

Serious Illness Like Cancer Requires Existential Care—But What’s That?

Cancer assaults our drive for meaning, morals and purpose, writes Adam Hayden. To address these *existential* problems, we need *existential care*!

November 16, 2023 By [Adam Hayden](#)

This post is dedicated to my friend, colleague, and mentor Elise Tarbi, PhD, whose support has brought more opportunities to think, write, and share on many of the ideas that sit behind this post.

It is more important to know what sort of person has a disease than to know what sort of disease a person has.
—Hippocrates

I launched this blog (originally hosted by Wordpress, now here on Substack), four months following hospital discharge. I had undergone an awake craniotomy (skull opening) and surgical resection (removal) of my seven centimeter primary brain tumor, soon diagnosed glioblastoma—an aggressive, malignant brain tumor. Given the size and placement of the tumor and the extent of resection, I experienced left-sided paralysis throughout my body in the days following surgery. Orienting myself to the neuro-ICU, I experienced a heaviness. I wasn’t immediately aware of the paralysis, and besides, my surgeon informed me that he had mitigated the risk of this outcome. Disbelief, confusion, or both, I felt more curious than alarmed when I realized that I couldn’t move my left arm, or my leg.

Lying in the hospital bed, I’d reach across my belly to move my left hand using my functional right arm. I remember the neurosurgeon’s enthusiastic reply later on rounds when he asked that I wiggle the toes on my left foot: “If you can move it, we can get it better!”

The reality snapped into focus when being transported in my wheelchair. Nurses would tape my left arm to the armrest of the wheelchair to prevent my left hand from falling into the spokes of the wheel. Years after the tape, these episodes are always close at hand (pun), especially associated with the persistent partial seizures that we’ve not been able to totally control with

medicine. My left arm postures, a clinical term used to describe involuntary muscle movements resulting from brain injury, lesion, mass, or stroke. I continue to experience mild posturing in my left hand. Often I'll be gripping a pen or maybe a fork at dinner, and I'll forget that I've clenched my hand around the object until noticing with my eyes or attempting to grab for something else. These are the parts of living with neurological impairment that both frustrate and fascinate me.

I was discharged from the hospital where I underwent surgery and admitted to the brain trauma unit of a rehab hospital, where I'd spend the next month undergoing intensive physical and occupational therapy, learning to walk, bathe, dress, and feed myself. I entered the hospital in a wheelchair, and I was discharged with a walker. After several months of outpatient therapy, I eventually graduated to a cane. For many, a cane is a display of weakness, injury, or aging; for me, a cane is the reward for my hard work and persistence.

My earliest blog posts took their cue from the philosophy graduate degree I had just completed, with a focus on the philosophy of science. It turns out that posts on the philosophy of science were not the preferred content by my audience—friends and family—who were more interested in me than characterizing the tumor in my brain. You could say that blog readers were keen to know what sort of person has this disease rather than learn about what sort of disease this person has! I shifted my writing strategy toward anecdotes and scenes from this healthy 34-year-old son, husband, and dad who suddenly found himself totally dependent on assistive devices and hospital aids to complete the activities of daily living, also known as the three S's: Shit, shower, and shave! That's a joke, obviously I don't shave!

It wasn't clear to me what I was up to when storytelling, until I read Arthur Kleinmann's book, [The Illness Narratives](#), and I quickly realized the voices of Narrative Medicine were speaking a language that I understood. Patients and families present their illness problems, Kleinmann explains, and a doctor translates these illness problems into a narrow set of technical issues, disease problems. Ah-ha! Here I would find the lightbulb to illuminate the purpose my writing brought to the page! The patients on the brain trauma unit with me deserved for their stories to be told. We are living, breathing people, not ICD-10 codes and biomarkers. We were experiencing unease while our bodies were in dis-ease.

