Living With a Trifecta of Pain and Cancer With Personal Reflections of COVID-19

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Abstract
The purpose of preparing this Feature Article was to explore and share my lived experience of living with multiple layers of chronic pain, with a diagnosis of advanced, aggressive and metastasized prostate cancer, and COVID-19. My exploration begins with the manifestations of chronic pain from a bicycling accident, psoriatic arthritis, with cancer treatments and the pain it creates during a pandemic has added to the challenges of social distancing, isolation, and medical treatments. As with many patient experiences, we the person as patient outside of health care sometimes struggle to find the right words, the proper sentence structure and as Tamas writes about the expectation of others to provide, “Clean and reasonable scholarship about messy, unreasonable experiences is an exercise in alienation.” I write this while living with extreme chronic pain, continue cancer treatments while the threat and additional anxiety of COVID-19 looms over me. This is my story.

Keywords
chronic pain, cancer experience, COVID-19, hermeneutics, patient perspective writing

Intention and Approach
My intention for writing this Feature Article is to offer, through my personal story, a conversation about the complexity of life during COVID-19 within the context of an already stressful and vulnerable existence due to multiple sources of chronic pain and with cancer treatments. Ironic as it seems to me, my perspective is that of an academic who previously researched the meaning for people living with chronic pain, osteoporosis, medical error, self-stereotyping, and now living this experience of chronic pain, himself. My research approach is rooted in philosophical hermeneutics which provides an interpretive/reflective structure to investigate the meaning of living with challenging life contents. The personal story (or narrative) becomes an opening into expression and meaning of events, expectations, experiences, and day-to-day engagement in the world. Hardy (1) writes: “Every day has its story. Whether it has been an ordinary day or an unusual one, we tell it over, to ourselves, to our journal, to other people” (p. xii). Storytelling seemed to be a natural way to share as my narrative unfolds through experiences of living with layers of pain and cancer during a pandemic.

Many readers, especially those with expectations of a certain sequence for academic papers, may not be aware that sitting and writing this article while in severe pain, physical and emotional, is in itself a challenge. I think it is most relevant to share another citation by Sophie Tamas (2) as it locates well this kind of storytelling. It also speaks to the fact that when stories are told from this patient perspective rather than from an academic one, the reader may have to work more than usual to interpret what the author is trying to say in order to understand its meaning and perhaps then find ways to include it into their own story.

Our non-testimonial, non-performative stories can still be very interesting and, in their own way, socially and politically useful. But I worry that they position the reader and the writer as voyeurs. If we are sitting in the gore and confusion of our own suffering, my sane, readable account of loss may reinforce the expectation that our trauma ought to make sense, and if it doesn’t, we must be somehow inadequate or failing. It implies that the order of the universe is, in fact, intact, and the traumatized who have lost faith in reason, language, and human decency are mistaken. (paragraph 18)

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Thinking back to before COVID-19 while I was on vacation and waiting for the next treatment phase (radiation therapy), I found myself reconciling different components of the complexity of living with chronic pain and cancer. I am often overcome with the worry and anxiety created by thinking about what I am doing/what I should be doing/what I can do. My precancer chemotherapy/androgen deprivation therapy (ADT) brain demands I do certain things and be “productive,” like researching, writing grant applications, student supervision, and day-today taken for granted activities like physical exercise. However, my posttreatment body is unable to respond like it used to. I do not feel like myself. I feel a mere shell of my former self and guilty that I am not able to achieve more. Learning to not be devastated by this, combined with the possibility of a negative cancer report, adds to my disorientation and vulnerability. I can only express this as feeling blank and perhaps for now, metaphorically, there is no need for pen to paper, finger to keyboard, brush to canvas nor to pull on the ribbon holding the gift of my life circumstances intact.

Layers of Pain

I live with layers of chronic pain. The first layer is a result of physical trauma after being hit by a car while bicycling home several years ago. This left me with severe chronic lower back pain and a painful burning numbness in my right foot. The degree of pain fluctuates hourly and daily; and although challenging, I’ve learned how to manage these sensations. I have learned over time how to coexist with this pain. The second layer presented itself within the last 3 years in as diagnosed of psoriatic arthritis. This added another new dimension of pain with the appearance of swollen joints and limited mobility. It has posed many challenges for work, socialization, relationships, and physical activity. This layer, too, I learned to navigate and make manageable. The combination of these pain-inducing events presented significant life-changing challenges to retaining my sense of personhood.

My cancer diagnosis was discovered when my rheumatologist sent me to have a magnetic resonance imaging (MRI) done to gain greater insight about my psoriatic arthritis. The next day, she made an emergency appointment with me to tell me that they discovered possible prostate cancer. I was immediately placed into the care of an oncologist at a local hospital. So, serendipity seems to have had a role in the discovery of my cancer. This third layer of pain ended up being explained by the diagnosis of advanced metastatic prostate cancer with metastatic disease in my lower spine and ribs. The diagnosis of advanced metastatic prostate cancer brought my life to a whole new level of anxiety, stress, and worry. I concurrently began ADT and chemotherapy treatments, which were followed by radiation therapy.

Chemotherapy was excruciating through a progressing pattern of pain, hair loss, vision changes, balance, and numbness of fingers and toes. I felt completely ill and nothing like the person I used to be (3). This was followed by a course of radiation therapy that coincided with the onset of the COVID-19 pandemic, city closures, and social distancing measures. I was fortunate to be able to complete my radiation treatments. For many persons living with cancer, this has not been the case as treatments have been delayed or altered as the pandemic raged in the city in which I live.

