



Volume 16
Issue 1
2021

Experiencing Cancer during the COVID-19 Pandemic: Reflections and Wagers

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In August 2019, I was diagnosed with advanced metastatic prostate cancer. My cancer treatments meant not only confronting the challenges of the cancer itself but experiencing them through the COVID-19 pandemic. This writing is an attempt to express the meaning of the experience of living with cancer under the umbrella of COVID-19. The overall context of the writing is both to try to make sense of my experience of living with cancer with the additional concern, anxiety, and fear of hospital visits, daily activities, and routine in the face of a previously unknown global event that hovered over and reshaped my cancer experience. Through this text, I have endeavored to explore this journey from different perspectives and to understand its meaning in my life.

My treatment regime began with androgen deprivation therapy (ADT) treatments, followed by chemotherapy, and then a course of radiation therapy. This treatment regimen coincided with the COVID-19 pandemic lockdown in my city. Each trip to the hospital created new sources of anxiety and stress. I questioned how I could safely get to

my treatment hospital. Upon arrival to the hospital, I was approached by hospital employees in personal protective equipment that I had never experienced before aside from viewing a science fiction movie. My wife who has been my constant support was no longer allowed to enter the hospital. I was alone with cancer, its treatment, and this pandemic. However, a new sense of purpose arose. With this manuscript I explore alternative ways to view the cancer experience, the prevalent language used, and my experiences as a patient perspective-researcher. Through a hermeneutical perspective, that explores the human tacit activities of living through challenging conditions as transformative possibilities, I explore the possibilities of turning the language of war to wayer and battle into a leap of faith in healthcare. These philosophical explorations of my experiences have offered a self-reflection that allowed a re-framing of cancer as something to engage with rather than a foe to battle. Cancer became an illness with wayers with multiple possibilities and multiple stories.

Finding a way through the complexity of a cancer diagnosis

I do not always have the words to describe my most difficult feelings. At these times I find it helpful to turn to authors from different kinds of literature. To begin to make sense of the moment my oncologist told my wife and myself about my diagnosis I turned to Richard Kearney philosophical essay *What is Diacritical Hermeneutics*. Kearney, in this work, suggested “diagnosis calls for endless dialogue: between disciplines, between text and action, between word and flesh, and above all between human persons who give and receive wisdom, attention, and healing” (2011, p. 9).

It often feels like I've been thrown into a surreally different life; one fragmented by a diagnosis of cancer. It was to me an unforeseeable eruption that invaded all aspects of my life. Cancer lives as an uninvited guest who can permanently change our sense of self, projections of the future, and the meanings of life previously understood. I hope to offer a new or different perspective on how we choose to live our lives through cancer stages, treatments, and a range of possible outcomes. Kurt Vonnegut wrote, "We have to continually be jumping off cliffs and developing our wings on the way down" (2014, p. 123). This quote spoke to me as cancer was a new, uncertain, and terrifying experience. No prior life experience had prepared me for cancer. I found the idea of being open to developing my wings while falling with cancer was somehow reassuring, empowering, and a creative way to begin a wager and leap into uncertainty.

Cancer as text

The introduction of cancer as text is offered to create awareness of personal narratives located around a specific topic of interest. I am continually adding to my cancer narrative using metaphors, challenging taken-for-granted language, and offering different ways to describe living with cancer. This was helpful for me as months of treatments continued to unfold. It might also be a helpful construct for others living with cancer, their families, friends, and healthcare providers. Text is not a single entity, but a composition (Davey, 2013). It is a composite of part-whole relationships, which constitute our evolving understanding of living with experiences such as cancer.

As Gadamer described

“genuine text... is exactly what the word literally says: woven texture that holds together. Such language, if it

really is a proper text, holds together in such a way that it stands in its own right and no longer refers back to an original, more authentic saying, nor points beyond itself to a more authentic experience of reality.” (1986, p. 142)

This article endeavors to bring forward my personal reflections and the interpretation of my cancer experiences as text, from the mundane to the life shattering. What we interpret can be considered as text—where text is the representation of our thoughts, emotions or perspectives—from a different perspective, in this case, that of living with cancer. The role of interpretation becomes the restoring of text from internal thinking (about cancer experiences) into living communication, through poems, short stories, paintings, photographs or artwork. In the context of cancer, these events interrupt us, our thinking, our reflection about the meaning through interpretation of *text*. Interpreting a *text* with others encourages new understandings that are greater than one’s own limited capacity and encultured horizon prior to these new understandings. We transform our understanding from the tension of having other perspectives that disrupt our way of knowing, sensing, or thinking. *Text* serves to invite or promote synergistic thinking, knowing, and sensing in relation to a topic, person, or thing. This personal narrative explores text within multiple contexts as a means to understand. This occurs through a hermeneutical sensibility about text and its ability to provoke our senses into understanding beyond what we see or hear. Since we as humans are always in the process of interpreting through our senses, this personal narrative about my cancer experience strives to offer a provisional, initial hermeneutical explication of that experience.

