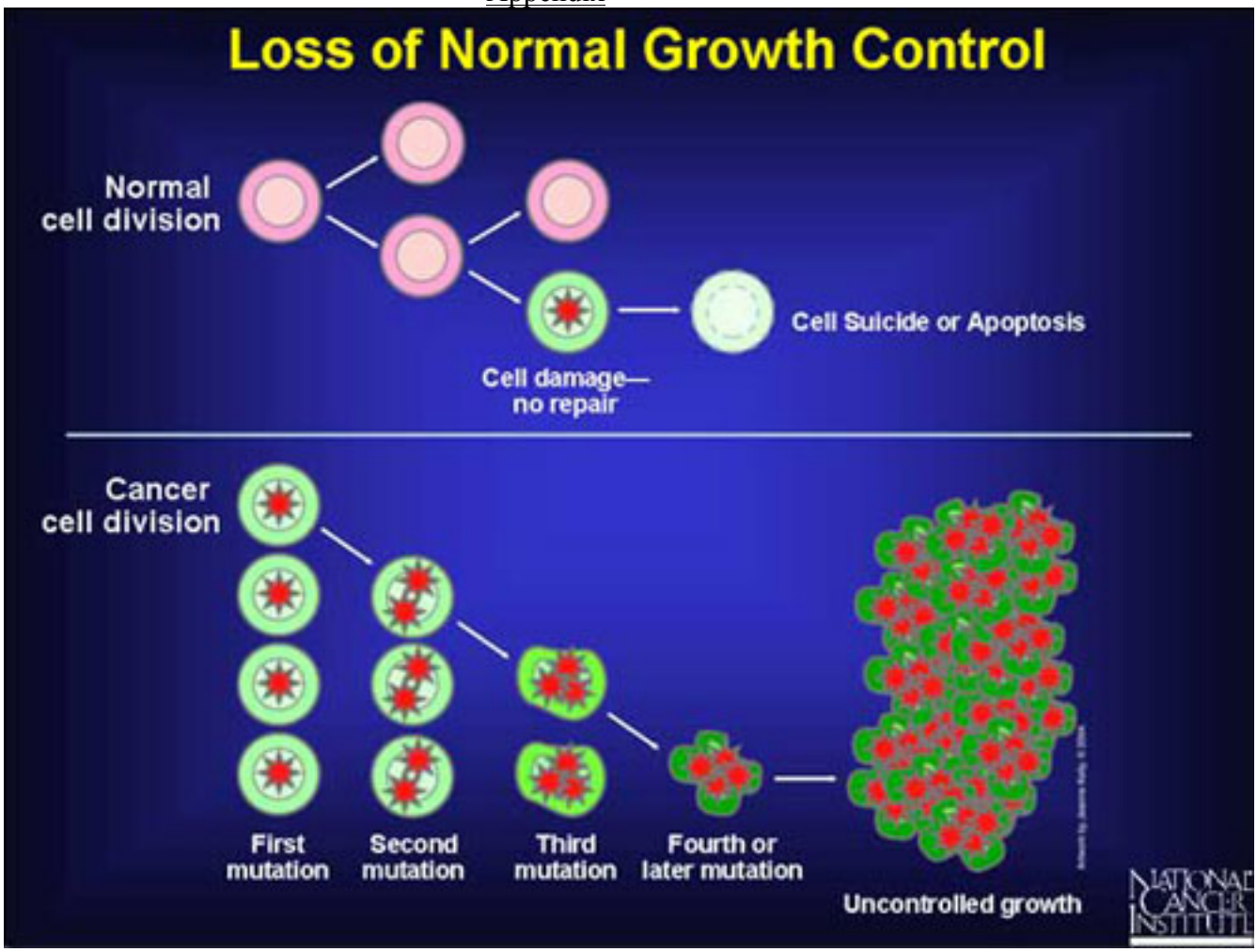

Figure 1: The basic cell process that starts the chain reaction creation of a tumor and cancerous cell growth (NCI Website)

