

## Beyond the Last Treatment: Language, Identity and Cancer

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In the first chapter of *Slaughterhouse-Five*, Kurt Vonnegut apologizes to the reader. His book, he asserts, is a “failure” (Vonnegut 22). It is the flawed result of a long exploration of the catastrophic firebombing of Dresden, an event that he personally witnessed. For years, Vonnegut struggled to encompass the story he wanted to tell, creating and abandoning several outlines. “The best outline I ever made,” he writes, “or anyway the prettiest one was on the back of a roll of wallpaper.” (Vonnegut 5)

I used my daughter’s crayons, a different color for each main character. ... And the blue line met the red line and then the yellow line, and the yellow line stopped because the character represented by the yellow line was dead. And so on. The destruction of Dresden was represented by a vertical band of orange cross-hatching, and all the lines that were still alive passed through it, came out the other side. (Vonnegut 5)

Vonnegut’s “...vertical band of orange cross-hatching...” divided his life into clearly distinctive phases of *before* and *after*. His line passed through; 18,000 others did not (Taylor).

In 1986, my father’s sister, Francis, was diagnosed with an aggressive form of breast cancer. She was in her mid-forties. Her decline was rapid and - to those of us who knew her, but did not understand cancer - it was alarming. Still, we knew the uncomfortable truth: Cancer was a killer. Her end was swift and it largely unfolded as her doctors had predicted. She passed away in 1987. In the period between her initial diagnosis and her subsequent death, I referred to her as a “cancer patient”. When asked about her in the years that followed, I would describe her as having been a “cancer victim”. I thought nothing of the integrity of these words. Francis’s story had been brought to an abrupt end. In Vonnegut’s terms, her “yellow line stopped”. The casual language that we used to refer to the memory of her illness was unimportant.

Either through good luck or good genes, my next exposure to cancer did not occur until nearly a quarter century after Francis’s death. In the fall of 2011 my mother-in-law, Endora O’Donovan<sup>1</sup>, was diagnosed with ovarian cancer. As is often the case with this type of cancer it was not diagnosed until a later stage (Goff 2068); in Endora’s instance, it was stage IIIc. Her surgeon, fresh from the operating room, informed us that he had found tumors in and around her pelvic area. His language was careful in that he did not use the phrase “ovarian cancer” until prodded for an explicit identification. Still, we knew the uncomfortable truth: Ovarian cancer is *The Silent Killer* (Jasen 491). Mindful that Endora’s mother had died of cervical cancer some thirty-five years earlier, I believed my mother-in-law’s prognosis was grim.

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<sup>1</sup> The name “Endora O’Donovan” is an alias used throughout this paper to refer to my mother-in-law in order to respect her desire for anonymity.

Endora O'Donovan concluded chemotherapy in early 2012. By midyear, her doctors declared her cancer free. We, her family, had a sober understanding that statistically she could experience a recurrence (Ovarian Cancer National Alliance). Yet she *was* cancer free and this was cause for celebration. Endora herself should have been overjoyed. She beat cancer and could move beyond the terror surrounding the disease to embrace life, meeting each new day with determination and optimism. This is what happens to everyone on the other side of a successful treatment, is it not?

It is not.

Because of the genetic potential of my wife to one day be diagnosed with some sort of gynecological cancer, I am keenly interested in the before, during and *after* effects of cancer treatments. In an interview about her post-treatment experiences, Endora O'Donovan expressed natural misgivings regarding a recurrence of the disease. This was to be expected. She went further, though, and described an overall anxiety about her current status and a palpable dread regarding her future. Despite being cancer free and otherwise physically fit, Endora told me that she was not happy. She missed the structure and security of her treatments. During chemotherapy, she explained, she had felt fully engaged, guided by a corps of caring, competent professionals through a matrix of examinations and treatments. Now, her calendar clear of appointments, she felt abandoned.

Endora also expressed unease with her post-treatment identity. A single, working mother, she had raised three children and had seen two through college. For decades, she had regarded herself as a "protector" and "provider". A more recent identity shift occurred at the end of a twenty year career in publishing, a welcome transition from "commuter" to "retiree". Then the cancer came just a year after her retirement and she was unceremoniously thrust into the role of "cancer patient". With treatment concluded, but facing a lifetime of anxiety, what role was she to take? She was no longer a "cancer patient". She was not a "cancer victim"... or was she? She was not ill, but she was not well. A common label many people use to describe this post-treatment state is "cancer survivor" but she felt uncomfortable with that phrase. No one had prepared her for the shift from patient to... something else. Her doctors had targeted the cancer, but had ignored the accompanying trauma of the cancer experience's aftermath (O'Donovan).

Endora's emotional state was a surprise to me and I wondered if it was atypical. I turned to the World Wide Web (WWW), knowing through my wife that there exist many on-line forums, blogs and personal essays maintained by survivors of cancer.

I quickly found a first person essay authored by Mary Elizabeth Williams at Salon.com, entitled "Now What? Life After Cancer Treatment". Williams identifies herself as a survivor of a Stage 4 metastatic cancer that had started in her lungs and had then aggressively spread. After many months of treatment, she was informed by her doctors that she was cancer free. Her friends were elated, but she hesitated, noting that despite the good news, she did not "... feel yet like partying." (Williams)

At least the dread of recurrence and the ongoing struggles of the side effects are the kinds of things that are easy enough to explain to people. But there are other aspects of wrapping up an initial course of treatment that are harder to discuss. There's an oddly sad

element to it, and an often awkward identity shift. It's almost like a graduation - there's the sense of accomplishment and anticipation, but it's mixed with a strong loss of security. Ending regular treatment means the reassuring, friendly doctors and nurses who are right now a near constant part of my life will become less frequent participants in it (Williams).

Williams is a polished writer. Salon.com is a publication of some cache. Indeed, without too much effort, I was able to find other first person narratives published in major media outlets. Each has a personal, yet shared perspective regarding post-treatment struggles (Trussel, Steingraber, Gubar).

For every one essay of this type published at Salon.com or the New York Times, there are a dozen personal blogs and forums in which post-treatment anxiety and a loss of identity are squarely addressed. Many are noteworthy. Marie Ennis-O'Connor's [www.journeyingbeyondbreastcancer.com](http://www.journeyingbeyondbreastcancer.com) stands out. O'Connor published an entry in 2009 entitled "The story doesn't end here..." about her personal post-treatment struggles. Her experience is reminiscent of the observations of Endora O'Donovan and Mary Elizabeth Williams:

When I was going through surgery, chemotherapy and radiotherapy, I felt as if I had a new full-time job on my hands, a project which took up all my time. It was structured around appointments and moved through defined stages to a clear goal in sight. I met new people and learned so many things. When treatment ended, that structure fell apart. (Ennis-O'Connor)

O'Connor's essay triggered twenty-two separate responses. The majority affirm a shared experience. One poster, Jody, wrote: "I think the challenge of cancer actually begins once treatment is done, and you must adjust to a new body, an altered mind, and a sense of betrayal about the nature of life itself." (Ennis-O'Connor) Another poster, Debbie, declared that "... cancer aftermath is post traumatic stress disorder qualified." (Ennis-O'Connor)

Every year, millions of people are met with the individual catastrophe that is a diagnosis of cancer. Coupled with treatments that are potentially as destructive as the illnesses they aim to cure, it is their personal firebombing of Dresden. Like Kurt Vonnegut, these people see a clear distinction of *before* and *after*. Not everyone makes it through the cross-hatching to the after. Endora O'Donovan did, yet she still struggled. I was initially curious if her post-treatment anxiety was unique. I have concluded it is not.

The American health care system effectively abandons cancer patients who survive treatment. In 1986, we did not speak of my Aunt Francis's post-treatment condition because it was a given that she would not survive. Twenty-six years later, there are plenty of survivors who exist in a post-treatment twilight state of emotional ambiguity. It is natural to infer that over the course of the past few decades, advances in medical technology have improved the prognosis of cancer, resulting in more survivors, but does that inference withstand scrutiny?

### **Statistics and Perception After 40 Years of War on Cancer**

Kurt Vonnegut describes the protagonist of *Slaughterhouse-Five*, Billy Pilgrim, as a man detached from the normal flow of time. Throughout the novel, Pilgrim bounces like a pinball through the chronology of his life. Pilgrim is born in 1922 while surviving a plane crash in 1968 as he watches Dresden burn in February, 1945. He is everything he has ever been and he is all those things at the same time.

