Cancer Health™

The Benefit of Death Talk

January 13, 2018 By Adam Hayden

I addressed a large audience of 250 friends, family, and community members in a public "talk," several months following my diagnosis of glioblastoma—a grade IV malignant brain tumor. I rehearsed my thoughts, writing posts for my personal blog, Glioblastology, beginning in October 2016, four months following my hospital discharge, after brain surgery and intensive rehabilitation therapy in an inpatient, acute rehab setting. I spoke openly about the population statistics for persons living with glioblastoma, punctuated by a five-year survival rate of roughly 5-8%. On the reality of confronting death, I acknowledged my fear, but I told the audience, "we face fear with familiarity."

Facing fear with familiarity would be my mantra during the following months of public speaking, blogging, and personal research and writing in the domains of research oncology, narrative medicine, and end of life care, culminating in the preparation of legal documents, including an advance directive. Next week I deliver a lecture in the auditorium of Riley Hospital for Children and broadcasted across the Indiana University (IU) Health Network. My lecture is next up in the monthly series organized by the Fairbanks Center for Medical Ethics. The topic is "Narrative and Physician-Patient Dynamics."

I earned the opportunities that are set before me: behind each lecture to a room of clinicians is a fumbling and awkward guest spot in an undergraduate classroom, for every intimate seminar discussion with fourth year medical students on the cusp of residency is a rambling Facebook live broadcast; each funded opportunity to attend a scientific meeting is supported by hours of personal research with "out of pocket costs" for very expensive clinical text books—don't bring this up with Whitney! She ought to be given an honorary CPA for her ability to stretch her hard work that results in our primary income and my disability disbursements and part time work to accommodate our kids' school fees, housing costs, and my Amazon habit. Each invitation to author a guest blog post or co-author an academic paper is supported by thousands of draft words in never-to-be-seen posts and papers.

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The likely course of my disease progression includes loss of executive function: inability to feed myself, maximum assistance with toileting, inability to speak, impaired reading, writing, and significant language deficits; all of these functions stand to decline as my brain tumor spreads. A palliative care doctor described this to me as a loss of contact with the world. Whether you personally know me, reading only this post may provide all the information needed to realize what a terrible loss this is to my sense of identity. It is terrifying to consider my own loss of connection. Worse still for my wife–so many Amazon purchases she has rationalized on my behalf.

Whenever asked to speak, write, give an interview, offer my perspective, join a committee, call my congress person, or travel to an event, I try to say yes! Anytime the following interjection is welcome in conversation I state one of my goals: to bring death, the topic of death, out of the shadows of taboo, and introduce this topic into regular discourse. The American conversation, writ large, is missing an appreciation for death. Plenty of complaining about taxes, little conversation about death, yet these are purportedly the only certainties in life.

Ironic.

This is all to say, being the recipient of a devastating cancer diagnosis has made me more vulnerable to bombastic claims about the roles of turmeric and curcumin in cancer care than honest and open dialog about death. Something about this is both culturally instructive and tragically unfortunate.

“Death is having its moment,” tweets The Guardian in promotion of this story, “How Death Got Cool.” Let me tell you: the reports of death’s coolness are greatly exaggerated. Many of those in my community, the brain tumor community, we are fixed in a rather unique situation. Our tumors are changing, growing new blood vessels to feed themselves, creating a poisonous “tumor micro environment” that results in deleterious effects to neighboring healthy cells and producing resistance to chemotherapeutic agents sent in to kill the very cancer cells, which are contributing to this drug resistant environment. Many persons living with lower grade brain tumors are set on a trajectory toward aggressive transformations of their tumors into higher grades. Those of us with grade IV gliomas, glioblastoma, are facing the same standard of care protocol that has been with us for for nearly 20 years.

We face death.

I am sympathetic to the trendiness of death talk. A necessary evil, as it were. An astonishingly small number of persons with brain cancer are referred to hospice services. Patient advocacy includes making our voices heard both with respect to treatment decisions, but also with respect to declining further, non-curative treatment. The medical community must do better to usher in these conversations earlier.

Though, I also face a nagging feeling that we are too ready to discuss death; that discussing our impending death is somehow a badge of honor that we resign ourselves to our fate. I notice champions of hospice and palliative care in our community applaud those who have been forthcoming with their end of life plans, and I think on this approach we are committing a grave error. The advance directive is the endpoint of a much longer conversation about values, priorities, considerations for our loved ones, and desires for our final minutes (hours, days, or weeks).

My relationship with the end of my life is the result of countless hours of tears, reflection, bear hugs, kisses, worries, and sleepless nights about my wife and our children.

My aim to bring death out of the shadows of taboo is not to ensure every American has an advance directive on file–though, that is not a bad result; rather, my espousal of end of life consideration is to promote the dialogue pertaining to death. The benefit of death becoming trendy is not realized in your producing a document. The document is novel. The document is the shiny toy. The document is the distraction. The benefit of death talk is that we reveal a more intimate and honest relationship with those who accompany us on our journey to our mortal end. It is the conversation that should be lifted up, not its designed outcomes.

The accomplishment I am most proud of is my relationship with the end of my life, because it is the accomplishment of my relationship with my wife, our children, and our open and honest dialogue. It is the accomplishment of hours of reflection, consideration, and hard-won acceptance.

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