And yet, friends, acquaintances, some family, anyone with access to my cell number or email address sent news clips and links to print articles about clinical trials, breakthrough therapies, "cancer diets," and supplements. It became apparent that even for those interested in me, that treating the disease was center stage, not only for my clinical team but for my social network, too. The illness problems that Kleinmann described were all but absent in everyday discourse, in favor of genomics, precision medicine, intertumoral heterogeneity, the blood-brain-barrier, and things like CAR-T therapy and oncolytic viruses. Meanwhile, residing on the locked brain trauma unit, kept from independence by my own impairment and bed and wheelchair alarms, I would lie awake overnight waiting for the 4:00am vitals check just to speak to somebody on the overnight shift with the time to tell me about her grandkids. That, my friends, is an illness problem!

Distinguishing between illness problems and disease problems is not new in the art and practice of medicine; clearly, Hippocrates isn't on the cutting edge of 21st century biomedical science! Besides Hippocrates and Kleinmann, another influential figure reminds us of a distinction between illness and disease. The 19th century physician and medical educator, William Osler, reminds us of the Hippocratic imperative at the turn of the 20th century, when Osler instructed, "A good

physician treats the disease, but a great physician treats the patient with the disease.” More recently still, in the words of endocrinologist Victor Monori, remarking on so-called precision medicine and standard of care protocols, “Are we treating patients like this, or are we treating this patient?”

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To better understand the distinction between illness and disease, between the condition and the person, we must understand what illness is. The answer, as I’ve tried to provide, is to characterize illness as a sort of existential threat, but that alone, to say illness is an existential threat, only manages to push the problem back a level because now we ask, “What is an existential threat?” Here, I turn to my philosophy background—look, it actually does come in handy!

“Existentialism is a concern about the foundation of meaning, morals, and purpose,” defines

philosophers Gregg Caruso and Owen Flanagan. They continue, “Existentialisms arise when some foundation for these elements of being is under assault.” They offer this definition in an edited volume, *Neuroexistentialism*, a book that I actually [reviewed](#).

How might we understand meaning, morals, and purpose coming under assault? It’s helpful to think more about how we understand our purpose in the world. I bet you have at least one project that you are working on. Us people are goal-directed, and we find tremendous meaning and purpose in working toward some aim or objective. I am privileged to co-facilitate a virtual [support group](#) for the brain tumor community. A consistent concern raised by participants in these meetings is the struggle to find meaningful work. It is very common for people living with a brain tumor to face difficulty with continuing employment. Many participants explain that without their work, it is easy to feel lost, aimless, and without purpose. While I’ll refrain from a full-scale critique of neoliberalism and its focus on the individual over the community, by societal norms, personal worth and value are wrapped up in our work. And work isn’t the only goal-directed enterprise. I was a young dad to very young kids when I was diagnosed, and that delivers on purpose. More, I was intending to pursue doctoral studies after completing my master’s, then I was diagnosed. Shit, there goes another goal. For my marriage, vowing “in sickness and in health” is one thing, but standing by your husband after he is diagnosed with terminal brain cancer is something else. What does sickness and health in marriage mean? What’s the moral responsibility for a young husband and dad who faces such a grim future?

Meaning, morals, and purpose—these are certainly under assault in serious illness, and we see that these illness problems are in fact existential problems! To address an existential problem, we need existential care!

Existential care restores the Oslerian imperative to treat the patient with the disease. Existential care accompanies allopathic, or traditional biomedicine, and ensures space for strategizing the response to the assault on meaning, morals, and purpose. How might we develop resiliency through existential distress? When we are cared with and for in a setting that prioritizes space for thinking, for exploring, for confronting and for incorporating a new life narrative in light of serious illness—this is existential care.

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Existential care does not define purpose, but it does delineate the space in which purpose may be defined. Existential care does not make meaning, but it makes space for someone to make their own meaning. Existential care does not tell someone their purpose, but it does craft treatment plans that acknowledge the purpose of medicine may not be to cure a disease, but the purpose of medicine may be to heal a person. And the encouraging news is that providing existential care is something that I advocate for in health care settings, but practitioners do not need credentials to offer existential care. Anyone with a trusted relationship, the ability to listen closely, and the presence to bear witness can provide existential care.

Ultimately, existential care fosters existential maturity, a state of wellbeing when someone approaches the completion of their life. More on that next time.

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