Pilgrim is surprisingly philosophical about his state. “It is just an illusion we have here on Earth,” he observes, “that one moment follows another one, like beads on a string, and that once a moment is gone, it is gone forever.” (Vonnegut 27)

The embers of Dresden were twenty-three years cold in the winter of 1971, when President Richard Nixon committed the United States to yet another military action, this time against nature itself. Nixon declared war on cancer. On signing the National Cancer Act on December 23, 1971, Nixon justified the legislation in patriotic terms, perhaps mindful of America’s seemingly continuous relationship with war. “More people each year,” he said “die of cancer in the United States than all the Americans who lost their lives in World War II.” (*Talk of the Nation*)

Were Billy Pilgrim real, he might lurch ahead some forty years later to the year 2012 and ask... Did we win? The answer depends on another question... are you an optimist or a pessimist? In popular conception, the campaign has not gone well despite over 105 billion dollars invested in cancer research. (Kolata, “Grant System”). This attitude is fueled perhaps by a steady stream of thoughtful, well researched articles that deconstruct the bleak state of our current understanding and treatment of cancer (Begley, Beil). These articles often close on an obligatory, hopeful note that some new breakthrough seems promising. Still, such half-hearted encouragement does little to mitigate the pointed message that despite considerable investments of time and money, *death rates due to cancer are climbing*. No less a source than the New York Times visualized the futility of the struggle in a graph constructed with data drawn from the National Center for Health Statistics (NCHS).

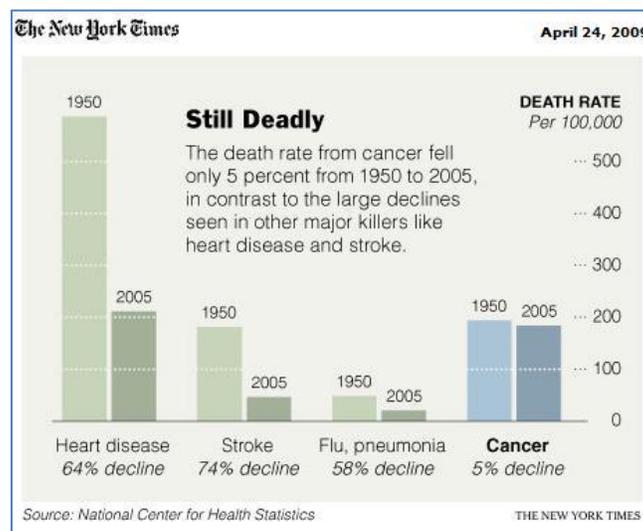


Fig. 1. Still Deadly, chart from Gina Kolata, “Advances Elusive in the Drive to Cure Cancer” (*New York Times*. 24 April 2009: A1.)

This pessimistic perspective is personified by Clifton Leaf, executive editor at Fortune magazine and author of “Why We’re Losing the War on Cancer”. Leaf, himself a survivor of Hodgkin’s disease, nonetheless states in the 2004 article that “...while there have been substantial achievements since the crusade began with the National Cancer Act in 1971, we are far from winning the war. So far away, in fact, that it looks like losing.” (Leaf 76) He later clarified in a 2012 interview with the Canadian Broadcast Company (CBC) that he bases his pessimism on the death rates of cancer, not the survival rates. “... I look at the raw numbers,” he said “because it keeps us honest. If we keep looking at the number of people getting this disease and dying of it, we see that those numbers keep going up.” (Canadian Broadcast Corporation)

Leaf draws his raw numbers from the National Cancer Institute and from the Centers for Disease Control and Prevention (CDC) (Leaf 76). He is a professional journalist writing for a respected magazine with a personal interest in the subject. I have no cause to doubt the absolute veracity of his assertions. However, I do have cause to question the relative context of those assertions. The word “cancer” is an umbrella term which refers to over 100 permutations of the disease (National Cancer Institute *What is Cancer?*). Some cancers are quite lethal, others are not. Some cancers are gender specific, others are not. Some cancers respond well to treatment, others do not. Drawing statistical inferences on the human race as a homogenous unit outside any contextual reference such as age, gender, socio-economic status or environmental condition washes out the details of this multifaceted illness. Shifting to an optimistic perspective and reexamining the raw numbers again, one finds that a global *increase* in mortality does not automatically imply a corresponding *decrease* in survival. This is not a zero-sum game. More people can die from cancer while, simultaneously, more people can live through it. The CDC reported in 2007 that:

The number of cancer survivors in the United States increased from 3 million in 1971 to 9.8 million in 2001 and 11.7 million in 2007—an increase from 1.5% to 4% of the U.S. population. Cancer survivors largely consist of people who are 65 years of age or older and women. Many people with cancer live a long time after diagnosis; more than a million people were alive in 2007 after being diagnosed with cancer 25 years or more earlier. (“Cancer survivors—United States, 2007” 270)

This is good news. Due to improved detection and treatment, more people are surviving a diagnosis of cancer, even if they are afflicted with an advanced stage of the disease. For those who eventually succumb, the period between initial diagnosis and eventual death is expanding from months to years to decades. More people are living through treatment to a post-cancer period that had otherwise been unattainable. These people appear to be largely ignored by a medical establishment and a popular culture that has yet to recognize that the population of cancer survivors is real, it is growing, and it presents an entirely new set of health related issues.

Why is this? There is an old saying in television and newspaper newsrooms that relates to human nature, “If it bleeds, it leads.” Focusing on grim statistics of cancer death rates may make for better copy, yet it also draws attention away from the very real issue of unaddressed physical and emotional trauma facing survivors. This is bad news.

Insofar as an encounter with a life-threatening event like cancer will induce a potential readjustment of self (Abernathy 199), and in conjunction with increased rates of cancer survival

as a relatively recent phenomenon, analysis of a post-treatment phase of identity crisis among cancer patients is limited. The authors of the paper “Cancer Survivorship and Identity among Long-Term Survivors” describe the state of academic research related to this issue, as of 2007:

Most research in psychooncology has, and continues to focus on the immediate and short-term effects of cancer, primarily at diagnosis, during treatment, or during the first years after treatment. Therefore, much of what we know about the psychosocial impact of cancer is from research on the earlier states of survival. (Deimling 759)

I agree with the authors of “Cancer Survivorship”. I believe this lack of academic analysis can be explained, in part, by a corresponding lack of any formal lexicon surrounding the concept of “cancer survivorship”. Indeed, the words “cancer survivor” are problematic: The phrase is relatively new; it lacks a universal definition; its application is contextual; its use is controversial. A recognized post-treatment framework to address long-term psychological issues among former cancer patients does not exist in the American health care system. That framework cannot be fashioned unless the very language of “survivorship” is defined, or at least discussed.

### **What Does it Mean to be a Cancer Survivor?**

Kurt Vonnegut wrote a letter to his family in May, 1945. In it, he described how he had been captured by German forces on December 19<sup>th</sup>, 1944 during the Battle of the Bulge. He went on to explain that he had lived through Allied friendly fire while under transport to a German military camp. He endured starvation, exposure and other harsh conditions while a P.O.W. Finally, he was taken to the picturesque city of Dresden, a place he thought was strategically uninteresting and therefore a safe haven from hostilities. He was wrong.

On about February 14<sup>th</sup> the Americans came over, followed by the R.A.F. [and] their combined labors killed 250,000 people in twenty-four hours and destroyed all of Dresden – possibly the world’s most beautiful city. But not me. (Vonnegut Letter)

Kurt Vonnegut was twenty-two years old when he lived through the experiences outlined in his letter. He was barely out of his teens, but knew a thing or two about what it meant to be a survivor. To Vonnegut, everyone living is a survivor of something. “Every so often,” he said in an interview with McSweeney’s, “I run into someone on the street who announces to me that they are really a survivor. I mean, who the fuck isn’t? If you’re not dead, you’re a survivor.” (“The Best Jokes”)

Vonnegut was correct in a literal sense but as it relates to cancer, many people in the condition of survivorship take umbrage to the very label itself. Physicians, patients and academia cannot agree on a basic set of terms to describe what happens after a cancer patient completes treatment. The language of medicine is usually scientifically precise. In this instance, it is not.

The actual “survivors” of the phrase “cancer survivors” can be direct when discussing their relationship to the language of post-treatment living. Personal reactions can range from outright rejection to mild discomfort to a willing embrace of the term “survivor”. A poster identified as “Anna Rachnel” minced no words in a response to a 2010 Slate.com article entitled “Who’s a Survivor?”, declaring “I must admit I’m a bit sick of all the ‘cancer catchphrases’ that

are floating around, ‘survivor’ being one of them. I think it’s part of the hero-worship that we, as a society are so quick to embrace.” (Schattner)

The internationally famous founder of the Lance Armstrong Foundation, a cancer advocacy group, disagrees. In his keynote address to the 2012 World Cancer Congress, Lance Armstrong triumphantly declared “I’m a cancer survivor.” (“Armstrong says he’s champ”). Tom O’Hara, a former cancer patient and editor of the Palm Beach Post, subsequently published an editorial in which he asked Armstrong to “Please shut up.” (“Advice to Lance”) O’Hara explained “Since [my] testicular cancer, I’ve had cancer of the bladder and the prostate. ... Surviving the disease does not make you special.”