It is provisional given that all interpretations are new or different until ones become available to add and extend our understanding of an experience. The text that follows is from the perspective of a person (myself) currently undergoing cancer treatments, (ADT, chemotherapy radiation therapy) expressing them as best I can reflectively, interpretatively, and philosophically.

The leap of faith (and belief in my healthcare team)

Faith is more than hedging your bets. A leap of faith requires something else in order to earn the name ‘faith’ rather than ‘belief,’ ‘guess,’ ‘opinion,’ or ‘wager’”. The difference between belief and knowledge is epistemic and has to do with how certain we are about a given proposition, while the difference between belief and faith is existential, ... having to do with our commitment to live in light of a certain proposition. (Treanor, 2010, p. 549)

A life threatening health condition necessitates a leap of faith that is existential concerning my personhood while coinciding with a belief that the healthcare system will do their best. Their knowledge and care are epistemic, based in decades of research, clinical practice, and commitment of helping persons diagnosed with cancer. There are however for the person living with cancer no guarantees, nor certainties of cures, remission, or life. It requires a wager of sorts. To me this epitomizes the hermeneutic wager outlined in the work of Kearney (2011). The wager requires risk. It is one not taken willingly, and it offers a multitude of possible outcomes. This kind of thinking then opens up other ways to approach the narratives of

cancer treatments, not only as a battle to win or lose, but rather as a wager confronting the risks. This wager all begins with a leap.

The imposition of other people's narratives

Often people diagnosed with cancer are told that they have entered into a battle or fight against this disease, a statement that, at first glance, offers a sense of purpose and strength against an unknown enemy. After my diagnosis, many friends and family defaulted to the battle narrative to encourage me into a fight against my cancer. "You're strong/you will beat this/you got this/kick its ass." There were also the friends or family members who told me of others they knew who had had the same kind of cancer and were fine now—as if one cancer story was interchangeable with another, as if those cancers and mine were identical, predictable, and would share the same outcomes. As well-meaning as these comments were, they were not helpful in the long run, as the treatments wear you down and you wait for the next "update" about your cancer "battle" status.

Cancer and philosophical hermeneutics

For me, cancer will always be intertwined with the arrival of the COVID-19 pandemic. They became an inseparable entity with increasingly complex engagements with healthcare at an unknown and unprecedented time for healthcare systems worldwide. In the midst of this experience, I encountered very early on the battle and war metaphors commonly used to describe cancer treatments, which I found uncomfortable and even repugnant. This language is pervasive in discourses surrounding cancer and other chronic health conditions. However, wars and battles suppose winners and losers. Consequently, from my per-

spective, I either win the battle and the war if my cancer goes into remission, or I am a loser if the cancer continues or I die. That is, I die a loser even though I did everything medically and humanly possible to win. I was able to find several specific articles that explore in detail the war and battle metaphors in healthcare. The following references are helpful for a reader to explore and who wishes to have more information: Hendricks et al., 2018; Nie et al., 2016; Tate et al., 2016; and Paris, et al, 2016.

In wars against anything, the battles fought aggressively and skillfully often dichotomize into winners and losers. The winners being survivors whereas the losers, leave us. Who wants to die knowing they were a loser in a battle they did not enlist into voluntarily—cancer conscription? Furthermore, there are no prisoners in this metaphor of war against cancer, other than the incarceration we feel as we go through cancer treatments. We wait as captives' in-between therapies, with a host of side effects that become inexpressible to others, coupled with the anxiety, the unknowing, and depression this process can create. When I had completed five out of six recommended chemotherapy treatments my side effects had become severe. I had potentially permanent damage to my peripheral nerves, vision, and internal organs. Yet due to the COVID-19 pandemic my oncology appointment was postponed. Much needed treatment verification methods such as MRI, PET scan, bone scans were delayed. I sat in limbo waiting to know about the progression of my cancer and for much needed information.