Appendix

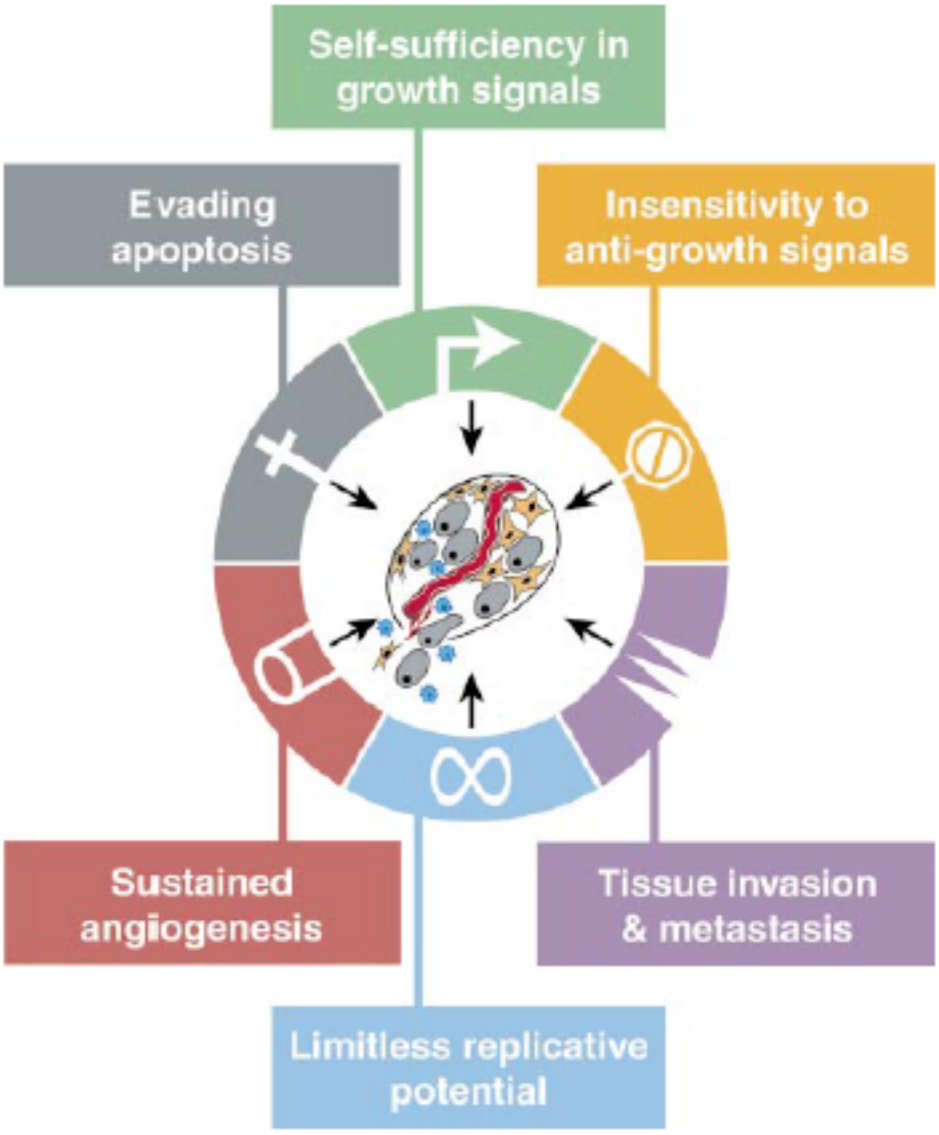

Figure 2: Hanahan and Weinberg's 6 original Hallmarks of Cancer (Hanahan and Weinberg, 58: 2000).

Appendix

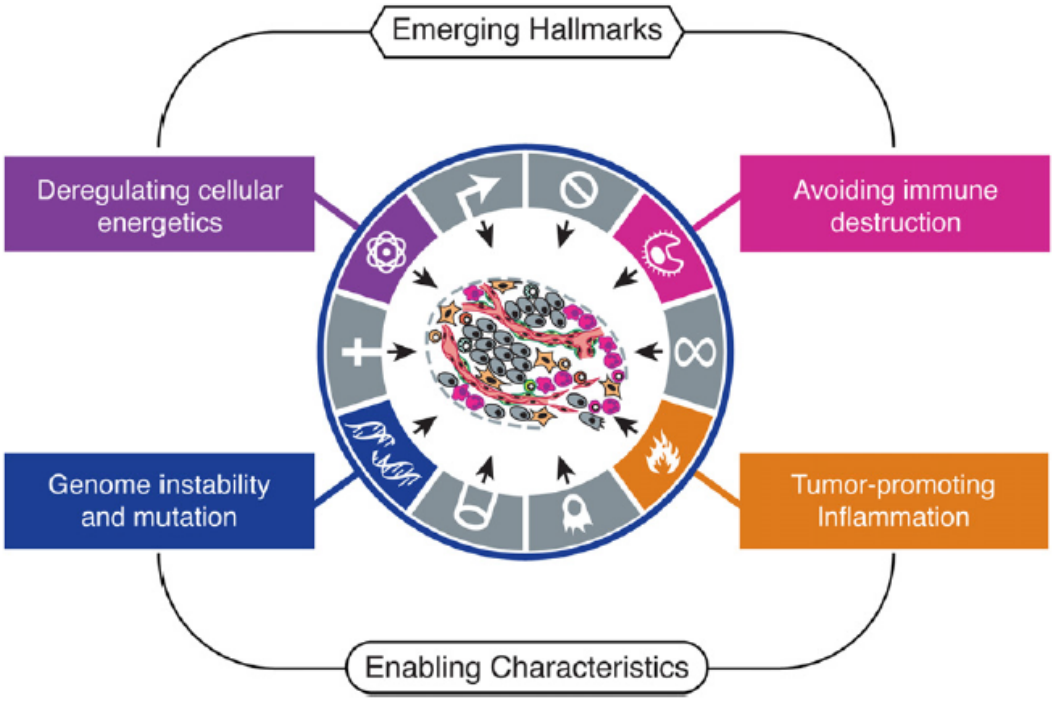

Figure 3: Hanahan and Weinberg's two new hallmarks and enabling characteristics (Hanahan and Weinberg, 658: 2011)

Appendix

Four Major Subtypes of Invasive Breast Cancer Used Clinically

Subtype	Standard Immunochemical Results and Cancer Grade	Overall 5-year Survival Rate (%)*	Frequency (%)	Comments
Luminal A	ER+ PR+ HER2–, usually low grade	90	50–55	Best prognosis, low Ki-67 levels
Luminal B	ER+ PR+ HER2–, usually intermediate to high grade	40	15	Generally more proliferative (high Ki-67 levels) with less marked hormonal receptor expression than luminal A tumors, approximately 30% are HER2-positive
HER2-enriched	ER– PR– HER2+, usually mid to high grade	31	15	Prognosis much improved since trastuzumab, 30%–40% of tumors also express ERs and PRs
Basal-like	ER– PR– HER2–, high grade	0	10–20	Often synonymous with triple negative

Note.—ER+ = tumor expresses ERs, ER– = tumor does not express ERs, PR+ = tumor expresses PRs, PR– = tumor does not express PRs, HER2+ = tumor overexpresses HER2/neu, HER2– = tumor does not overexpress HER2/neu.
*Data from reference 10. Overall survival rates have improved with new treatment options, particularly trastuzumab therapy for HER2-enriched cancers and new chemotherapy regimens for triple-negative tumors.