On this topic of terminology, it has been suggested to me from several quarters that I should obtain and read Dr. Susan Gubar’s *Memoir of a Debulked Woman*. Diagnosed with ovarian cancer in November 2008 (Gubar 1), Gubar has written extensively about her experiences with living through and after treatment. She is a distinguished emerita professor of English and Women’s Studies at Indiana University and prior to her diagnosis, was perhaps best known for her book *The Madwoman in the Attic: The Woman Writer and the Nineteenth-Century Literary Imagination*, described by The New Yorker as “an early work of feminist literary criticism” (Errico). Gubar has a professional and personal relationship with the use (and potential misuse) of language. In a thoughtful essay entitled “Not a Cancer Survivor” published on September 6, 2012 in the digital edition of The New York Times, Gubar explained her own discomfort with the word “survivor”.

Does the celebration of the triumphant cancer survivor cast those who died from the disease in the role of victims who somehow failed to attain the requisite resiliency to overcome it? An American propensity to circulate stories of valiant individuals triumphing over great odds must make people coping with recurrent, chronic or terminal illness feel like duds. And even for those patients with cancers that can be cured, claiming to be a survivor might feel dangerous — like a jinx, a sign of the sort of chutzpah or hubris that could bring about dire reprisals from the powers that be. (Gubar “Not a Cancer Survivor”)

“Cancer survivor” is not an innocuous phrase. However, a through and sustained academic examination of the language of survivorship appears to be sparse. Perhaps it is an issue of timing, given that long-term survival rates are a fairly-recent development. The simplest explanation may be that the medical establishment has not yet had an opportunity to fully recognize and otherwise address this consequence of its successes in treating cancer. Or, it may be due to the American style of health care delivery in which primary health care physicians (PCPs), charged with the overall health of a patient, are typically undercompensated when compared to their specialist counterparts (Peeples). A PCP will conduct a follow-up; a specialist may not. This means that an oncologist, for example, will treat a patient’s cancer, and then move on to the next case. He or she may assume that the patient has a PCP to tend to after-treatment issues. However, there is a critical shortage of PCPs in the United States – medical students have a financial incentive to become specialists (Smith). As a result, many patients may not *have* a primary care physician to address post-treatment survivorship issues.

Whatever the reason, the authors of “Defining Cancer Survivorship: A More Transparent Approach Is Needed” offer a concise summary of this problem:

There is a lack of a consistent, operational definition of what it means to be a cancer survivor despite the widespread use of the term. The term carries positive connotations of ‘beating’ cancer, but some people living past cancer do not identify with this portrayal. (Khan 33)

Curiously, professional and nonprofit organizations in the United States that advocate for cancer research have a consistent definition of the phrase. Here are three significant examples:

**The National Cancer Institute:** An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition (“Survivorship Definitions”).

**American Cancer Society (ACS):** The American Cancer Society has chosen to adopt the broadest definition possible for a cancer survivor -- that being all those who choose to define themselves as survivors, from the time of their diagnosis and through the balance of life (“American Cancer Society Definitions”).

**The National Coalition for Cancer Survivorship (NCCIS):** NCCS’s definition of a survivor, from the time of diagnosis and for the balance of life is now the norm for the cancer community and beyond. NCCS has expanded its definition of survivor to include family, friends and caregivers (“Our History”).

Of course, a thing that is consistent is not automatically useful. In practice, several respected organizations have adopted a definition of the phrase “cancer survivor” that has been summarily rejected by many cancer survivors. It is understandable why these organizations would seek to define the post-treatment cancer experience. However, they have failed to do it in a way that is useful. Acknowledging that this is a real problem and accepting that developing a solution is potentially worthwhile, one may instinctively jump to the problem’s *why* and its *how*. The *who* and the *when* would seem impossible to determine or of secondary importance. Still, my own instinct when examining **any** problem is to go back to the beginning. In that context, I invite the reader to reexamine the three definitions of “cancer survivor” given above, as they share several characteristics. The definitions are overly broad; they are open ended; they include not only patients but caregivers and family members; and most importantly they share the phrase “balance of life”.

Could it be that these definitions share a common origin?

The answer is yes. The current language of survivorship can be traced to a single author: Dr. Fitzhugh Mullan (Mullan).

### **The Language of Survivorship: Origins**

Thus far, I have maintained an upbeat perspective on the topic of cancer and its post-treatment challenges. There is reason to be hopeful. In the 40 years since President Richard Nixon signed the National Cancer Act, medicine has made significant advances in the detection and treatment of cancer. The population of people living years - and in some instances decades - beyond an initial diagnosis of cancer has grown (Cancer survivors—United States, 2007). If not eradicated outright, many cancers can be reduced to a manageable, albeit chronic level.

I wonder, though, if some of my optimism has a cultural basis. I am an American. My European friends tell me that Americans are a sunny lot. I am reminded of something Kurt Vonnegut once said about Americans and optimism:

It goes against the American storytelling grain to have someone in a situation he can't get out of ... There is the implication that if you just have a little more energy, a little more fight, the problem can always be solved. (Vonnegut 259)

Our media, an engine of “the American storytelling grain”, is saturated with stories in which the good guys win and the underdog overcomes. With its connotations of healing and closure, I suspect that the concept of the word “survivor” as it applies to cancer is a uniquely American construct. This belief is confirmed by the authors of “Defining Cancer Survivorship: A More Transparent Approach Is Needed”. Khan, et al. concede that the cultural impact of survivorship outside the United States is poorly understood (Khan 35). Nevertheless, they note that:

Whereas in the USA the term [survivor] has become part of the discourse of living past cancer, it has not been widely used outside of the USA. Consequently, the term has not entered regular parlance amongst patients with cancer in countries such as the UK. (Khan 34)

Academic research solely focused on global attitudes towards survivorship is limited, so one is left to pick through research focused on perceptions of cancer as an illness instead. In 2007, The Lance Armstrong Foundation commissioned a far-reaching report of “the cancer problem” (Cancer Stigma) from 10 separate countries, not including the USA, to “... better understand how cancer is portrayed and perceived.” (Cancer Stigma) In poorer countries (India, Mexico), the effects of cancer on an individual and his or her entire family were found to be potentially devastating. In richer countries (France, Japan), the study found nascent frameworks for understanding survivorship. A country’s cultural attitudes towards survivorship are a function of the size of its economy. Post-treatment issues are more relevant in richer countries that consistently deliver better health care to a wider percentage of their populations.

Given the wealth of the United States and a decades-old, federally sanctioned investment in cancer research, it is no surprise that America would be the first to cross a threshold of treatment options that open a passageway to a new, uncharted territory of cancer survivorship. Given the American preference towards optimism, it is no surprise that the survivorship culture in the United States should present a positive narrative. This is the classic American frontier mentality reincarnated in a modern setting. To Americans, the best endings are happy ones.

In reality, endings are often unsatisfying or unfortunate or boring and inconclusive. Sometimes, despite a valiant struggle against seemingly insurmountable odds, the hero simply... dies. Sometimes the odds that seemed insurmountable are in fact insurmountable. Kurt Vonnegut knew this. "It strikes me as gruesome and comical," he once said, "that in our culture we have an expectation that man can always solve his problems. This is so untrue that it makes me want to cry — or laugh." (Vonnegut 259)

Thus far, I have maintained an upbeat perspective because I am an American, and like my fellow citizens am most comfortable with happy endings. I see now that this is terribly unfair to those who are certain to die of cancer but do not know when. Or those who believe that they have just weeks or months to live. Or those who are so scarred by treatments that they lose a part of their pre-cancer identity. Or those who live with the constant fear of recurrence. Or those who develop a secondary cancer caused by a treatment for a primary cancer that has lethal, long-term effects.

In the current lexicon of the cancer culture in the United States, the people I have described above are "survivors". For them it is a terrible misuse of the word. For example, a person with pancreatic cancer is 95% likely to die within five years of diagnosis ("Pancreatic Carcinoma"). To this person, cheerful statistics of the increased rates of survival are meaningless, if not outright insulting. If you believe that cancer will eventually kill you, is it ever appropriate to describe yourself as a "survivor"?

