

**Living While Dying, A Contingency Plan by Adam Hayden**  
**End Well Symposium, December 5, 2019**

Start of Transcript

Now listen the timer is going so I appreciate the applause, but we got to get down to business. Listen, the right drug for the right patient at the right time that's the mantra of precision medicine, Optimistic predictions stemming from the human genome project in the late 1990s, forecasted that within 15 to 20 years medicine would be revolutionized by connecting DNA to diseases, improving treatment ultimately prolonging life. Here we stand on the precipice of 2020 and despite the hype, by and large results have not yet come to fruition. For example, the disease that I am living with the aggressive brain cancer glioblastoma [01:00] it was the first cancer sequenced by the Cancer Genome Atlas in 2006. We have a wealth of genomic data available and yet not a single new drug approved for the treatment of GBM in over 30 years.

Now this is not to suggest that we should abandon the project it is important work that must continue. But maybe we should take a look at medicine think about the next 15 to 20 years what we'd like medicine, what should medicine look like then.

Precision medicine is a tool in the toolkit of industrialized health care which physician author activist Victor Montori criticizes for standardizing practices for patients like this but failing to care for this patient. [02:00] Now that is Dr. Montori's line so if you tweet that tag him C. Montori.

So, as computational biologist bench researchers continue the pursuit of cure, I'd like to remind us about another one of medicine's aims and that is to care. In this aim we offer another form of precision medicine storytelling. Medical sociologist Arthur Frank says, "Thinking with a story is a sedimentation of personal experience."

Now this resonates. It was May 28th 2016, I lay in a hospital bed on the recovery ward of my treating hospital just days after brain surgery, an awake craniotomy where I would be alert and responsive to my surgeon's commands as he resected [03:00] a 71-millimeter primary brain tumor from my right parietal lobe. 71 millimeters that is 7 centimeters that's roughly the diameter of a baseball. The parietal lobe that's a functional area of the brain responsible for sensory and motor input and control for the opposite side of your body. A few hours into that procedure my surgeon said, "Adam I have removed the majority of your brain tumor. I can continue to resect more tumor to be more aggressive, but this comes at the risk of permanent left-sided paralysis or we can stop the procedure now, protecting most of your motor function, but leaving a residual tumor in the margins of your surgical cavity. Adam what do you want to do?" [Laughter] Thinking of stories this is a cliffhanger. [Laughter]

I spent a few days in the neuro intensive care unit before I was transferred to the floors where I would tap out an email on my phone to a friend, a professor in the Medical Humanities and Health Studies program at my University. In the subject line I typed, [04:00] "A unique personal experience". Thinking with stories we are reconstructing our past in an effort to make sense of our present moment thinking with stories, telling our stories this is a narrative arc that we apply to our lives to make sense of to give value to the present moment because that's what we have is the present moment. We imagine ourselves into the future, a future of dreams and aspirations [05:00] or facing serious illness, loss, unwanted change it may be a future that we fear. But one thing is for sure, our future ultimately includes the conclusion of our mortal journey.

So, this is the story of living while dying it is my high story as a young man facing an incurable brain cancer, but it is our story because each one of us in this room we are right now living while we are dying. It's a sedimentation of our personal experience. It's my unique personal experience and I tell my story because we must restore the patient voice in medicine. [Applause]

Storytelling is a pathway towards a meaningful life, but more than that **[06:00]** for a clinician to listen to our stories, to press a healthcare system bent on profit margins to make room for storytelling to hold space for storytelling the morally injured clinician stands to gain just as much if not more than the patients whose stories they hear [laughter]. The stories have gone silent in health care my friends we are rich with data short on humanity to much what do we cure, not enough why do we care.