Figure 4: Comparative table of the four types of breast cancer. DCIS typically falls in Luminal A and B. (Trop et al, 2014: 1181)

Appendix

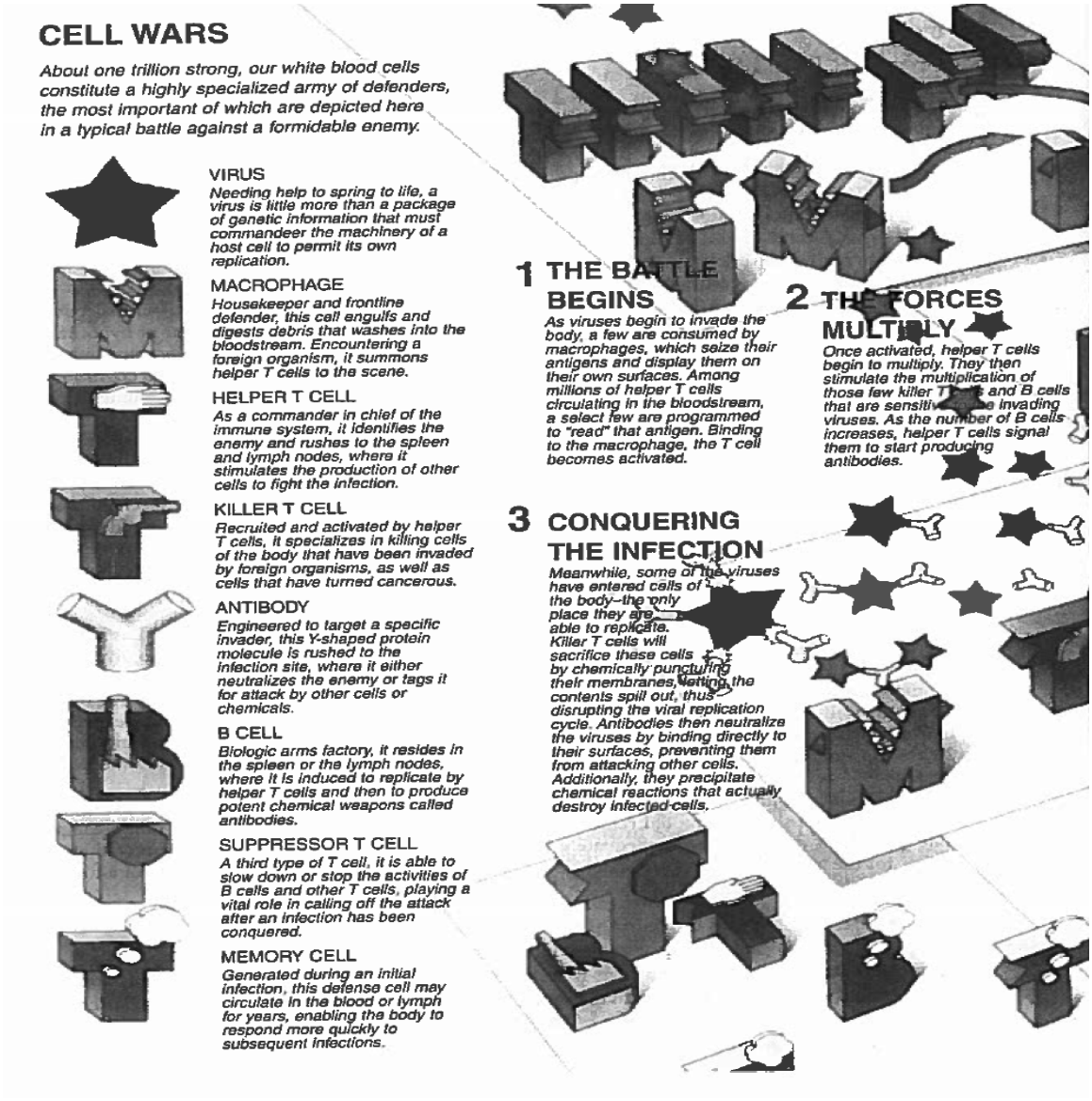

Figure 5: Illustration of cell wars and the war metaphor (Joralemon 2006: 6)