This issue was brought into sharp relief for me recently during an email exchange with a woman who was diagnosed with breast cancer in 2007. I asked her if she considered herself to be a survivor. She unflinchingly replied:

... I am one who very much dislikes the term "survivor". The word implies that the cancer experience is over, in the past. I happen to have a genetic mutation which makes the likelihood of new cancers, not just a recurrence, very high. So while I currently have "no evidence of disease", remission is not an appropriate term, but cancer remains and will always be a part of my life. I cannot accurately say that I HAVE cancer, and that's one reason I started using "I HAVE HAD cancer", but do not consider myself someone who survived it, as if it was an isolated event. It is part of my life, but I am not in active treatment, so yes, it is part of my identity. (Personal Interview)

If the value of the word "survivor" to describe people living beyond cancer is so approximate as to be useless in many contexts, why is the term still used? It is instructive to examine the first application of the word in this sphere, a 1986 paper published in *The New England Journal of Medicine* by Dr. Fitzhugh Mullan, "Seasons of Survival: Reflections of a Physician with Cancer". As the title suggests, Mullan himself had been diagnosed with cancer and had personally encountered what he describes as "seasons of survival" during and after the illness. As a physician, he recognized that the medical establishment at that time had not yet recognized after-care survival as a necessary aspect of treatment.

... we have done very little in a concerted and well-planned fashion to investigate and address the problems of survivors. It is as if we have invented sophisticated techniques to save people from drowning, but once they have been pulled from the water, we leave

them on the dock to cough and sputter on their own in the believe that we have done all that we can. (Mullan 273)

Dr. Fitzhugh Mullan had the unique perspective of someone who had been afflicted with cancer and who was an active member of the medical community. He took the very reasonable step of suggesting a way of describing – and therefore thinking – about the total cancer experience. He chose the word “survival”.

Survival is a much more useful concept [than the word cure], because it is a generic idea that applies to everyone diagnosed as having cancer, regardless of the course of the illness. Survival, in fact, begins at the point of diagnosis, because that is the time when patients are forced to confront their own mortality and begin to make adjustments that will be part of their immediate and, to some extent, long-term future. (Mullan 271)

In the paper, Mullan regards the word “cure” as unnecessarily dichotomous. “Although the binary notion of cure versus noncure is understandably appealing to everyone concerned with cancer, most agree that it is not an accurate characterization of the experience.” (Mullan 271) He describes the before, during and after of cancer as three linked phases, the “Seasons of Survival”. There is an initial diagnosis and treatment (acute survival) which hopefully yields to a period of “watchful waiting” (extended survival) and that finally evolves to a phase in which cancer is either cured or in long-term remission (permanent survival) (Mullan 272).

The term “cancer survivor” has nonetheless proven to be controversial. In a 2004 interview with National Public Radio (NPR), Mullan observed that while the term is imperfect, there is no better substitute.

I would say... give me a better term, and I would happily use it. I think it works pretty well and certainly the concept is a very powerful one and I feel quite wed to that... if we had another label to put on it I would happily do that but I have not found one. (“Debating ‘Cancer Survivor’”)

It is a matter of opinion. In my view, Mullan is correct. There is no more accurate label that can replace “survivor”. “Seasons of Survival” provided cancer advocacy groups with a new way of thinking and talking about cancer. Still, one cannot ignore that the use of the term is problematic. Mullan’s justification for the use of the word “survival” as an alternative to the word “cure” contains two unavoidable flaws. First, the phrase “... long-term future...” effectively abandons millions of people with cancer who have no long-term future. Second, the word “survival” is so broad that it is susceptible to reinterpretation.

### **The Language of Survivorship: Implications**

The first flaw is unavoidable because of the reality that some cancers are aggressively lethal and some conditions are regrettably hopeless. The problem of how to treat the short-term needs of this demographic is real. However, it is not the problem that Mullan's "Seasons of Survival" addressed. The widespread adoption of Mullan’s framework means that patients with a grim outlook may resent a forced association to the word "survivor".

The second flaw is unavoidable because cancer is a diverse disease with a continuum of conditions and treatments. Any single term used to describe cancer *must* be broad. Mullan chose the term "survival" because it is a "... generic idea that applies to everyone diagnosed as having cancer, regardless of the course of the illness..." (Mullan 271). Any term this generic, though, is vulnerable to interpretation. Twenty-six years after the publication of Mullan's paper, there is no universal definition among the public, researchers or cancer advocacy groups about who or what a "survivor" is. The National Cancer Institute, for example, is representative of this inconsistency as it presents an outward facing definition of survivor, one that includes family and caregivers, while concurrently utilizing a separate, internal definition restricted to only those diagnosed with the illness for its own statistical analysis (Twombly 1414).

This problem of definition was addressed in a surprising way in the opening editorial of the 2007 inaugural issue of the *Journal of Cancer Survivorship*, an academic periodical ostensibly dedicated to publishing "... basic research, clinical investigations and policy-related research that can impact the quality of care and quality of life of cancer survivors." ("Description" *Journal of Cancer Survivorship*) Editor Michael Feuerstein acknowledged that in the planning stages of launching the journal, the most common question he encountered was "How are you going to define 'survivorship?'" (Feuerstein 5) In Feuerstein's words:

Each of the existing definitions of and perspectives on cancer survivorship has their purpose (e.g. Policy related, disease statistics accounting, adjustment/coping, and advocacy). However, none of them, including the one in this journal will use, provide an evidence based definition of survivor or survivorship. These will emerge as the field does. (Feuerstein 5)

I should make clear that my observations regarding the structural flaws of Mullan's framework of survivorship should not be taken as an attack on the concept of survivorship itself. It is difficult to overstate the positive impact that Mullan has had on cancer advocacy in the United States: Prior to the publication of "Seasons of Survival", there was no nationally recognized need to address physical and emotional issues encountered by people living years beyond an initial diagnosis of cancer. By bounding the problem with language, Mullan empowered cancer advocacy groups to move forward in ways that have benefitted millions. It is possible to acknowledge the limitations of the term "survivor" without questioning the overall efficacy of its use. Thus, it is a legitimate question to ask what can be done to improve the situation.

I believe there are three options: Accept the limitations of the term "survivor" and move on; reject the term outright and try to invent a new language to describe survivorship; tweak the existing language of survivorship to make it more useful.

The first option amounts to doing nothing. Accepting the limitations of the term without trying to improve it is a valid, active choice. In the United States, the care and treatment of cancer - including post-treatment follow up - is an institution of many disconnected moving parts. Barring some sort of enforcing agency, doctors, patients and families are currently free to use whatever language they prefer to describe survivorship. It is helpful to everyone involved,

however, to be mindful of the reasons why a language of survivorship is necessary, and to understand its limitations.

The second option, to reject the term “survivor” outright, is already a conscious choice for many people. In an e-mail questionnaire of my own design, I have asked respondents to rate various labels to describe their post-treatment identity on a scale of one to ten. Choices included “cancer survivor”, “cancer patient” or “other”. Ten people replied. Four respondents have given the phrase “cancer survivor” a score of either zero or one. Of those four, two suggested a preference for the more neutral phrase “person who had cancer”. The most vigorous responses have come from women who have lived through breast cancer. Indeed, there appears to be a counter-advocacy movement among members of the breast cancer community against the term “survivor” and, importantly, images conveyed by that term. In a 2008 paper entitled “The meaning of the survivor identity for women with breast cancer”, Dr. Karen Kaiser points to a cultural image of a breast cancer survivor that is "... most often represented as triumphant, happy, healthy and feminine..." (Kaiser 80). This idyllic image may not represent what many women living through breast cancer actually experience, though. The image may instead have the unintended consequence of encouraging them to hide the effects of what can be disfiguring treatments. "Women who work to project an image of perfect health following cancer," Kaiser writes, "pay an emotional (and monetary) price for pretending to be well and whole." (Kaiser 81) She cites examples of women who have rejected the survivor identity, replacing it with identities of their own choosing, such as "thrivers" or "breast cancer warriors". (Kaiser 80)

The third option is to expand on the existing language of survivorship, to repurpose it slightly so that it becomes more relevant to more people. This is the “evidence based definition” that Dr. Michael Feuerstein wrote about in his 2007 editorial for the *Journal of Cancer Survivorship* and that Nadia F. Khan, et al. confirmed was lacking in 2011 in that same journal (Khan 33). There appears to be a general consensus among researchers that *something* must be done, but there is no agreement about what *should* be done. I have found several well-meaning attempts by oncologists and others to expand Mullan’s original framework by either introducing new “seasons” of the survivorship experience or by expanding Mullan’s original definitions (Miller, Jones). No single idea seems to have garnered much excitement in the academic community, reminding me of Feuerstein’s observation that a definition of survivor will “... emerge as the field does.” (Feuerstein 5) The field, it seems, has not emerged enough.

