Finding Purpose Between Power and Helplessness

“Sent from my iPhone” isn’t just a status, or to indicate traveling correspondence, but to assert, “I may be nauseated, but I’m not dead.”

March 6, 2017 By Adam Hayden

I write this post a day after delivering a public talk, Inside My Head: A Story of My Personal Walk with Brain Cancer, and a day before my next eight-week MRI scan. In this post I report the strange emotional dichotomy, recognizing my power of positive impact through public speaking while suffering under the helplessness of the course of my disease.

“In two days I will be changing into hospital socks and oversized scrub pants. I consider the ongoing depersonalization of the American healthcare patient: name, date of birth, diagnosis c71.9, malignant neoplasm of brain, unspecified; one-size-fits-all standard of care, cinching tight the drawstrings on the waistband of my comically-too-big scrubs while I shuffle to the MRI bed.” I delivered these words Sunday afternoon, March 5, to a packed house of 250 or more friends, family, and colleagues gathered in support of me, my wife and young children, and to make a dent in median overall survival by raising money and awareness for brain cancer research.

It is the day after my talk. It is the day before my next eight-week MRI scan to monitor disease progression. This morning I suffered a minor “event” or “episode” or something. I lost my footing in the living room, grasping for a door frame to prop myself up. I tapped out two more emails on my iPhone when seeking respite on the couch following my “something.” I continue my “work”: seeking venues to deliver talks, spread awareness, and raise funds to support my young family after I am long past useful.

I returned home last night following an unmatched display of support from my community. I hugged my older boys for bed. I rocked my youngest for sleep while participating in the monthly #BTSM chat. This month’s topic: survivor guilt. Other persons with with brain tumors, many living with the disease longer than I have, poured out the contents of their hearts in 140-character confessions, searching for purpose, meaning, and self-worth in contrast to the ever-lengthening list of old friends, now deceased. The longer you walk this road with others, the older friends are lost and new ones join in the march. What lessons live on from the last generation to lend to the newly diagnosed?

My youngest son received his 18-month check-up this morning. He is a dot on a curve representing a percentile. All lines trend up. At a point in all of our lives we reach an apex and become a downward trending dot.

My wife returns home with our little guy in tow. She notices me hunched over my phone on the couch, seeking respite yet tapping away.

“You have to rest!”

There is no resting for me these days, only sleeping when tired.

“You have to take it easy.”

I tap on my phone to pitch my next talk, to schedule a meeting to contribute to a caregiver- and patient-facing website offering resources to people in the path of disease, to connect with the tweet-savvy to grow my network, to share my blog, to gain more followers, to carry out a mission beset by chemotherapy, fatigue, and nausea. To find self worth in my own personal quest toward a meaningful life.

“Sent from my iPhone” isn’t just a status, or business, or to indicate traveling correspondence, but to assert, “I may be nauseated, but I’m not dead”; “I am ‘working from home’ under a blanket, tapping away at the lessons to lend to the next generation.”

It is the day after my talk, the day before my next scan. Name, date of birth, scrub pant size? The same system I criticize, I trust myself to its care. I cry over this journal today because I am afraid; terrified, really. Do not mistake my comfort and articulation when discussion my morbidity or mortality for hope that I may evade the advancing line. Acceptance does not ameliorate fear; it embraces fear. If one-size-fits-all standard of care depersonalizes the American healthcare patient, we must recapture our personhood. What is more personal; what is more human, than realizing our own mortality. “The path through fear is familiarity,” I spoke yesterday.

The day after my talk, the day before my scan. I am seeking purpose somewhere between the power of my influence and helplessness of disease progression. Between power and helplessness, a person’s place in the world, surviving.

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