Appendix

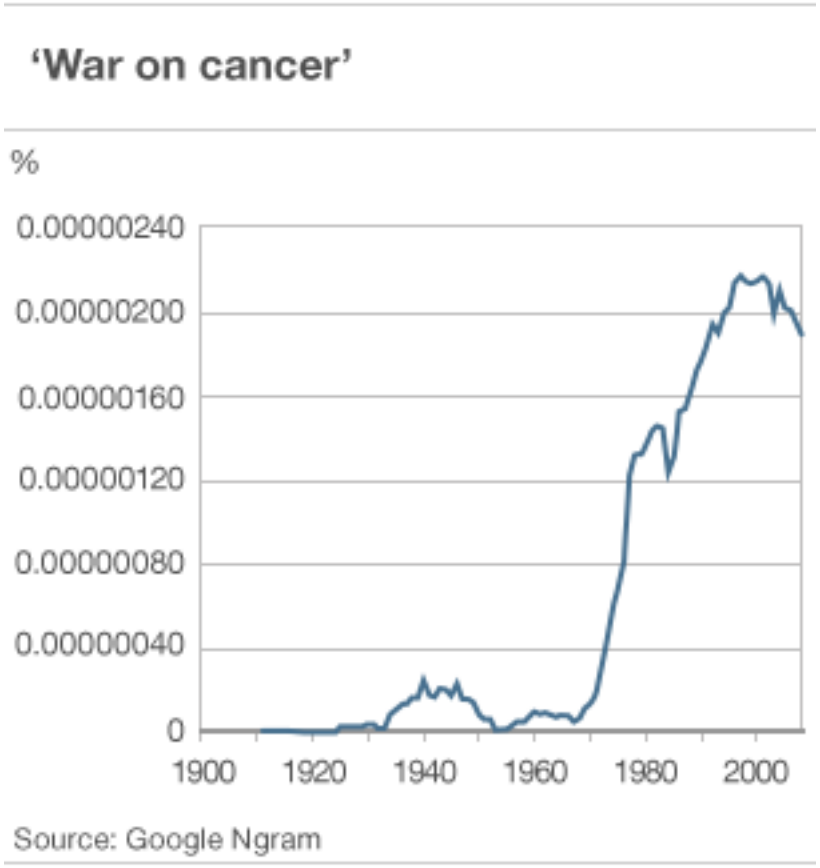

Figure 6: Increase in the terminology of "War on Cancer" after the 1950's (Greystone, Viewpoint BBC).

Appendix

TABLE 2
Results of Metaphor Analysis

Conceptual Metaphor	*Proportion of Women Using Metaphor*	*Proportion of Linguistic Metaphors*	*Proportion of Use Among the Individual Women*
Life is a journey	1.00	.385	.17–.58
Cancer is an obstacle on life's journey			
Emotional effect is physical contact	1.00	.075	.04–.13
Emotional strength is physical strength	1.00	.06	.02–.09
Self is a container	1.00	.06	.02–.09
Cancer is a fluid within the self container			
Life is a gambling game	1.00	.06	.01–.10
Cancer and its treatment is a game			
Understanding is seeing	1.00	.07	.02–.13
Cancer clears vision and allows for new understanding			
Healing is a choice, cancer is not	0.83	.03	.01–.09
Cancer is entity from a different world	0.67	.03	.02–.10
The body is a machine	0.50	.03	.05–.07
Cancer is war	0.83	.03	.01–.05
Cancer is a teacher	0.83	.03	.01–.07
Psychological distance is physical distance	0.83	.02	.01–.04
Happy is up and sadness is down	0.67	.02	.01–.06
One must stay up to heal			
Emotions are natural forces	0.83	.01	.01–.03
Life and cancer are natural processes	0.67	.01	.01–.05
Life is a bank account	0.67	.01	.01–.03
The self is made of different parts	0.67	.01	.01–.05
Cancer helps uncover these parts			
Cancer is a wake-up call	0.33	.01	.01–.03
Mind is a brittle object	0.33	.01	.01–.03
To heal one must keep it together			
Life is a play	0.50	.01	.01–.02
Cancer offers one new roles			
Psychological growth is biological growth	0.33	.01	.01–.02
Cancer helps us grow			
Understanding is grasping	0.33	.01	.01–.01
Cancer is an alien self	0.17	.01	.01–.01

Figure 7: Complete list of metaphor usage under Gibbs and Franks interviews (Gibbs and Franks 2002: 152)

Appendix

Table. Distribution of Treatment Preferences Across the 3 Different Terms

Treatment Options	Terms Used to Describe Ductal Carcinoma In Situ, No. (%) of Participants			*P* Value
	Cancer	Lesion	Abnormal Cells	
Surgery (n = 394)	186 (47)[a]	136 (34)	124 (31)	<.001
Medication (n = 394)	79 (20)	70 (18)	82 (21)	
Active surveillance (n = 394)	129 (33)	188 (48)[a]	188 (48)[a]	

[a] Represent the most popular treatment preference for each term used to describe ductal carcinoma in situ.

Figure 8: Statistical distribution for Dr. Esserman's study (Esserman et al, 2013: 1830).

Appendix

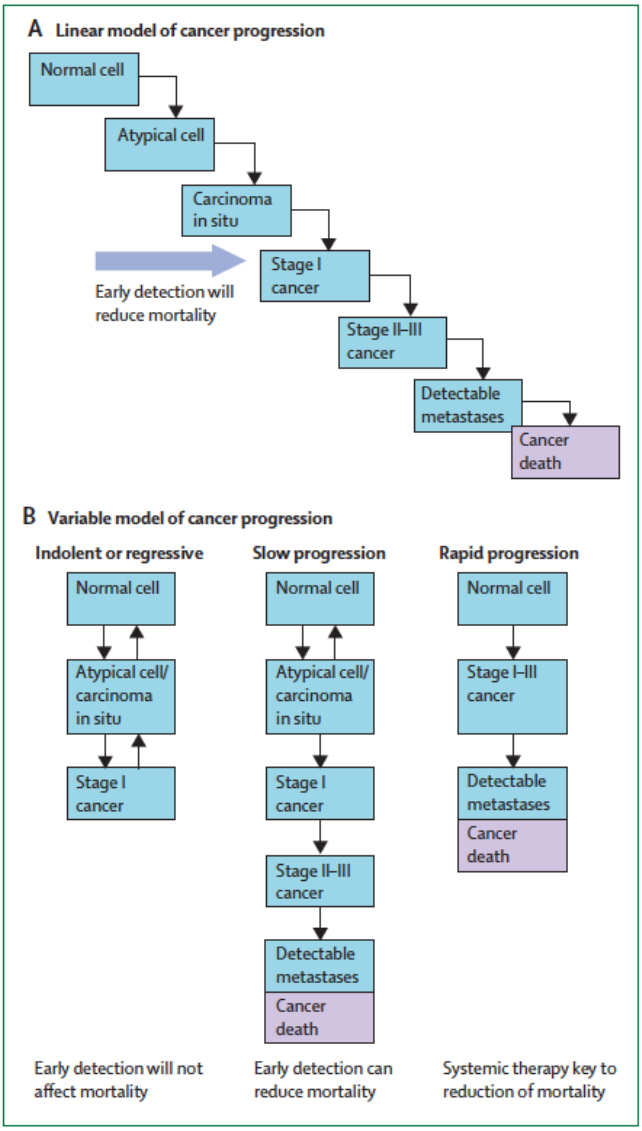

Figure 9: Comparison of linear cancer progression (original model) with the concept of a variable cancer progression (new model). Language could be based off of this second model to produce better outcomes (Esserman et al, 2014: e235)