So, how to move forward? Do nothing, rebel, or redefine? On some reflection, I have decided that the choices are not mutually exclusive. Why not do all three?

An attempt to police the definition of survivorship is not practical, particularly in the American model of distributed health care delivery. Cancer patients, family members and caregivers in the United States are already free to adopt or reject the label “survivor” independently of how the term is regarded in academic circles, and this should continue. Those who live with and through cancer should be encouraged to define themselves in whatever way is most useful to them. For those who seek some guidance, health care professionals should be prepared to discuss the issue starting with an as-yet undetermined operational definition, but continue the dialogue in a way that is mindful of the individual’s unique condition. In plainer

terms, my conclusion is this: We should develop a universal definition of the word “survivor”, but we should not be slaves to it.

When I set about this research, it was my intention to examine why there is no consistent post-treatment regimen applied to cancer patients in the United States. I recognized quickly that there is an ongoing controversy about how to identify people who live in a post-treatment phase. The phrase “cancer survivor” appeared again and again in research and newspaper articles, books, Internet forum postings and even in personal interviews. I was struck, however, by another phrase that was invoked frequently, a phrase that seems at home among martial talk of a “War on Cancer” fought by “cancer veterans”. That phrase is Post Traumatic Stress Disorder, and I have witnessed its effects first-hand.

### **My Grandfather, My Mother-in-Law, and Post Traumatic Stress Disorder**

Now if we go back we will be weary, broken, burnt out, rootless, and without hope. We will not be able to find our way anymore. And men will not understand us ... We will be superfluous even to ourselves; we will grow older, a few will adapt themselves, some others will merely submit, and most will be bewildered. (Remarque 275)

My grandfather, Charles Henry DeBow, was a United States Marine who served in the Pacific Theater during World War II. Though a young man – he was a 24 year old platoon sergeant in 1942 – he was already a military careerist with eight years served when he was shipped overseas. Sent to the island of Okinawa, he experienced hand-to-hand combat, was wounded twice, and was eventually sent home. Unwell both physically and mentally, he was discharged in 1945 to the care of my grandmother, Catherine. His doctors counseled her that while his physical wounds would heal relatively quickly, his emotional wounds might persist for some time. How long, they did not know. He was diagnosed with a condition that, in the language of the day, was called *gross stress reaction* (Andreasen). He would return to normal, they assured my grandmother, but the timeframe was unknowable. She just had to be patient.

I am told that there was a period in the 1950s and 1960s when Charles DeBow did reasonably well. My grandparents bought a farm in rural Mississippi and for many years Charles DeBow dedicated himself wholly to the care of his land, his animals and his family. At some point in the late 1960s something ... slipped. The people around him, his wife and three daughters (he had no friends, otherwise), did not recognize any precipitating event. His suffering was nonetheless apparent and would persist for the remainder of his life. Well into my teenage years, some forty years after the end of World War II, my grandfather continued to be haunted by the war.

My memories of him fit into general categories: My grandfather sitting in a swing in our backyard on hot summer afternoons; my grandfather in his easy chair in a darkened room watching the news and chain-smoking; my grandfather in his bed at night, hand writing page after page in a series of spiral bound notebooks. I have other, more active memories of him, certainly, but they are few. Those three stations – the backyard swing, his easy chair, his bed – those were the places where he took refuge. One thing was consistent: He was always talking to himself. He could engage in regular dialogue with others when necessary and appropriate, but when he was alone – or thought he was alone – he talked to himself. It was never clear to me

what he was talking about, but I guessed that he was reliving the past. I would strain to hear what he was saying, but it was always a low, unintelligible murmur. During one of these self dialogues, though, he said something loudly and clearly, something I have never forgotten and that I recognized at the time as being significant even though I was a child. What he said was this: "I never saw a superman."

My grandfather traced the arc described by Erich Maria Remarque in *All Quiet on the Western Front*. He initially adapted to civilian life. He eventually submitted to his inner demons. At the end, he was bewildered by the lingering effects of what had happened to him. In the spring of 1986, he died, quietly and peacefully, of a massive cerebral aneurysm.

Though I lack expertise in the field of psychology, I have long believed that my grandfather suffered from Post-Traumatic Stress Disorder (PTSD).

My mother-in-law, Endora O'Donovan, never served in the military. She has experienced deep trauma – a divorce, the loss of her parents to cancer, the loss of a teenage son in a car accident – but nothing akin to what my grandfather encountered in World War II. (Family legend has it that he killed ten men. The number is suspect; the fact that he killed and witnessed wholesale carnage is not.) O'Donovan's diagnosis in 2011 of cancer was traumatic and personal. She did not witness death in others; it was presented to her as a possible outcome to her illness. She was treated in a professional, clinical setting and that treatment was successful. There was no blood, no gore, no explosions, there was no significant physical pain. Despite this, O'Donovan did not consider herself to be well, even after months of living cancer free. Similar to my grandfather, she found that her emotional damage persisted, even though her physical wounds healed.

I have observed my mother-in-law closely as she passed through the cancer experience, which started with several months of anxious expectation in which she self-diagnosed her cancer and that culminated post-treatment in a twilight state of anxiety and fear. In the months that followed her final chemotherapy treatment, Endora O'Donovan became withdrawn, distant, and taciturn. She became preoccupied with death. She began talking to herself when no one was around. I perceived, dimly at first, that her behaviors mapped approximately to the behavior displayed by my grandfather in the last years of his life. The comparison snapped into place during an interview with O'Donovan in which we discussed the apparent discrepancy between her inner mood and her outward health. She declared "I'm not Wonder Woman. No one is a Wonder Woman. I haven't figured out yet how to move on from this. I may never be the same as before the cancer." (O'Donovan) Like my grandfather, my mother-in-law had never seen a superman.

I believe Endora O'Donovan was experiencing nascent symptoms of PTSD, and I suspect that she is not unique among cancer survivors.

O'Donovan recently pointed me to a blog posting at the Washington Post that contained a short poem that O'Donovan explained captured her ambivalence towards life after cancer:

Prefatory  
By Sandra Steingraber

I am often unsure  
 how to begin  
 as a bird  
 who holds in her mouth  
 the first twigs  
 of a new nest  
 and not far below  
 the gray cat  
 squinting  
 in the full sun (Steingraber 25)

The posting's author, Donna Trussell, observes elsewhere in the post that "There's a lot of talk about PTSD in military circles, but very little in cancer circles." (Trussell) This is not quite accurate. I have observed many lively discussions about PTSD among survivors (Ennis-O'Connor, "Loss of Identity", "Derailed", "Panic Attacks/Anxiety") and I have found significant academic research on the subject (Smith, Cordova, Alter, Rustad). It is apparent that physicians and researchers draw a clear connection between a diagnosis of cancer and the potential of PTSD and it is equally apparent that this information is not communicated to cancer patients. Cancer patients are not routinely evaluated for behavioral and genetic characteristics that may indicate an increased probability of an onset of PTSD. Cancer survivors are not routinely evaluated for PTSD during post-treatment checkups. This disconnect is puzzling and deleterious.

### **The History and Definition of Post Traumatic Stress Disorder**

In *Henry IV, Part 1*, William Shakespeare manufactures an exchange between Sir Henry Percy and his wife, Kate. Percy was widely considered to be one of the finest soldiers of his day, so ready and aggressive in battle that the Scots referred to him as *haatspore* (Cannon 507), anglicized by the English as the honorific *Hotspur*. Though Sir Henry is a hardened warrior, Shakespeare depicts him in the play as troubled in ways that only his wife can sense. When she encounters him in Act II, Scene 3, Hotspur is alone, brooding over an impending rebellion against the English king. "O, my good lord, why are you thus alone?" she asks. Her husband has been distant and uncommunicative of late. Lady Percy gently prods him:

Tell me, sweet lord, what is't that takes from thee  
 Thy stomach, pleasure and thy golden sleep?  
 Why dost thou bend thine eyes upon the earth,  
 And start so often when thou sit'st alone?  
 Why hast thou lost the fresh blood in thy cheeks;  
 And given my treasures and my rights of thee  
 To thick-eyed musing and cursed melancholy? (II.iii.30-36)

Every generation has its war. This was true of Sir Henry Percy in the 14<sup>th</sup> century and it was true of my grandfather in the 1940s and it is true of me in the present day. I served in the United States Navy on a guided missile destroyer. I was in the First Persian Gulf War. though I was lucky in that I was never near a combat zone. While life on a warship was certainly dangerous, I never witnessed the kind of death and destruction that my grandfather encountered

on the island of Okinawa in World War II, and I never came face-to-face with my own mortality as my mother-in-law did when she was diagnosed with late stage ovarian cancer.