Treatments as wagers

The physical and emotional toll of chemotherapy was becoming unbearable. In consultation with

my oncologist, I decided to stop chemotherapy. This is an example of a wager where I chose to not to risk a sixth treatment. The outcome of this wager is difficult to know, but a risk was taken, not a battle fought. There was no war. The internal work of chemicals, hormone treatments, radiation, and cancers are beyond my sight and hearing, but all of this can be felt deeply as I change physically and emotionally. In the midst of it all, I realize I have no control other than being compliant and committed to the treatments. In this way, I am developing my wings and changing perspectives in order to find my balance once more.

Wagers and leaps

Progressing through cancer treatments has led me to the ever clearer understanding that this indeed resembles more of a wager than a war. In this personal leap of faith, there are many things at stake: my belief in the doctors, pharmacists, nurses, healers (with the sciences to support their actions), and my belief in those treatments, coupled with my own strong will for self-healing (self-empowerment). This differentiates a reckless leap from a wise, considered leap of faith where a healthcare team is working together with me to do the best they can for my healing. I use the word healing rather than cure for when cancer cannot be cured, we must help heal the person as they approach uncertain futures and expectations. The “push off the cliff” is an intense image and I offer it as a metaphor for accepting a cancer diagnosis as a leap of faith, with the accompanying trust in a healthcare team to help one grow wings as one metaphorically plummets downward. A leap of faith means, sometimes, just jumping headfirst into your treatments, even if you do not know

where you are going yet (cancer status update). The process simply unfolds, and you must trust in its efficacy.

We learn as we go, open to all possibilities. Open to the assistance of others from our social networks, healthcare professionals, and those who unexpectedly “show-up” to help play out our wagers and leaps of faith. We can replace the win-lose scenario of the war metaphors with one of leaps of faith and wagers, where many possibilities exist (often not only black and white/win-lose scenarios). All of this unfolds within grey areas (differing degrees of healing and even death) and we learn to accept them with grace, dignity, and character of our personhood through these wagers. Our personhood continues to evolve throughout these challenges we are confronted with over and over.

Why our stories matter

I am using “story” as a form of medicine because this keeps me as an active participant during my leap of faith. It helps bring thoughts from my reflections out into the world for me and for others to read. Frank (2013) wrote:

The wound becomes a source of stories, as it opens both in and out: *in*, in order to hear the story of the other’s suffering, and *out*, in order to tell its own story. Listening and telling are phases of healing: the healer and the storyteller are one. The sufferer is made whole in hearing the other’s story that is also hers, and in having her own story not just be listened to but heard as if it were the listener’s own, which it is. The illusion of being lost is overcome. The healing may not cure the body, but it

does remedy the loss of body-self intactness associated with suffering. (p. 183)

Unlike other experiences that have also disrupted my life—some profound, like the deaths of loved ones, failed dreams, learning to live with chronic pain and arthritis—cancer is in a league of its own. Learning from others was instrumental in helping develop my own wings as I leapt off this precipice imposed by a diagnosis of cancer, calling on my leap of faith and belief. This, and a reconceptualization of this process (treatments), is reframed through using the term *wager* rather than a war with battles. A *wager* implies a degree of risk, unlike a battle in which there is a winner and loser. In the context of a *wager*, we now have degrees of success and disappointments. The hermeneutic *wager* neither excludes nor denies the possibility of death due to cancer, but there are no winners or losers—only the acknowledgment and interpretation of existing as a human being. Our finitude becomes a source of conversation, unsilenced, and unconcealed.

The hermeneutic wager

While progressing through my cancer treatment I reflected upon the work of Richard Kearney and his work on the hermeneutic *wager*. This *wager* is comprised of five reflections and/or conversations to engage in that I have adapted to learn about living with cancer and its treatments. The hermeneutic *wager* has five points of reflection: imagination, humility, commitment, discernment, and hospitality. These will be used to provide examples of how to offer insight into one's experiences. Through these kinds of reflections on cancer, particularly during the time of the COVID-19 pandemic uncertainty can help us develop wings for the journey into the unknown uncertainty that often a diagnosis of cancer requires.

Imagination makes the wager or leap possible by opening up alternative ways of seeing or experiencing a situation. There are many possibilities associated with cancer: type, location and stage, combined with a continuum of treatments. This represents one leap and wager that includes all impossibilities. Imagination keeps the conversation open with others who can help when the treatments and the emotional aspects of cancer become unbearable, or even unimaginable.

