Cancer Health™

I’m a Liability, But I’m Worth the Risk

Those on the margins of society or with life-limiting illnesses and other social determinants offer a wisdom that often goes unrecognized.

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Introduction

Theory meets reality in this post about two frameworks, or schemas, about illness and systems of belief. I get a little technical, but you may learn something along the way! I discuss sick role theory, standpoint theory, and what it means for a person living with serious illness. The take home message is that those on the margins of society, those with life-limiting illnesses, disabilities, and other social determinants offer a wisdom that often goes unrecognized.

A Sanctioned Deviance

Sickness is a form of social deviance. A “sanctioned deviance,” to be more specific. That was sociologist Talcott Parsons’s view in his “sick role theory” that he advanced in the 1950s. The sick person, according to Parsons, is subject to both rights and obligations. The rights that protect the sick person include a base assertion that a sick person is not responsible for having their illness and a general dismissal from performing expected societal roles and functions – the *deviant* aspect of the sick role. And yet, the sick person is bound by obligations that include the obligation to seek treatment, to get well, and to return to performing expected social functions—the *sanctioned* qualifier.

From Normal to Alternative Overnight

In the early months of my illness, I embraced sick role theory. This theory resonated with important characteristics of my identity: After moving from Arizona to Indiana, a coming home for our family, I felt out of place. (I was born in Indiana, but at four or so years old, we moved across the country for Dad to pursue an ambitious and noteworthy appointment in his career.)

My social context shifted significantly. My childhood in Arizona was shaped by late 80s, early 90s West Coast trends. Skater culture was big, and the typical clothing style, activities, and attitudes of my peer group in Arizona reflected California, owing to geographical proximity and regional climate. I represented this West Coast cultural setting, not by any deliberate or overt decision on my part, only as an extension of where we lived. Like basketball is endemic to Indiana, kids in Arizona naturally grew up skateboarding or rollerblading.

What was a fairly normal cultural context in Arizona was *counter*-cultural in Indiana. A “skater kid” in Indiana carried a lot more cultural baggage than in Arizona. I went from "normal" to "alternative" overnight, with a cross-country move. I harbor no regrets or resentment against mom and dad for their decision to move. I enjoyed a loving relationship with both sets of grandparents before their death in Indiana that wouldn't have developed had we stayed in Arizona. Yet the labels, *deviant*, *punk*, *skater*, *alternative*, *counter culture*, were to some extent foisted on me because West Coast culture just hadn't made its way to the Midwest when we moved. Our family's relocation out-paced the trends. I remember when Pacific Sunwear, later "PacSun," opened in the Greenwood Park Mall, and it was mostly just the same shit that was in any random department store in Arizona. Because I didn't fit in accidentally, by high school, I didn't fit in on purpose.

Why do I share this?

I'm recently 39 years old, and I've felt like a deviant for most of my life. Reading the sick role work from Parsons met me where I was, feeling so out of place. Out of place culturally, and with the diagnosis of glioblastoma, a rare disease with only one or two cases per 100,000 people, and an average age of diagnosis 20 or 30 years older than me, I was again out of place in the "disease space." No doubt that we're out here, and I've met many of us, but there are not many young-30s parents to young kids who get this disease.

A Liability

I gave a few community talks, telling my story, beginning in March 2017, not quite a year after diagnosis, and these events honed my skills and opened doors to giving bigger and bigger talks.

Adam rehearsing a community talk in 2017Courtesy of Adam Hayden

I experienced one of the most significant professional accomplishments to date when I delivered my End Well talk in San Francisco in 2019. I recall a candid conversation with End Well Project founder, Dr. Shoshana Ungerleider, in 2018, after I applied to be an End Well speaker. The selection process begins more than a year before the End Well symposium, and together Dr. Ungerleider and I made a shared plan to periodically update her on my health status in case I wouldn’t be well enough to travel and give this talk. (Whitney traveled with me; otherwise, traveling and speaking would not have been possible. Thank you, Whitney, for everything, always.)

After receiving the diagnosis, I worked hard to reconcile myself to accepting a grim prognosis, and Whtiney and I worked hard to help our kids understand, but that conversation with Dr. Ungerleider was one of my first experiences comprehending the professional implications of living with a life-limiting diagnosis.

I was the sanctioned deviant.

Over the past couple years, this theme recurs over and over. It's a risk to book me for future speaking events. It's a risk to accept me for nonprofit appointments. It's a risk to place me in a job role that demands increased responsibilities and the performance of required hours and tasks each week. (I write this, having recently accepted a new job role, knowing, even, that some of the folks involved in that decision may be reading now!)

