Cancer Health™

Visible Scars; Invisible Diseases

The best I can do is not hide my abilities in shame or guilt; I should carry my strength and embrace opportunities to share my story.

May 19, 2017 By Adam Hayden

In this post I reveal complex emotions involving survivorship, other cancer survivors, and the general population. I share my vulnerabilities and insecurities. Yet also, in this post, I find strength.

I feel guilty that I am not more sick.

That is a strange emotion, isn't it?

I feel guilty that I am not more sick.

I have incurable brain cancer. It is very unlikely that I live longer than four or five more years, and that prognosis is on the positive end of the normalization curve. Statistically only 37% of us with high grade gliomas make it to the milestone I just celebrated: one year post-diagnosis.

Yet, the sentiment remains.

I feel guilty that I am not more sick.

Of course, Whitney and I should not invite you to "save the date" for my funeral—that would be premature. Just this past week I was hanging out with other brain tumor survivors in Washington, D.C., for the National Brain Tumor Society (NBTS) annual advocacy event, Head to the Hill (#Head2Hill). In Washington, Whitney and I met new friends, a few who have been diagnosed with glioblastoma multiforme (GBM), the brain cancer with which I have also been diagnosed. A few of these survivors are five years post-diagnosis, a milestone, which, according to the population statistics, only 5% of those diagnosed manage to achieve. Pace the statistics, at five year survival, many are looking well.

These friends lend hope to Whitney and me, and for me specifically, I benefit from these new relationships in unexpected ways. It is our scars.

Our balding or shaved heads are marked with telltale scars whose origin could only be traced to the razor sharp scalpel on the neurosurgeon's instrument table. The surgeon's confident and skilled hands unzip our scalps to reach our skulls.

With survivors, I do not feel guilty that I am not more sick. I notice our scars, and I know what these surgical wounds conceal: our invisible diseases. Seizures, headaches, light sensitivity, overstimulation and brain fatigue, memory trouble, word-finding issues, slowed speech and language processing, visual field cuts, proprioceptive deficits—that is, trouble finding our bodies in space, muscle weakness, off-balance walking like we are always stepping from stone to stone to cross a moving stream. The gestures that Jeep drivers and Harley Davidson owners signal to each other as they pass, our scars indicate to each other that we have a meaningful connection; that we understand.

The cancer patient experience is supposed to go like this: our hair falls out, we lose weight, we turn gray, we require IVs for pain meds, chemo infusions, and saline to keep us hydrated. We are nauseated and bed-ridden. We are sick—visibly sick. There is no hiding that we feel terrible. Hence, when we manage to rally and go out to dinner, or attend a concert, or take a vacation, our friends and acquaintances say things like, “I am so happy you are doing so well,” or, “you are such an inspiration,” or, “wow, you’re looking fantastic,” or, “you are so strong.” This all makes sense, because, you know, we kind of look like shit, with the baldness, thinness, pale color, and poor appetite. Within the proper framework, namely, the context of our diseases ravaging through our vulnerable bodies and toxic chemotherapies killing the healthy cells we have left, in they context a trip outside the home is viewed as victory.

And for many, it is.

But for me?

I do not look this way at all.

Instead.

I feel guilty that I am not more sick.

For many of these sick cancer patients, god willing, their chemo infusions, radiation treatments, surgeries, and immunotherapies will shrink their tumors. Ultimately, the oncologist will declare the cancer is in remission, and all that will be left to remind us of their emaciated bodies, gray faces, and bald heads will be the photographs. In place of these sick and frail bodies returns the glow of good health. They have “beat” their diseases. They are true “survivors”—‘survivorship’ is a term with which I wrestle. In ordinary language many English speakers apply ‘survivor’ to a person who has faced a disease, condition, circumstance, challenge, and so forth, and this person has come out “victorious,” these people are “survivors.”

I recently commented in a science forum that I am “a survivor of glioblastoma” and the first reply stated, “congratulations you survived GBM, that’s a hard one to beat!”