The next possible reflection to consider is *humility* which flows from recognizing the necessity of imagination. It reminds us that beliefs about cancer, treatments, and future are interpretations rather than empirical facts. Taken together, humility and imagination remind us that there are always other translations and interpretations of the possibilities of how one lives or dies with cancer. It is our commitment within the cancer wager, which safeguards us from indecision or denial, that ensures our lived, existential experience. Humour related to humility helps people engage with one another. Often, as I waited for my treatments or appointments with my oncologists, I heard laughter, saw smiles, and sensed generosity of people living with a diagnosis of cancer, their families, and social support network. This phenomenon is one that is part of a shared understanding of what the other is going through. Even if we never know the specifics of their condition, we share in a common experience, which brings out the kindness and generosity of others.

The third reflection is that of the *commitment* to the leap of faith or belief that our healthcare team is doing everything they can to help us live with and through the cancer experience. It speaks to hope and confidence in those around us to know that as we metaphorically develop our

wings while falling from the cancer-cliff, we are not alone; we have access to multiple forms of help and support. This was invaluable for me, as once I was able to let go of fears and doubt about my treatments, I was able to enter into them with confidence and hope.

Discernment, the following reflection, adjusts imagination by reminding us that not all possibilities are available to us (for example, a cure) and moderates' commitment by reminding us that some wagers will evolve in ways we did not hope would be our outcome. This is important because having realistic expectations helps our emotional equilibrium. We know that being positive and hopeful is realistic, but there are always the possibilities of setbacks or discouraging news along the path.

Finally, *hospitality* tempers discernment in order to ensure that we remain as loving to ourselves and others as best as possible, even believing in the possibility of the impossible, so that discernment does not become primarily a negative interpretation. This reflection prevents fear and anxiety from becoming the driving forces of the leap of faith. Our belief in the hermeneutic wager will play out regardless. Hospitality offers an openness in the face of our natural tendency to fear and exclude the stranger, in this case, cancer. It also means we need to be open to whatever comes our way: the good, the disappointments, the nervousness as we wait to hear about our cancer status. All of these need to be welcomed parts of the process. They might be anxiety provoking, but if we welcome them all as expected, the wait they carry might lessen or even dissipate. Taken together, these five reflections combined with humor, support and define each other. They are open rather than closed; humble rather than victorious; imaginative rather than unembellished; en-

gaged rather than passive; and exploratory rather than closed-minded.

During this quietude of waiting for the next set of scans, I reflected on what might come next. I was anxious, nervous, and exhausted, but I am willing to leap again and wager the outcomes. The metaphorical wager may be joyful and exuberant at times, while realistically I also know they may not play out in my favor. In this context however, I am not ever going to be a loser of a battle, but rather a risk taker and believer. I don't know yet how these will play out in the long run. But this lifts hope.

A treatment trifecta

The chemotherapy was over, while the ADT continued with monthly injections, and with radiation therapy next in line. This occurred right at the beginning of the COVID-19 lockdown, when going to the hospital added an additional layer of distress. Living with an already compromised immune system I felt the extra vulnerability. However, treating advanced and aggressive cancer while risking exposure to COVID-19 was another necessary wager.

I use the term trifecta because of its connection to the act of wagering; betting on the first three horses to finish in the correct order. In this narrative, those three horses are chemotherapy, ADT, and radiation. Exhausted by the continued monthly ADT injections and 21 weeks of chemotherapy now completed, I witnessed my body endeavor to slowly return to itself; my vision improved, and my hair began to grow back. My fingernails and toenails, however, are changing texture and colour. This is not winning a battle, but rather, it is how the wager plays out while I await the third leg of the cancer treatment trifecta (radiation therapy). What remains is the unpredictable

chronic fatigue that changes my level of enthusiasm towards everything, including how and when I can accomplish my day-to-day tasks. I surrender and adjust and mend my damaged wings as I continue to fall from my cancer precipice.

Radiation therapy started at the beginning of March 2020 and represents the third leg of my leap of faith and belief in my healthcare team. This is the continuation, with a new aspect, of the cancer wager. This process was rather painless. The main discomfort of the treatment was attributed to the placing of “seeds” into my prostate gland. Prostate brachytherapy is a form of radiation therapy used to treat prostate cancer. It involves placing radioactive sources (seeds) into the prostate gland, where the radiation can kill the cancer cells while causing less damage to healthy tissue nearby (Mayo Clinic, 2020).

Now, I await the side-effects of this trifecta on my physical and emotional equilibrium. The continued extreme fatigue coupled with lower back pain from the metastatic disease in my spine has been the worst to navigate. A recent meeting with my oncologist revealed the metastatic bone-based cancer has shrunk in several places while others remain unchanged. This wager was helpful. I did not win or lose, but neither did I surrender. My cancer treatments remain in play and risks continue to be wagered daily.