However, I still needed to return to the hospital for MRIs, bone scans, blood tests. Fortunately, the course of my therapy consists mostly of telephone conversations with my oncologists in addition to monthly ADT injections at my home by a nurse practitioner. Going through the cancer treatment trajectory with layers of chronic pain has been challenging to say the least; the worry, uncertainty, stress, and anxiety were at times absolutely intolerable.

COVID-19 as a Magnifying Glass

The COVID-19 pandemic magnified all of my concerns with an increased sense of vulnerability and uncertainty. It revealed that my strength to live with a trifecta of pain and cancer was challenging enough. Still, with COVID-19 everything changed once again. COVID-19 ushered in an additional and volatile component in managing my health conditions, hospital visits, and my everyday life.

One can always attempt to look for silver linings but COVID-19 is simply a completely unwelcome addition to my health concerns now because of the additional precautions needed to protect myself and others from contracting this virus. I am now even more vulnerable physically and emotionally as well. During chemotherapy, even before COVID-19, my compromised immune system required a form of self-isolation. I was already exercising some level of self-isolation and social distancing prior to the COVID-19 pandemic. Heartbreakingly, I have experienced many individuals who do not understand this needed level of self-isolation and fail to take needed precautions to lessen the illness’ potential. COVID-19 adds another significant layer of concern, which are both for the most part, is out of my control. Any lack of control increases a sense of vulnerability.

The Feeling of Blank

I sometimes feel blank. This sense of emptiness is like the blank sheet of paper waiting to be brought back to life, through text, characters, stories, and meaning. It also reveals in its blankness the need to displace the uncertainly through a new narrative of living through the COVID-19 pandemic. This kind of pandemic paralysis makes me feel blank or empty, without any motivation to find a way back to care for things that used to matter to me. At times, it is simply too much living with chronic pain and the added shadow of COVID-19 leaves me devoid of passion.

Prior to COVID-19, I cannot be sure what this feeling is due to specifically. Nor if it is an accumulation of physical
and emotional fatigue compounded by the pandemic. The 12 months of recently completed cancer treatments, ongoing monthly ADT injections, side effects, relentless pain in my back, and hips coupled with the unknown status of my cancer makes everything and everyday challenging. These are difficult days for me. I tell people I am ok when I am barely holding “it” together (4). I am intellectually, physically and emotionally exhausted/ burnt out. I now understand the difference between being tired-exhausted and fatigue-exhausted. Being tired or even exhausted before meant catching up on sleep through taking a break or having a long weekend to replenish. However, the fatigue-exhaustion from cancer and its treatments has shown me a whole new level of anguish. Everything that used to be taken for granted is now difficult. Getting out of bed, getting up from a chair, walking in snow or just having enough energy to meet people for a few hours depletes. This exhausted state is like none other I have ever experienced before. I wonder if this fatigue will be a permanent way of life. COVID-19 means that activities that used to be helpful like spin classes at the Young Men’s Christian Association (YMCA), physiotherapy, massage, and even haircuts are unavailable. I also realize that this is true for everyone. Yet, I have witnessed my pain-imposed and reduced social connectedness shrink even more in the present unexpected circumstances.

In trying to make sense of this current state I am experiencing; I am waiting in the liminal. This is an in-between of what was my life was previously and what it might become. Waiting to hear about treatment tests results is like this. On one hand, no news creates a different kind of distress. Although the cancer status is unknown, the not knowing remains suspenseful and anxiety provoking. What if the cancer has become worse? COVID-19 has added a new layer of vulnerability.

The intersection of living with pain, cancer, and treatments during a pandemic is distressing. Hospital visits are regulated, and new safety protocols are in place and often intimidating. I go to the hospital with a mask and gloves for protection and wait in a room with spaced out seating to keep people separated. Previously, people seated in the waiting room shared a sense of unspoken but acknowledged community. Smiles were exchanged and small talk engaged in. During COVID-19 times, these have changed to a palpable disease wherein everyone is evaluating each other for COVID-19 symptoms. People move to other seats if they believe someone might be too close or possibly contagious. The multiple hand sanitizations, the general atmosphere, and heightened anxiety pervades the waiting room. COVID-19 now exacerbates the already existent sentiment and predisposition to anxiety that persons with cancer inevitably have related to disease progression, treatment, and possible death. During the COVID-19 pandemic, while these continue to be present, there is also a sense that they are no longer the utmost and most immediate concern.

We are far from being finished with the COVID-19 pandemic. In my lifetime I never thought going to the hospital, getting groceries, visiting a pharmacy, or going for a walk could be dangerous or trigger feelings of extreme vulnerability. Persons such as myself who are hyper vigilant to ensure that not only are we safe but that those around us are too. Through writing this Features Article and sharing my story, I hope to shed light on what it might mean for someone already vulnerable through chronic pain or cancer to live with the heightened vulnerability that has arrived with COVID-19, including our elderly in nursing homes, people living with disabilities, and the chronically underserved through a pandemic. I have been nonetheless fortunate to have a wonderful support system with my wife many friends, colleagues, and graduate students.

Authors’ Note
This feature article was written from the exclusive perspective of the author Dr. Richard Hovey. I am comfortable with what and how I have shared it for potential publication.

Declaration of Conflicting Interests
The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding
The author(s) received no financial support for the research, authorship, and/or publication of this article.

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