Appendix

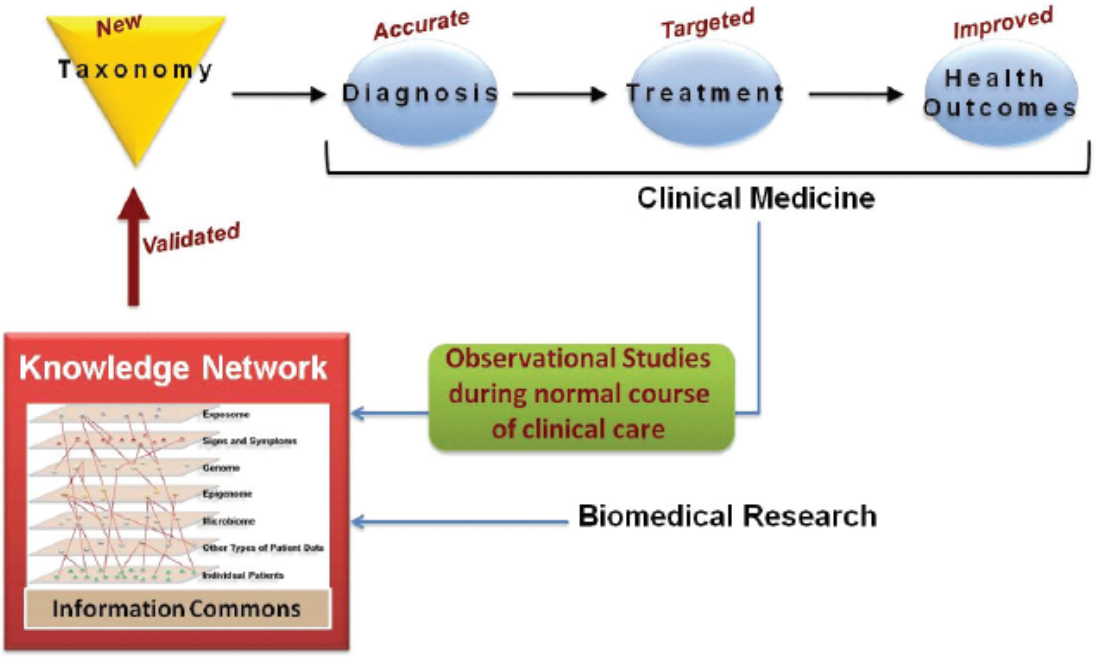

Figure 10: The Committee on a Framework for Developing a New Taxonomy of Disease's basic outline of how the Knowledge Network would inform a New Taxonomy, and how this informs patient outcomes in the future (NAS, 2011: 2).

References

Antony van Leeuwenhoek (1632-1723). (n.d.). Retrieved April 1, 2015, from University of California Museum of Paleontology website: http://www.ucmp.berkeley.edu/history/leeuwenhoek.html

Beck, M. (2014, September 15). Some Cancer Experts See Overdiagnosis: Question Emphasis on Early Detection. *The Wall Street Journal*, Health Care. Retrieved from http://www.wsj.com/articles/some-cancer-experts-see-overdiagnosis-and-question-emphasis-on-early-detection-1410724838

Berg, C. (2013). Resolving the Ductal Carcinoma In Situ Treatment Conundrum. *Journal of the National Cancer Institute*, *105*(10), 680-681.

Breast Cancer. (n.d.). Retrieved March 1, 2015, from Center for Disease Control website: http://www.cdc.gov/cancer/breast/

Cancer: a Historic Perspective. (n.d.). Retrieved March 31, 2015, from SEER Training Center website: http://training.seer.cancer.gov/disease/history/

Capurso, N. A., & Robey, R. B. (2014). Letters to the Editor: Changing the Terminology of Cancer. *Journal of the American Medical Association*, *311*(2), 202-203.

Childress, J. F. (1992). [The War Metaphor in Public Policy: Some Moral Reflections]. In J. C. Ficarrotta (Ed.), *The Leader's Imperative: Ethics, Integrity, and Responsibility* (pp. 181-197). West Lafayette, IN: Purdue University Press.

de Parry, B. (2011, March 11). Candid Cancer: Progress has Been Erratic in the 40 Year War on Cancer. *The Ann Arbor News*. Retrieved from http://www.annarbor.com/health/candid-cancer-a-report-on-the-war-on-cancer-part-i/

de Parry, B. (2011, March 18). Candid Cancer: Victories are Mounting in the 40-Year War on Cancer. *The Ann Arbor News*. Retrieved from http://www.annarbor.com/health/candid-

cancer-a-report-on-the-war-on-cancer-part-ii/

de Parry, B. (2011, April 1). Candid Cancer: War as a metaphor for cancer can be relieved of duty. *The Ann Arbor News*. Retrieved from http://www.annarbor.com/health/candid-cancer-war-as-a-metaphor-for-cancer-can-be-relieved-of-duty/

Depression (PDQ®). (2014, August). Retrieved April 5, 2015, from National Cancer Institute website: http://www.cancer.gov/cancertopics/pdq/supportivecare/depression/HealthProfessional/page1

Deutscher, G. (2010). *Through the Language Glass: Why the World Looks Different in Other Languages*.