See illness and the medical interventions used to treat disease it pulls apart our experience from a model that conceives of our bodies as objects to be tested, diagnosed, treated, charted, rounded, autopsy. Serious illness is an existential crisis it attacks our meaning, our morals, **[07:00]** our purpose. Illness questions what our lives are about and so thinking the stories we are forced to shift the narrative. We are forced to write and tell new stories. We have to reconcile this imagined plan for our lives with a very real interruption of a serious illness and yet the medical model we have now does not address the existential distress it just favors this model; bodies as objects. Taking a patient as only their disease not as a person that's a detriment to clinical care, but it harms the clinician. Medical practitioners were brought some medicine to do the good work of healing and that may not include, curing.

Physicians are burning out because profit-driven administrators and payers have erected obstacles to patient care. It is no surprise that obstacles to patient care **[08:00]** result in physician burnout. Favoring patients as people is underwritten by a long history in medical education. How long you might ask, Hippocrates in a quote attributed to him said, "It is far more important to know what a person's disease has than what disease a person has." I'm sorry Hippocrates I sort of butchered the quote, but that's okay it's all Greek to me. [Laughter]

At the turn of the 20th century medical educator William Osler said, "It is the good physician to treat the disease, but it is the great physician to treat the patient with the disease."

Contemporary biomedicine touts sophisticated diagnostic protocols increasing success **[09:00]** characterizing molecular biomarkers, improved prognostication using machine learning. The mechanisms of disease exist in the biological details yet the experience of illness that's not detectable on lab work, light microscopy, magnetic resonance imaging. No, it is only through the perspective of the patient the subject of the experience that we may understand illness replete with nuances, social impact, trauma, risks to personal identity.

Listen, I was 34 years old a recent graduate with a master's degree in philosophy married to my very best friend three beautiful children at home they were four, two and eight months old. For a year I experienced episodic weakness dizziness lightheadedness that with the inertia of a moving train increased in frequency, **[10:00]** duration, intensity. I took myself as my own case study and in of one I began to gather data, jumping up and down, stretching contorting my body shaking my head anything I could do to bring on or to dissipate these episodes.

Lacking clinical terminology, specialists would listen to my descriptions, but dismiss my reports. Hearing hooves and inferring horses not zebras, I was told by one physician "If there was something seriously wrong with you, you would be in much worse shape." It turns out I was in much worse shape.

See, a robust understanding of the illness experience cannot be reduced to a simple set of criteria. It is not the presenting symptoms it is the life world in which they present. And so standardized practices, standard early detection screening **[11:00]** etcetera you know this is nothing to benefit the art of healing which pays no mind to biomarkers and once only for a clinician to grasp one's hands to offer presence and attention.

So, what I call us to today is a project of reconciliation where we will close the gap between the scientific description of disease offered by the biomedical model and a rich characterization of serious illness offered by authentic human centered care; the type of care that many of you in this room offer. Closing the gap between treating disease and addressing illness, and yet with continued innovation the tools of medicine drive a deeper wedge between clinician and patient.

Where my case and cases alike mine **[12:00]** ultimately lead, radiographic data, immunohistochemistry, next generation sequencing, cell-free DNA, organoids, mathematical algorithms, computerized models. We can learn so much without ever having to touch a patient. We can learn so much about the patient without ever getting to know the person.

Personalized medicine friends we are far from it. We need to criticize medicine while uplifting its practitioners that is an act of rebellion in the words of my good friend Liz Salma. "We are bringing punk rock to health care." [Laughter] So, we are going to embrace illness with grace honesty vulnerability. We will incorporate illness into our stories not to abandon our values and goals but to realign our values in light **[13:00]** of a serious debilitating life-threatening illness. So, do not fear the path forward.

"I do not want to be back here in a year regretting the decision I made today", I told my surgeon. He said, "You can't think about what could be the case. Make your decision based on your life today." So, thinking of my children thinking of my wife I said well let's conclude the procedure now. That's a decision based on my quality of life not a decision on pathology or biostatistics. Only through the voice of the patients might we understand that decision; we can't recapitulate that in the lab. So, that even while dying I might continue living.

**[14:00 END]**