At any rate, I am a survivor so far as I am not dead yet, and when I connect with other survivor sisters and brothers, well, this strange and unwelcome emotion turns up.

I am guilty that I am not more sick.

I tolerate my chemotherapy, which is administered in pill form, not IV infusion, and even though it is a chemically altered grandchild of mustard gas, and even though stated directions advise wearing gloves to handle the pills, and even though the morning after chemo I often both vomit and face constipation—a frustrating, confusing, and absurdly humorous combination of side effects, despite these ills, my treatment occurs within my house, not at the infusion lab, and if you were to join me for a meal, if it weren't for my cane and awkward gait, you may not realize there is a thing wrong with me.

I see my survivor sisters and brothers hacking away at the underbrush of side effects as they trudge the overgrown path toward a clearing of rest, relaxation, and treatment breaks, toward remission. Sisters and brothers, you look like hell, but we are cheering you on! You feel terrible, but we are cheering you on! You haven't had the strength to get out of bed in a month, but we are cheering you on!

Now maybe you are beginning to understand my counter-intuitive emotion.

I am guilty that I am not more sick.

I love public speaking, and I am better than competent telling my story and connecting a personal message to illuminate the illness experience for other survivors and caregivers. I went to D.C. to advocate on the Hill. I had a proposal accepted for an academic conference in June. I applied for financial aid to attend the Stanford Med X program in Southern California in September—fingers crossed. I continue to book speaking gigs, I accepted an offer to volunteer my time to a patient advisory council with a large non-profit cancer advocacy organization. I interview with local media outlets to say more about my family and surviving brain cancer.

I can do all of these things, so long as I pay attention to my nutrition, stick to a routine sleep cycle, double check my medication dosing and schedule, and continually monitor my fatigue. Keeping an eye on each of these variables helps to mitigate my headaches, seizures, balance issues, and so on.

I know that many of you are surprised when you meet me. Journalists who interview me, you know, for an interview with a terminally ill brain cancer patient, are often surprised. They non-verbally communicate their surprise when I greet them smiling and offer coffee or tea.

It is with anxiety that I face the uncertainty of feeling well today; it is heartbreaking to realize I am not as physically ill as my lung cancer sisters and brothers who cannot walk to the mailbox without extreme fatigue.

I am guilty that I am not more sick.

Your scars, my brain tumor survivor sisters and brothers, your invisible diseases for which we must fight to gain awareness from the general population, your friendship reminds me that the very best I can do is not hide my abilities in shame or guilt, nor should I shy away from discussions of my symptoms, but I should carry my strength and embrace opportunities to share my story, advocate, and change attitudes about what is the look, attitude, and ability of a typical cancer patient. The daily restrictions I place on my diet and activity earn me a generally good health. I am proud of my good health.

Still.

I feel guilty that I am not more sick.

We absolve ourselves of guilt when we recognize we could not have done otherwise. Maybe shallow guilt turns to deep regret when we recognize we could have done otherwise, yet we chose not to do so. To liberate our emotions of guilt it is important to communicate, contextualize, and identify the circumstances of our feeling guilty, and next to recognize how things could have been handled differently. If you feel guilty, ask, “could I have acted otherwise?”

I feel guilty that I am not more sick, but my body’s subservience to cancer and its concomitant toleration of treatment are both beyond my control. Neither guilt nor regret should grip us, so long as we take active steps to maintain our awareness of possible actions and outcomes in all situations, and we work to promote that awareness with others.

I must work to absolve myself of these guilty feelings of survivorship. The better use of my health, if better than other survivors’ health or not, is to stay the course of my advocacy and lend voices to those whose have been silenced by disease.
I wear my scars for what it communicates to other survivors. It cuts through the bullshit. And for those who may notice their own guilt for not recognizing the invisible diseases in friends, family, and acquaintances, absolve your guilt by seeing things through and choose to act otherwise. To survive we need us all at our very best, not feeling guilty that we are not at our worst.

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