Being presented with death or the possibility of death must carry with it certain emotional baggage. I have an intuitive understanding that the weight of that baggage must vary from person to person. However, I do not understand how that baggage is quantified. Why are some people permanently crippled by trauma while others recover? My grandfather was emotionally scarred from witnessing the violence of mass-produced mechanized war. In contrast, my mother-in-law was gently informed of her statistically probable death in a safe, clean environment, surrounded by loved ones. Despite the disparate circumstances, my mother-in-law displays the same psychological symptoms that plagued my grandfather. The possibility of PTSD affecting returning war veterans is familiar to me; the potential of PTSD among cancer patients is not. Should it be? I admit I have no psychological training, and what I know of PTSD comes from a general cultural understanding of the syndrome, due primarily to the tide of returning veterans from the wars in Iraq and Afghanistan. As my knowledge of PTSD is limited, a brief examination of how mental health professionals define and diagnose PTSD is in order.

The *Diagnostic and Statistics Manual of Mental Disorders (DSM)* is a tool used by researchers and clinicians who deal with mental health issues (American Psychiatric Association). The purpose of the DSM is to classify, codify and categorize mental disorders. It is thus a logical starting point when examining the nature of any mental illness. The first incarnation of the manual, DSM-I, was published in 1952 (Andreasen 1321) and the manual has been steadily revised at various intervals. The most recent revision, DSM-IV-TR, was published in the year 2000. It contains diagnostic code #309.81: "Posttraumatic Stress Disorder".

The essential feature of Posttraumatic Stress Disorder is the development of characteristic symptoms following exposure to an extreme traumatic stressor involving direct personal experience of an event that involves actual or threatened death or serious injury, or other threat to one's physical integrity; or witnessing an event that involves death, injury, or a threat to the physical integrity of another person; or learning about unexpected or violent death, serious harm, or threat of death or injury experienced by a family member or other close associate (Criterion A1). The person's response to the event must involve intense fear, helplessness, or horror (or in children, the response must involve disorganized or agitated behavior) (Criterion A2). (DSM-IV-TR)

This description certainly matches what I have observed in both my grandfather and in my mother-in-law.

There are four other criteria that combine to form a diagnosis of PTSD and like the two cited above, are familiar to me through observation: An avoidance of situations or artifacts associated with the trauma (Criterion C); an increased "arousal" which refers to active or passive states such as insomnia or fits of anger (Criterion D); a duration of symptoms in excess of one month (Criterion E); and an overall degradation or complete paralysis of "social, occupational, or other important areas of functioning" (DSM-IV-TR) (Criterion F).

It has been observed that at least some of the symptoms described above are also described by William Shakespeare in *Henry IV* (Figley 6-7). Lady Percy comments that Hotspur is unable to sleep, that he is startled easily, and that he is generally morose and taciturn. She says:

Thy spirit within thee hath been so at war  
 And thus hath so bestirr'd thee in thy sleep,  
 That beads of sweat have stood upon thy brow  
 Like bubbles in a late-disturbed stream (II.iii.46-49)

Humans have experienced and reacted to extreme trauma since achieving sentience, so it is not an overstatement to say that the phenomenon of PTSD, known by many names throughout recorded history, is coupled to the human condition itself. In the Civil War, it was known as *Da Costa Syndrome* or *soldier's heart* (Grinage 2401). The term *shell shock* was used during World War I. In World War II, my grandfather was diagnosed with *gross stress reaction* (Andreassen 1321). While the introduction of the phrase “Post Traumatic Stress Disorder” is relatively recent, the syndrome is clearly not new. It is also not rare and it is not arcane. Researchers estimate that the lifetime prevalence (LTP) of the disorder in the United States to be somewhere between eight and nine percent (Grinage 2401).

There is no precise way to identify who will get PTSD in response to a traumatic stressor. Two different people can experience the same trauma at the same time, albeit with different results. A percentage of combat veterans will suffer from PTSD, as will emergency or first responders, victims of rape, violent crime and – relevant to the topic at hand – survivors of cancer. The DSM-IV-TR definition of PTSD lists several examples of trauma that can facilitate PTSD, including “... being diagnosed with a life-threatening illness”. (DSM-IV-TR)

A cursory survey of the literature shows that research into the causes, diagnosis and treatment of PTSD is both broad and deep. Researchers know about PTSD. They are interested in it and they are studying it vigorously. There is also a sustained academic effort to understand the effects of PTSD within the sphere of cancer survivors.

### **Validating the Link between PTSD and Cancer**

One evening Sam came into the study and found his master looking very strange. He was very pale and his eyes seemed to see things far away.  
 “What is the matter, Mr. Frodo?” said Sam.  
 “I am wounded,” he answered, “wounded; it will never really heal.”  
 But he got up and the turn seemed to pass, and he was quite himself the next day.  
 (Tolkien 1002)

It is a story that is familiar to millions: The Hobbit Frodo is entrusted with a dangerous and sacred task, to escort an evil, powerful talisman to its point of destruction. The quest is difficult but ultimately successful and Frodo has every reason to rejoice. But the effects of Sauron's ring are cancerous and permanent. In the closing pages of *The Lord of the Rings*, set

many years after the conclusion of Frodo's epic quest, the reader finds that, while not outwardly sick, Frodo is not entirely well.

Could it be that the Hobbit Frodo suffered from Post Traumatic Stress Disorder PTSD?

In the previous section, I briefly examined the long history of the phenomenon that is now known as PTSD. There is an equally interesting short history that begins with the formal introduction of the phrase "Post Traumatic Stress Disorder" in 1980 and that continues even now, as of this writing. PTSD is not as clearly defined as one would expect of a clinical diagnosis. The component symptoms that combine to form a diagnosis of PTSD have been reformulated, and it is possible that they will be modified again. While it is my wish to examine those aspects of PTSD that are unique to cancer, the definition of the syndrome have generated enough controversy that I feel compelled to substantiate the claim that PTSD is an ailment that can, in fact, be applied to cancer patients and cancer survivors.

The phrase "Post Traumatic Stress Disorder" was formally defined in 1980 with the publication of the third edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-III) (Rustad 213). The disorder was described as a set of prolonged psychological symptoms that manifest after exposure to a traumatic event and that significantly impair an individual's ability to function productively. The DSM-III definition of PTSD detailed five criteria, four of which are dependent on *Criteria A*, "The person has experienced an event that is outside the range of usual human experience and that would be markedly distressing to almost anyone." (DSMIII) The authors of this original definition of PTSD were responding, in part, to the needs of military personnel deployed to Vietnam. (A member of the research group assigned to update and edit the DSM, Dr. Nancy C. Andreasen, has observed that the phrase "Post-Vietnam Syndrome" was initially considered as a label, thought it was eventually rejected in recognition of the potential of traumatic experiences outside combat as triggers for the disorder (Andreasen "Acute").) The precipitating trauma described in *Criteria A* was to be a discrete, uncommon event that could be, within some reasonable approximation, isolated to a time and place. Examples of qualifying stressors included natural disasters, terrorist incidents, rape and combat (Rustad 214).

The qualifying symptoms outlined in DSM-III substantially changed in 1994 with the publication of the fourth edition of the manual, DSM-IV. *Criteria A* of PTSD was rewritten as:

- A. The person has been exposed to a traumatic event in which both of the following have been present:
- (1) the person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others
  - (2) the person's response involved intense fear, helplessness, or horror.
- (DSM IV)

What initially appears as a mundane clerical function, i.e. to expand and clarify the language of a clinical definition, was to have far reaching consequences inside the medical community and eventually to cancer patients. While the definition of *Criteria A* used in DSM-III

was broadened to include experiences outside of combat, the focus was mindfully tightened to a limited range of events, relatively uncommon and conceptually easy for researchers to identify. With the publication of DSM-IV, Criteria A included both the reality and the perception of mortality to oneself and others. The authors of DSM-IV cast the net for qualifying stressors for PTSD quite a bit wider than their predecessors, and as a result granted clinicians the latitude to apply the PTSD label to individuals who receive a diagnosis of a life-threatening or otherwise debilitating condition. This change was and remains controversial. Professor Richard J. McNally of the Department of Psychology at Harvard University has described the DSM-IV change to Criteria A as “a kind of conceptual bracket creep”, declaring that “With such diverse events deemed causally relevant to PTSD, it will be difficult to identify common psychobiologic mechanisms underlying symptomatic expression.” (McNally 231) Dr. Nancy Andreasen herself, integral to the drafting of the original definition of PTSD in 1980, has expressed reservations, writing that “In my view, this broadening should be reconsidered. Giving the same diagnosis to death camp survivors and someone who has been in a motor vehicle accident diminishes the magnitude of the stressor and the significance of PTSD.” (Andreasen “Acute”) Returning briefly to the hero of *The Lord of the Rings*... did Frodo suffer from PTSD because of the mass killing and wholesale mayhem that he witnessed during his journey to Mount Doom? Answer: Most certainly. Did he suffer from PTSD because of the insidious effects of Sauron’s ring? Answer: Researchers cannot seem to agree.