I discovered in the past few months that I am a risk to potential publishers of my work because without a completed manuscript in hand and the usual author expectations to promote a book through readings, events, and writing promotional articles, I am an uncertain investment in an already difficult market. This places me in the odd circumstance that the thing that makes my work so important is the same thing that makes it less attractive.

Shared Cognitive Dissonance

A tragic irony of this advanced cancer diagnosis is that most of the people I meet, both friends and random encounters with folks, say something to the effect of, *I could get hit by a bus tomorrow*! This is such a stupid thing to say, but I know it is well intentioned. The point, I guess, is to find some relatability in the illness, so as to feign some common ground of understanding. I get that. Life is fragile and precious, sure, and I see you, supporting me with the language and conceptual framework that you have onboard. I'm good. You're good. I only ask that we keep in mind that most people don't wake up each day wondering if today is the day that they'll be struck down by a wayward bus, while I *do* wake up each day wondering if today is the day that I'll have a catastrophic seizure, brain bleed, or some other event. Shit, I had a pretty bad seizure only a few days ago that Whitney described with raw honesty.

At any rate, that culturally we have this notion of unexpected death as a way to interpret serious illness, while we also shy away from taking risks on people who *actually are* going to die sooner than they should, is a shared cognitive dissonance. If your random risk of death is in a similar category to those with life-limiting illnesses than why subject the sick person to the greater risk/reward calculus? Now, in practical terms, I understand the difference here, but in the abstract, we find that *that* risk is a matter of degree, and mortality is universal.

Whitney and I live our lives out loud. We post regularly about living with brain cancer. This is no surprise. How many pictures have you posted about your pets, your kids, your dinner? Same here, documenting our lives, it is just that the normal for us is the daily struggle of a devastating illness, and while it is a feel good to get the likes on MRI scan days, life is exceedingly difficult in between, and within the past few months, Whitney and I have found it important to be transparent with not only the good but also the impossibly hard.

Adam and Whitney in Washington D.C. for National Brain Tumor Society’s Advocacy Event, Head to the Hill, 2017Courtesy of Adam Hayden

But doing that, we’re taking our risk, to trust our friends and acquaintances to stay engaged; not turn away.

Worth the Risk

Truth is that I may not be able to maintain the new job role and schedule. That isn’t a declaration, it is only the relevant context. What does it mean for me, for my employer, if this new role turns out to be unsustainable? Might I be worth the risk?

There is a philosophical theory called Standpoint Theory that was first articulated and advanced within feminist philospohy. Standpoint theory takes a person’s perspective and social station as integral to understanding systems of belief and knowledge. The theory holds that marginalized folks are privy to understanding systems, power dynamics, and relationships in ways that those with power do not. This isn’t, or doesn’t need to be, controversial. I suspect that I have a better perspective on the Social Security Disability Income program than even the program designers and policymakers because I’ve had to navigate the program for our family’s livelihood, not as an abstract policy discussion at the Social Security Administration or in Budget Committee meetings. I know the policy up and down, this way and that, because I live it every day. That is the power of starting thought on the margins to inform the center.

What I have come to understand—and reject!—about sick role theory is that its interpretation of illness, its value judgment about illness, say, why illness is bad, according to sick role theory is this dismissal from societal functions. It is ultimately the loss of social and economic productivity that is the badness of illness, according to Parsons. The sick deviant is just that, a *deviant*, who may be excused from work, but that excusal must be policed because sick role theory takes economic productivity as a normative good, that is, a good that we should aspire to.

I am a liability to my employer. I am a liability to my nonprofit programming commitments. I am a liability to our family when I am at home with the kids and Whitney is at work. I am a deviant. I do not participate with the same productivity that I did pre-diagnosis and in ways that are commensurate with my peer group. As of just recently (last month), I depended on social welfare programs to support our family, and so not only do I not contribute with rigorous productivity, I am also an expense.

Am I worth the risk?

When we replace sick role theory with standpoint theory, we find that insight and wisdom come from the margins, and in a world designed by those who historically have held power, what you may characterize as taking a risk on me, and others systemically pushed to the margins, is the wisest investment that you can make.

I’m here to tell you that you are not a liability at all; instead, your marginalized status gives you perspective that those in the center would never achieve with you.

What are the liabilities in your life? What liability do you present? I’m here to tell you that you are not a liability at all; instead, your marginalized status gives you perspective that those in the center would never achieve without you. This is why we must dismantle the systems that undermine and oppress, and instead, work to amplify the voices that power has sought to silence, but that, friends, is another blog post entirely.

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