Ductal Carcinoma In Situ (DCIS). (n.d.). Retrieved February 25, 2015, from New York University Langone Medical Center website: http://surgery.med.nyu.edu/oncology/patient-care/breast-cancer/carcinoma-situ

The Economic Case for Health Care Reform. (2009, June). Retrieved April 7, 2015, from The White House website: https://www.whitehouse.gov/administration/eop/cea/TheEconomicCaseforHealthCareReform/

Eldridge, L., MD. (2015, January 18). Cancer Cells vs Normal Cells. Retrieved January 21, 2015, from About Health website: http://lungcancer.about.com/od/Biology-of-Cancer/a/Cancer-Cells-Normal-Cells.htm

Emmanuel, E. J., & Millum, J. (2012). *Global Justice and Bioethics*.

Esserman, L., Thompson, I., & Reid, B. (2014). Re: Overdiagnosis in Cancer: an Opportunity for Improvement. *European Urology*, *65*, 797-798.

Esserman, L. J., Thompson, I. M., Reid, B., Nelson, P., Ransonhoff, D. F., Welch, H. G., . . . Srivastava, S. (2014). Addressing Overdiagnosis and Overtreatment in Cancer: a Prescription for Change. *Lancet Oncology*, *15*, 234-242.

Esserman, L. J., Thompson, I. M., Jr, & Reld, B. (2013). Overdiagnoses and Overtreatment in Cancer: An Opportunity for Improvement. *Journal of the American Medical Association*, *310*(8), 797-798.

Foucar, E., Caldiron, B. M., Mellette, J. R., Jr, Hruza, G. J., Helm, T. N., & Garcia, C. A. (2014). Correspondence to Addressing Overdiagnosis and Overtreatment in Cancer:. *Lancet Oncology*, *15*, 306-307.

Geddes, L. (2014, April 1). Catching cancer: The riveting quest for a killer virus. *New Scientist*. Retrieved from http://www.newscientist.com/article/mg22129621.300-catching-cancer-the-riveting-quest-for-a-killer-virus.html#.VCrzoCldXTa

Gibbs, R. W., & Franks, H. (2002). Embodied Metaphor in Women's Narratives About Their Experiences with Cancer. *Health Communication*, *14*(2).

Graystone, A. (Writer). (2013, November 24). The Rhetoric of Cancer [Radio episode]. In *The Documentary*. Retrieved from http://www.bbc.co.uk/programmes/p01lf8vh

Groopman, J. (2014, September 15). The Transformation: Is it possible to control cancer without killing it? *The New Yorker*, 46-56.

Gross, T. (Writer). (2010, September 15). Bacterial Bonanza: Microbes Keep us Alive [Radio episode transcript]. In *Fresh Air*. Retrieved from http://www.npr.org/templates/story/story.php?storyId=129862107

Hadju, S. I. (2011). A Note From History: Landmarks in History of Cancer, Part 1. *Cancer*, (117), 1097-1012. Retrieved from

http://onlinelibrary.wiley.com/store/10.1002/cncr.25553/asset/25553_ftp.pdf?v=1&t=i5x03zls&s=37ce498677775a7d81f099b096697daf7fb488d3

Hajdu, S. I. (2011). A Note From History: Landmarks in History of Cancer Part 2. *Cancer*, (117), 2811-2820. Retrieved from http://onlinelibrary.wiley.com/store/10.1002/cncr.25825/asset/25825_ftp.pdf?v=1&t=i5x05s4b&s=d1b06428f7afb5f06ecc5cdc1c45de9c95a121da

Hanahan, D., & Weinberg, R. A. (2000). The Hallmarks of Cancer. *Cell*, *100*, 57-70.

Hanahan, D., & Weinberg, R. A. (2011). Hallmarks of Cancer: the Next Generation. *Cell*, *144*, 646-674.

The History of Cancer. (n.d.). Retrieved February 8, 2015, from The American Cancer Society website: http://m.cancer.org/acs/groups/cid/documents/webcontent/002048-pdf.pdf

Hsieh, P. (2013, September 9). Why The Federal Government Wants To Redefine The Word 'Cancer'. *Forbes*. Retrieved from http://www.forbes.com/sites/paulhsieh/2013/09/29/why-the-federal-government-wants-to-redefine-the-word-cancer/

Jane, S. L. (2013). *Malignant: How Cancer Becomes Us*. Berkeley, CA: University of California Press.

Jimenez Diaz, H. (2013). *How Mendel's Pea Plants Helped us Understand Genetics* [Video file]. Retrieved from https://www.youtube.com/watch?v=Mehz7tCxjSE

Joraleman, D. (2006). *Exploring Medical Anthropology* (2nd ed.). Boston, MA: Pearson Education Inc.

Katsnelson, A. (2013). Momentum grows to make "personalized" medicine more "precise". *Nature Medicine*, *19*(3).

Key Features of the Affordable Care Act By Year. (2010). Retrieved April 7, 2015, from U.S. Department of Health and Human Services website: http://www.hhs.gov/healthcare/facts/timeline/timeline-text.html

Labeling Theory. (n.d.). In C. Calhoun (Ed.), *Dictionary of the Social Sciences*. Retrieved from http://www.oxfordreference.com/view/10.1093/acref/9780195123715.001.0001/acref-9780195123715-e-910?rskey=SYqC8Y&result=3

Lakoff, G., & Johnson, M. (1980). *Metaphors We Live By*. Chicago, IL: University of Chicago Press.