Experiencing death, the ultimate wager

People die. We hope we die in older age, painlessly, perhaps in our sleep, but that is not always the case. A diagnosis of aggressive metastatic cancer brought the topic of death to the forefront of my mind swiftly. This was not a someday far-off notion pushed aside. It became real and imminently present. When contemplating death Gadamer (1986) wrote:

We must ask ourselves what knowledge of death really means. For there is a deep connection between the knowledge of death, the knowledge of one's own finitude, that is, the certainty that one day one must die, and, on the other hand, the almost imperious demand of not wanting to know, not wanting to possess this sort of certain knowledge. (p. 64)

Cancer reminds us that we are all vulnerable to the possibility of death well before we believe we are ready. It moves it from an unknown distant event to one closer at hand. Prometheus, in Greek mythology, is credited with helping mankind by taking away the knowledge of the exact day and time of our death.

Before man had been brought by Prometheus this gift of concealment concerning his own death, he must have lived wretchedly and unproductively in caves and created none of those cultural achievements which distinguish mankind over all other living creatures. (Gadamer, 1996, p. 64)

As a person aged 62 at the time of writing this article, my pre-cancer vision of life has faded away. Now, with the onset of COVID-19 world-wide, the vulnerable have become even more vulnerable. The gift from Prometheus is now in question as cancer reveals an uncertain future where the perception of decades of life shrink to years or even months. Gadamer wrote:

For every living person there is something incomprehensible in the fact that this human consciousness capable of anticipating the future will one day come to an end. Likewise, for those

who witness it, this final coming to an end has something uncanny about it.
(1996, p. 63)

Cancer reveals our repression of the idea of death with respect to our own life, but it must be confronted as part of the reality of the wager we entered into through our cancer treatments. The outcomes are uncertain, but we continue to have faith in ourselves and belief in our care.

The experience of death remains the ultimate human mystery. We fear the thought of our own finitude, we keep the talk positive and hopeful, treatments offer a wide range of possibilities from highly effective to ineffective. The cancer wager includes all possibilities with the understanding that not all wagers pay off and we may not get what we expected or hoped to receive, a lost wager.

Metaphorically, the losing of a wager does not mean the person who dies from cancer was a loser. They were rather a human whose leap of faith and belief in their healthcare could have no other outcome. The wager ran out. The person however has found peace in the leap and belief of throughout this ultimate human experience. We die not as a failure of a battle, but as a person who did everything possible to live. No wars fought, no battles lost or won, just a human being human. The wings we develop on the way down the side of the cliff become inspirational and life affirming.

It has now been two years since my cancer diagnosis. I have landed from my precipice cancer fall. The metaphoric wings I developed over this time are neatly tucked away for now. The reflections about my experiences from the hermeneutic wager were always helpful to shed light on my feelings and thoughts during dark times riddled with anxiety, exhaustion, and doubt. As I finish writing this

manuscript I feel better as I heal, but I am continually reminded I am not cancer free. I will have to learn to live with it for the remainder of my life. Treatment and efficacy monitoring continues each month. It is not the significant wager of months ago when I experienced cancer through chemo and radiation therapy. It is now a series of smaller yet still significant wagers revealing my monthly status of living with cancer. Each month's new wager presents the possibility of either my cancer being controlled or not. I perpetually live with a sense of risk.

There never was a war against cancer for me, no battles or even skirmishes, only constant reflection about the distressing times applied through wagers of risk, with faith and belief in the care and treatments I received. My story, like so many others of those who are fortunate enough not to write a conclusion but end this text as a coda. Life continues, just differently.

Coda

There is no conclusion to this manuscript. Rather I end with the term coda as a means to say something about the ongoing possibilities of expression to help people living with cancer and cancer treatments. Coda is a musical term originating from the Latin word *cauda*, which means tail, or the end. The hermeneutic wager, however, is not something that is concluded abruptly. Based on my cancer experience, during this time of COVID-19 and the vulnerabilities it has exposed, I have adopted another interpretation of the word coda:

Used in a more complex sense, as in a movement in music that echoes and replays the basic structure and motifs of the work as a whole, and, in doing so reminds us of how a story has unfolded

in both what was amplified and perhaps what is still hidden in the silences. (Lund, 2012, p. 131).

This is where the possibilities of a wager resound over and over by breaking through the silence of our hidden thoughts and lived experiences, for the person, their family and their friends. Conceptually, the idea of a leap of faith and belief that all that can be done is being done is in itself healing. Within the hermeneutic wager, reflections of imagination, humility/humor, commitment, discernment, and hospitality bring into presence our inner reflective thinking, emotions, and self-empathy to help ourselves and others who suffer alongside us.

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