Objections to the redefinition of Criteria A introduced in DSM-IV have merit and are readily apparent when PTSD criteria are considered within the context of the cancer experience. Indeed, the application of a PTSD diagnosis to a patient or survivor of *any* chronic disease can be problematic as the definition of PTSD in DSM-IV is predicated on the identification of a specific, quantifiable stressor. Criteria B, for example, pertains to re-experiencing a past event (the stressor) in the form of recurring dreams or flashbacks. However, the diagnosis, treatment and eventual survival of cancer constitute a series of potentially traumatic events such that isolating a single stressor among them can be impossible (AAETS "Conceptual Fit", Rustad 214). Furthermore, as noted by Cordova, et al., cancer patients and survivors can experience persistent anxiety in anticipation of *future* events, such as impending invasive treatments, a recurrence of the disease, and death (Cordova 313).

Despite these flaws, there is a growing body of evidence that the conceptual model of PTSD outlined in DSM-IV does, in fact, fit with the matrix of traumas related to cancer to a degree that is informative and useful for diagnosis. The authors of a 2012 paper published in the *Journal of Palliative and Supportive Care* entitled “Cancer and Post-Traumatic Stress Disorder: Diagnosis, Pathogenesis and Treatment Considerations” surveyed attempts by researchers to extrapolate the existence of PTSD in several samplings of cancer survivors using data collected by means of a standard diagnostic tool, “The PTSD Checklist-Civilian Version” (PCL-C). The PCL-C is a questionnaire with items that correspond to the underlying symptoms of PTSD outlined in DSM-IV. Respondents are asked to rate their experience with each symptom on a scale of 1 (not at all) to 5 (extremely), the so-called *Likert Scale* (Cordova 307). It was determined that, to a reasonable extent, the responses provided by cancer survivors in four separate studies qualify as symptomatic of PTSD. The authors of “Cancer and Post-Traumatic Stress Disorder” summarized their results in this table:

Author (Year)	Type of Study	Findings
Smith et al. (1999)	EFA on PCL-C data collected from a sample of 111 adult patients with cancer who had undergone bone marrow transplantation an average of 4.04 years previously	Four distinct patterns of symptom responses: 1) numbing-hyperarousal, 2) dreams and memories of cancer treatment, 3) hyperarousal, and 4) responses to cancer-related reminders and avoidance-numbing.
Cordova et al. (2000)	CFA on PCL-C data from a sample of 142 survivors of breast cancer.	Factor structure of PTSD in this sample is better described by the DSM-IV three-symptom cluster than by a single, global PTSD symptom structure.
DuHamel et al. (2004)	CFA on PCL-C data from 236 cancer survivors who received a bone marrow or stem cell transplant.	Four-first-order-factor model of PTSD with re-experiencing, avoidance, numbing, and arousal provided the best fit to the data
Shelby et al. (2005)	EFA on PCL-C data from 148 women with stage II or III breast cancer after completion of cancer treatment.	Four-factor solution including re-experiencing, avoidance, numbing, and arousal factors.

CFA, confirmatory factor analysis; EFA, exploratory factor analysis; PCL-C PTSD Checklist Civilian Version.

Fig. 2. Factor Analytic Studies of PTSD in Cancer, table from Rustad, et al., “Cancer and Post-Traumatic Stress Disorder” (*Journal of Palliative and Supportive Care*, 2012.)

Diving into the details of these four research efforts, it appears that numbing and avoidance symptoms (Criteria C) among cancer patients are not as significant as with the greater PTSD population. Despite this qualification, the strict definition of PTSD published in DSM-IV is an acceptable fit (that is, applicable as a diagnosis) to what some cancer patients and cancer survivors experience. The prevalence of PTSD increases depending on a patient’s prognosis and the severity and duration of his or her treatment (Rustad 216).

### **The Effects of PTSD on the Well Being of Cancer Patients**

Christopher Hitchens died on Thursday, December 15, 2011 in a Houston, Texas hospital. Hitchens had been diagnosed with advanced esophageal cancer a year before, but as is often the way with the final days of cancer, it was Hitchens’s immune system that terminally betrayed him. The cancer may have felled Hitchens initially, but it was a bout of pneumonia that proved deadly.

Between diagnosis and death, Hitchens underwent an aggressive series of chemotherapy treatments. He wrote of the experience in a posthumously published collection of essays entitled *Mortality*.

Allow me to inform you, though, that when you sit in a room ... and kindly people bring a huge transparent bag of poison and plug it into your arm, and you either read or don't read a book while the venom sack gradually empties itself into your system, the image of the ardent soldier is the very last one that will occur to you. You feel swamped with passivity and impotence: dissolving in powerlessness like a sugar lump in water. (Hitchens 112)

Hitchens’s observations are evocative of the feelings of “intense fear, helplessness or horror” used to describe the qualities of a stressor in the currently accepted definition of PTSD

(DSM-IV). Given that Christopher Hitchens was abruptly presented with the prospect of his own mortality, could it be that he developed PTSD with chemotherapy as the stressor?

In the previous section, I demonstrated that PTSD can be a valid, verifiable outcome to a diagnosis of a life-threatening disease such as cancer. The statistics are remarkable: Whereas the lifetime prevalence of the disorder in the United States is estimated to be between eight and nine percent (Grinage 2401), researchers have demonstrated that up to 35% of cancer patients display the full spectrum of symptoms of PTSD after treatment concludes (National Cancer Institute).

To say that PTSD is debilitating is not simple rhetoric. It is a statement of definition. The matrix of criteria referenced in the entry for PTSD in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) lists Criterion F: “The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.” (DSM-IV) In other words, the effects of PTSD are such that a person who has it is incapable of performing basic life skills. This is true regardless of the person’s physical fitness as even the most robust combat veteran can be crippled emotionally by the disorder. If the effect of PTSD is thus debilitating for a person who is otherwise healthy, what is the effect on those with a coinciding illness?

While one cannot draw an explicit relationship between PTSD and other secondary and physical illnesses, there is evidence that the prevalence of certain diseases – including cancer - can be statistically linked to the disorder. The authors of a 2007 paper published in *Psychosomatic Medicine* found that “...PTSD remained significantly associated with several physical health problems including cardiovascular diseases, respiratory diseases, chronic pain conditions, gastrointestinal illnesses, and cancer.” (Sareen 242) Even without advanced knowledge of psychology or anatomy, one can suppose a deleterious relationship between the biologic condition of cancer and the emotional consequences of PTSD, as PTSD has well documented comorbidities that can undermine a cancer patient’s already fragile health. These comorbidities include smoking, depression, substance abuse, and other suboptimal lifestyle choices (Rustad 217) that are known to weaken the immune system. Cancer treatments such as radiation or chemotherapy can also weaken the immune system. The effect is cumulative: If a cancer patient has PTSD, he or she is thus predisposed to comorbidities that, in conjunction with invasive and toxic cancer treatments, dramatically increase the potential for additional ailments and prolonged infection.