Leading Causes of Death in Females United States, 2011 (current listing). (n.d.). Retrieved March 1, 2015, from Center for Disease Control website: http://www.cdc.gov/women/lcod/2011/index.htm

Leading expert claims effective treatment for DCIS is vital for continued reduction in Australia's breast cancer mortality rate. (2014, August 18). Retrieved February 25, 2015, from Macquarie University website: http://mq.edu.au/newsroom/2014/08/18/leading-expert-claims-effective-treatment-for-dcis-is-vital-for-continued-reduction-in-australias-breast-cancer-mortality-rate/#ixzz3ShLi0HlT

Leichleiter, J. (2014, August 5). To Bend The Healthcare Cost Curve Downward, Stop Focusing On Minor Cost Cuts. *Forbes*. Retrieved from http://www.forbes.com/sites/johnlechleiter/2014/08/15/to-bend-the-healthcare-cost-curve-downward-stop-focusing-on-minor-cost-cuts/

Link, B. G., & Phelan, J. C. (2011). Conceptualizing Stigma. *Annual Review of Sociology*, *27*, 363-385.

Martin, M. (Producer). (2013, August 7). *Will Changing Cancer Terminology Change*

Treatment? [Radio program transcript]. Retrieved from http://www.npr.org/templates/story/story.php?storyId=209843351

Mazzarello, P. (1999). A Unifying Concept: the History of Cell Theory. *Nature Cell Biology*, e13-e15.

McWhorter, J. (2014). *The Language Hoax: Why the World Looks the Same in Any Language*.

Microscope history: Robert Hooke (1635 - 1703). (2010). Retrieved April 1, 2015, from History of the Microscope website: http://www.history-of-the-microscope.org/robert-hooke-microscope-history-micrographia.php

Milestone (1971): The National Cancer Act. (n.d.). Retrieved October 29, 2014, from National Cancer Institute website: http://dtp.nci.nih.gov/timeline/noflash/milestones/m4_nixon.htm

Muir, C. S., & Percy, C. (1991). [Chapter 7. Classification and coding of neoplasms]. In C. S. Muir, O. M. Jensen, D. M. Parkin, R. MacLennan, & R. G. Skeet (Authors), *Cancer registration: principles and methods* (pp. 64-81). IARC.

Mukherjee, S. (2010). *The Emperor of all Maladies: a Biography of Cancer*. New York: Scribner.

Mulcahy, N. (2013). NCI Panel: Stop Calling Low-Risk Lesions 'Cancer'. *The Journal of the American Medical Association*.

National Cancer Act, S. 1828 (1971). Retrieved from http://legislative.cancer.gov/history/phsa/1971

Neighmond, P. (Writer). (n.d.). When Treating Abnormal Breast Cells, Sometimes Less Is More [Radio episode]. In *National Public Radio*. Retrieved from http://www.npr.org/blogs/health/2013/08/05/208239545/when-treating-abnormal-breast-

cells-sometimes-less-is-more

Nixon, R. M. (n.d.). Remarks on Signing the National Cancer Act of 1971 [Speech transcript]. Retrieved October 29, 2014, from The American Presidency Project website: http://www.presidency.ucsb.edu/ws/?pid=3275

ObamaCare Enrollment Numbers. (n.d.). Retrieved March 31, 2015, from ObamaCare Facts website: http://obamacarefacts.com/sign-ups/obamacare-enrollment-numbers/

Parker-Pope, T. (2013, July 30). Scientists' report cites need to redefine cancer: Overdiagnoses create fear, poor treatment, it says. *The Boston Globe*. Retrieved from http://www.bostonglobe.com/news/nation/2013/07/29/scientific-panel-urges-stricter-definition-cancer/phP25Xnl7z3XSqEjIwQ01H/story.html

Pollack, A. (2014, September 28). Roche Breast Cancer Drug Perjeta Appears to Greatly Extend Patients' Lives. *The New York Times*. Retrieved from http://www.nytimes.com/2014/09/29/business/roche-breast-cancer-drug-appears-to-greatly-extend-patients-lives.html?rref=health&module=Ribbon&version=origin&region=Header&action=click&contentCollection=Health&pgtype=article&_r=0

Quammen, D. (2013, September 6). Lives of the Cells: George Johnson's 'Cancer Chronicles'. *The New York Times*. Retrieved from http://www.nytimes.com/2013/09/08/books/review/george-johnsons-cancer-chronicles.html?pagewanted=all&_r=0

Ramsey, L. (2015). Management of Ethical Issues Will Make or Break ACO's [Press release]. Retrieved from http://www.bioethicsinstitute.org/media/press-releases/press-release-management-of-ethical-issues-will-make-or-break-acos

Reisfield, G. M., & Wilson, G. R. (2004). Use of Metaphor in the Discourse on Cancer. *Journal of Clinical Oncology*, *22*(19), 4024-4027.

Robert Hooke (1635-1703). (n.d.). Retrieved April 1, 2015, from University of California Museum of Paleontology website: http://www.ucmp.berkeley.edu/history/hooke.html

Royal-Woods, L. (2012, June 4). *The Wacky History of Cell Theory* [Video file]. Retrieved from https://www.youtube.com/watch?v=4OpBylwH9DU

Samarasinghe, B. (n.d.). Hallmarks of Cancer 8: Tumor-Promoting Inflammation. Retrieved January 7, 2015, from Scientific American website: http://blogs.scientificamerican.com/guest-blog/2014/04/18/the-hallmarks-of-cancer-8-tumor-promoting-inflammation/

Samarasinghe, B. (n.d.). Hallmarks of Cancer 5: Sustained Angiogenesis. Retrieved January 7, 2015, from Scientific American website: http://blogs.scientificamerican.com/guest-blog/2013/10/18/the-hallmarks-of-cancer-5-sustained-angiogenesis/

Samarasinghe, B. (n.d.). Hallmarks of Cancer 4: Limitless Replicative Potential. Retrieved January 7, 2015, from Scientific American website: http://blogs.scientificamerican.com/guest-blog/2013/10/09/the-hallmarks-of-cancer-4-limitless-replicative-potential/

Samarasinghe, B. (n.d.). The Hallmarks of Cancer 9: Reprogramming Energy Metabolism. Retrieved January 7, 2015, from Scientific American website: http://blogs.scientificamerican.com/guest-blog/2014/10/08/the-hallmarks-of-cancer-9-reprogramming-energy-metabolism/

Samarasinghe, B. (n.d.). Hallmarks of Cancer 1: Self-Sufficiency in Growth Signals. Retrieved January 7, 2015, from Scientific American website:

http://blogs.scientificamerican.com/guest-blog/2013/09/18/hallmarks-of-cancer-1-self-sufficiency-in-growth-signals/

Samarasinghe, B. (n.d.). Hallmarks of Cancer 7: Genome Instability and Mutation. Retrieved January 7, 2015, from Scientific American website: http://blogs.scientificamerican.com/guest-blog/2013/11/26/the-hallmarks-of-cancer-7-genome-instability-and-mutation/

Samarasinghe, B. (n.d.). Hallmarks of Cancer 6: Tissue Invasion and Metastasis. Retrieved January 7, 2015, from Scientific American website: http://blogs.scientificamerican.com/guest-blog/2013/10/30/the-hallmarks-of-cancer-6-tissue-invasion-and-metastasis/

Samarasinghe, B. (n.d.). Hallmarks of Cancer 3: Evading Apoptosis. Retrieved January 7, 2015, from Scientific American website: http://blogs.scientificamerican.com/guest-blog/2013/10/02/the-hallmarks-of-cancer-3-evading-apoptosis/

Samarasinghe, B. (n.d.). Hallmarks of Cancer 2: Insensitivity to Antigrowth Signals. Retrieved January 7, 2015, from Scientific American website: http://blogs.scientificamerican.com/guest-blog/2013/09/25/the-hallmarks-of-cancer-2-insensitivity-to-antigrowth-signals/

Samarasinghe, B. (n.d.). Introduction to the Hallmarks of Cancer. Retrieved January 7, 2015, from Scientific American website: http://blogs.scientificamerican.com/guest-blog/2013/09/11/introduction-to-the-hallmarks-of-cancer/

Saul, J. M. (2003). *Feminism: Issues and Arguments*. Oxford, United Kingdom: Oxford University Press.

Scheper-Hughes, N., & Lock, M. M. (1986). Speaking “Truth” to Illness: Metaphors,

Reification, and a Pedagogy for Patients. *Medical Anthropology Quarterly*, *17*(5), 137-140.

SEER Training Modules: Historical Background. (n.d.). Retrieved April 10, 2015, from National Cancer Institute website: http://training.seer.cancer.gov/coding/history/

Sekeres, M. (2015, March 28). Trying to Fool Cancer. *New York Times*, Opinion. Retrieved from http://www.nytimes.com/2015/03/29/opinion/sunday/trying-to-fool-cancer.html?smprod=nytcore-iphone&smid=nytcore-iphone-share&_r=0

Sex Cells Have One Set of Chromosomes; Body Cells Have Two: Theodor Boveri (1862-1915). (2011). Retrieved April 1, 2015, from DNA Learning Center, Cold Spring Harbor Laboratory website: http://www.dnaftb.org/8/bio.html

Shakespeare, W. (n.d.). Romeo and Juliet: Entire Play [MIT online]. Retrieved March 11, 2015, from http://shakespeare.mit.edu/romeo_juliet/full.html

Smith, S. (n.d.). *Vice Special Report: Killing Cancer Full Episode (HBO)* [Video file]. Retrieved from https://www.youtube.com/watch?v=e8SvBAjXGyQ

Sontag, S. (1978). *Illness as Metaphor and AIDS and Its Metaphors*. New York: Picador.

Storella, J. (Presenter). (n.d.). *A Rose By Any Other Name* [Reading].

Trop, I., LeBlanc, S. M., David, J., Lalonde, L., Tran-Thanh, D., Labelle, M., & El Khoury, M. M. (2014). Molecular Classification of Infiltrating Breast Cancer: Toward Personalized Therapy. *RadioGraphics*, *34*(5), 1178-1195.

US Department of Health, Education, and Welfare National Center for Health Statistics. (1970). *Vital Statistics of the United States 1970: Volume II: Mortality*. Retrieved from http://www.cdc.gov/nchs/data/vsus/mort70_2a.pdf

van den Tweel, J. G., & Taylor, C. R. (2010). A Brief History of Pathology. *Virchows Arch*, 3-

10.

Viewpoint: Did Richard Nixon change the way people describe cancer? (2013, November 18). *British Broadcasting Company Magazine*. Retrieved from http://www.bbc.com/news/magazine-24985184

Virnig, B. A., Tuttle, T. M., Shamliyan, T., & Kane, R. L. (2009). Ductal Carcinoma In Situ of the Breast: A Systematic Review of Incidence, Treatments, and Outcomes. *Journal of the National Cancer Institute*, *102*(3), 170-179.

Walther Flemming (1843-1905). (2011). Retrieved April 7, 2015, from DNA Learning Center website: http://dnaftb.org/7/bio.html

The Weight of a Word: ASCO Members Discuss "Cancer" Name-Change Debate. (2013, August 15). *American Society of Clinical Oncology*. Retrieved from http://connection.asco.org/Magazine/Article/ID/3622/The-Weight-of-a-Word-ASCO-Members-Discuss-Cancer-Name-Change-Debate.aspx

What is Cancer? (n.d.). Retrieved February 10, 2015, from National Cancer Institute website: http://www.cancer.gov/cancertopics/cancerlibrary/what-is-cancer

White, C. (2005). Explaining a Complex Disease: Talking to Patients about Hansen's Disease (Leprosy) in Brazil. *Medical Anthropology Quarterly*, *19*(3).