Another, less documented consequence of PTSD on the treatment of cancer entails diagnostic Criterion C of the disorder. Criterion C refers to avoidance of settings that remind a person of a stressor. For a person who was present at the World Trade Center on the morning of September 11, 2001, avoidance might manifest in an unwillingness to travel in or around lower Manhattan. For a victim of violent assault, it might mean the person avoids situations that are reminiscent of the crime. For cancer patients, there is a danger that the individual may associate medical settings with the trauma of the illness. The treatment itself of cancer may be the stressor that predicates PTSD. This concern was described by Sophia Smith of the Duke Cancer Institute in a 2011 interview with Reuters: “You worry if the patient is avoiding medical care, you worry they might not be getting follow-ups. We don’t have data to support that, but we worry about it.” (Joelving)

At this point in the discussion, I feel compelled to ask: What is the ultimate goal in treating a patient with cancer? The answer informs what practical steps can be taken with the information presented in this paper regarding PTSD and cancer. If the goal of treatment is limited to the eradication of the illness alone, doctor and patient need look no further than the last radiation session, the final surgery, or the completion of chemotherapy. However, if the goal is the short term elimination of cancer **and** the long term vitality of the patient, the paradigm of treatment shifts. Ideally, the treatment of cancer should seek to minimize the possibility of recurrence. To that end, physicians should administer an initial screening soon after diagnosis to determine if an individual's profile matches certain socio-economic predictors of PTSD, such as a personal or familial history of depression, a history of drug or alcohol abuse, lower income, or a previous diagnosis of cancer (AAETS, Grinage 2403). At-risk patients should be informed of what PTSD is, how it manifests, and what steps can be taken to prevent or ameliorate the condition. During regular follow-ups after treatment, patients should be evaluated for late onset PTSD. (It should be noted that evaluations of this type are not difficult to administer. A battery of diagnostic tools are available, ranging from structured interviews facilitated by a trained therapist to various self assessment questionnaires (Adult PTSD Self-Report Measures).) Families and caregivers, too, should be given this information as education about the syndrome is considered to be fundamental in prevention and treatment of PTSD.

It is clear from talking to cancer survivors and from monitoring online cancer support forums that many - perhaps most - patients, family and caregivers are unaware that a link between PTSD and cancer has been firmly established. As part of my research, I surveyed a small group of cancer survivors about PTSD. I wanted to know if, at any time in their treatment or post-treatment follow-ups, they had been given information about the disorder. Of the ten survivors who replied, zero had been given any information about the syndrome by their health care providers; four were aware of links between PTSD and cancer through their own research; two had been given information about PTSD by family members.

In a perfect world, every cancer patient would be assigned to a team of professionals dedicated to the patient's current illness and future health. Treatment of the disease would be an immediate goal; whole health wellness would be the ultimate goal. The team would consist of an oncologist tasked with treating the cancer itself and it would include a nutritionist, an exercise physiologist, a therapist, perhaps even a somnologist. The patient's habits would be evaluated and, if necessary, corrective steps encouraged. In the real world, of course, resources are scarce. Insurance policies are limited; personal finances are finite. Health care professionals move rapidly from patient to patient with little or no thought to follow-up. Individuals are equated with their illness and their humanity forgotten. Medical science has ensured that lives are extended, but the quality of those lives is often undermined by unhealthy lifestyle choices. I cannot recommend a solution for these problems as they are big and complicated and beyond my ability to grasp. However, I can make one recommendation that I am certain will help cancer patients: Screen them for PTSD.

## Endings and Beginnings

Since the War on Cancer was initially declared in 1971 by President Richard Nixon, modern medicine has made slow and steady progress in the detection and treatment of cancer. A consequence of this success is a growing population of former patients, people who are living through and beyond treatment for many years. Cancer patients and survivors are largely ignorant of this fact. Even within the cancer advocacy movement, a collection of organizations dedicated to the support of cancer patients, the long term needs of cancer survivors are often overlooked. The medical establishment itself has yet to formally recognize its own success, and has yet to systemically address the long term physical and emotional needs of a survivor population that is projected to grow into the tens of millions (“Cancer survivors—United States, 2007” 270).

The primary focus of this paper has been the post-treatment experience of the cancer survivor demographic. Structurally, the paper consists of two parts. The first part explores the evolution of language used to describe those who transition from “cancer patient” to something else. This nebulous state has yet to be formally defined beyond the seemingly benign label “survivor”, a term that, as I have demonstrated, is emotionally charged in subtle ways. The second part examines the emotional challenges that cancer survivors face. Researchers have confirmed that an initial trauma of diagnosis, followed by a series of traumas linked to potentially invasive treatments, can induce PTSD in a statistically significant portion of the cancer survivor population. Despite this, survivors are rarely evaluated for the syndrome and potentially debilitating and costly secondary illnesses are likely to result.

These are the issues raised by this paper: That the language of survivorship is lacking and that the potential of PTSD in cancer patients is ignored. No agency or institution, to my mind, is at fault. These issues result from the relative newness of the phenomenon of a growing population of cancer survivors. In my own lifetime many diagnoses of cancer have evolved from a perceived death sentence to a manageable, albeit chronic, condition. The long term needs of cancer patients are unaddressed for the simple reason that the medical establishment and the culture at large have not realized that those needs exist. There are some stirrings that indicate the situation may be changing. The National Coalition for Cancer Survivorship was founded in 1986, and counted Dr. Fitzhugh Mullen as one of its founding members (NCCS “History” NCCS “Events”). The National Cancer Institute has an Office of Cancer Survivorship that has been in operation since 1996 (NCI “History”). 2007 saw the publication of an academic journal, the *Journal of Cancer Survivorship* (SpringerLink). Still, continued education is needed and continues to be the best proactive solution. When a cancer patient understands that he or she is likely to live beyond cancer and that continued survival will present new, unforeseen demands, the patient and his support network will be prepared for the both the illness itself and any long-term challenges that come afterward. Ultimately, the survivor population will require a comprehensive solution that entails extending the infrastructure that is currently built around a cancer patient to monitor his or her health to the post-treatment phase. An argument can be made that the cost of ignoring the future health of a population already given to at least one incident of a serious illness is greater than the cumulative cost of an ongoing investment in prevention.

There is another, less obvious, issue raised by this paper. I have presented my research in a way that does not question the method by which the medical establishment has chosen to

counter *any* disease, including cancer. In the United States, there is an emphasis on the treatment of illness, while efforts geared towards preventing illness are underfunded and underutilized. The approach of modern medicine in the developed world is deterministic in a Newtonian sense (Robin 2273). The human organism is regarded as a device of many moving parts; when a part is defective, Western medicine repairs or replaces it. It does not seek to mitigate the circumstances that caused the part to fail. This mechanistic perspective enables a mercenary approach to medicine that, in the United States at least, is more focused on the post-diagnostic effects of illness than the pre-diagnostic causes. In a telling article published on The Huffington Post website in 2011, Dr. Abdulrahman El-Sayed of Columbia University observed that in the American health care system, "...the fundamental billing unit is the 'procedure' -- doctors charge per action, diagnostic or curative..." Dr. El-Sayed draws the provocative conclusion that this focus on discrete, quantifiable and *billable* actions has spawned a "...market-driven system [that] introduces perverse financial incentives for medical providers that don't align with the health or wellbeing of Americans." (El-Sayed) Of the total U.S. annual expenditure on health care, approximately five percent is used for prevention (Wright). In terms of cancer research, financial investments in treatment are four times larger than corresponding investments in prevention (Bailar).

I have said that there is a growing population of cancer survivors because of improved detection and treatment, but there is a deeper truth. In absolute terms, there are more cancer survivors because there are more cancer patients. While cancer mortality rates have declined since the War on Cancer was declared in 1971, rates of incidence have increased for nearly all cancers (World Health Organization) and by one estimate are expected to rise by an astounding 75% by 2030 (Medical News Today). With the American health care system's preference for treatment over prevention, these trends can be expected to continue. What is needed is a paradigm shift in how industrialized nations regard illness, particularly in the United States and particularly with regard to cancer. I have offered a variety of limited solutions throughout this paper to the issues facing cancer survivors... primary care physicians should be involved more closely with their patient's oncological issues; academics should settle on a definitive label to describe those who live beyond treatment; cancer patients should be immediately informed of the possibility of PTSD at the time of diagnosis; follow-ups should include an evaluation for late onset PTSD. These are limited solutions to the limited issue of cancer survivorship. A permanent and lasting solution, though, is for patients and doctors to demand that prevention be the primary goal of medicine, not just an afterthought. It is unclear to me how or if change is possible. As Dr. El-Sayed of Columbia University observed, there are powerful financial incentives built into the health care delivery model in the United States that prevent this kind of transformation from occurring.

By all accounts, health care costs are projected to rise consistently for years to come, and could eventually consume a whopping 20% of America's GDP (Kaiser). The United States may one day find itself in an impossible scenario: Unable to afford its health care system and unable to change it.

The inspiration for this paper came from my mother-in-law, diagnosed with ovarian cancer in mid-2011 and subjected to a series of chemotherapy treatments for the remainder of that year. It was through a continued dialogue with her that I came to realize that the end of her

treatments did not represent the conclusion of her cancer experience. For her and millions like her, diagnosis and treatment is a phase. The last treatment is not the end. “It is not even the beginning of the end.” as Winston Churchill once said. “But it is, perhaps, the end of the beginning.” (Churchill 265)

As of December 12, 2012, my mother-in-law, Endora O’Donovan, was pronounced cancer free by her oncologist. Now, we wait.

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