Cancer Health™

The Sick Role

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August 22, 2019 By Adam Hayden

Last week Whitney and I launched a GoFundMe campaign, and we published our needs to the community with this blog post. We reached our goal within hours of the post, and in the following days, we doubled our goal. We are incredibly thankful for the amazing community that continues to support us, now in our third year facing brain cancer. We received generous contributions from all areas of our lives! The Facebook community of friends and family shared our campaign almost 60 times! On Twitter, the home of my academic networking, many of our followers retweeted the blog post and contributed. On LinkedIn, despite it being the social platform where I am least engaged, we managed to drum up support after a friend and healthcare professional shared the blog post, calling it a “must read.” For the generosity and social awareness, thank you does not adequately express the months, if not years, of easier breathing our family will experience after your selfless giving. Thank you.

I am most humbled by the fellow patients, care partners, and widowed members of our community who left comments and shared posts explaining that our family’s financial struggles, though painful and contextualized to our circumstance, are nevertheless common to nearly everyone facing serious illness and advanced cancer. When I manage to capture in writing the experience shared by so many others, I am reminded of my strengths and the privilege I have to raise my voice. The call was to help us financially, and we thank you for that, yet what I carry with me are the thanks offered by others for explaining financial toxicity in an accessible way.

In the 1950s a sociologist named Talcott Parsons described a concept he called the “sick role.” According to Parsons, people who are ill have both rights and responsibilities. The rights are to protect the dismissal from normal functions in society, while the responsibilities of the ill are to partner with healthcare professionals in an effort to get well.

Illness is a social deviance, according to Parsons. Deviant because the seriously ill are no longer meeting the expectations of their assigned social roles. And so while not responsible for their illness—not blameworthy for illness—the seriously ill operate under an umbrella of sanctioned deviance. Deviance that is policed.

I was discharged from the hospital after deemed medically stable after brain surgery. I was transferred to an inpatient acute rehab facility, where I started in a wheelchair. I was discharged from the inpatient facility able to walk with the use of assistive devices. While inpatient, my bed and wheelchair were outfitted with alarms that would alert staff if I tried to get up or transfer on my own. I rang the call button if I had to use the toilet. For weeks I had someone standing with me in the bathroom. Policed deviance.

These days, I work part-time, but I report my earnings every month to two different agencies. I undergo medical review annually. We submitted a “doctor’s note” to lobby the school transportation office to allow a bus stop in front of our home so I would not need to navigate potential weather conditions to walk the several houses to the assigned bus stop. I am offered the occasional honorarium (a one time payment) for speaking in conference settings, but rather than thank the organizers and take pride in my work, I complete paperwork to account for my earnings.

This is policed deviance. This is the sick role, some sixty years after Parsons introduced the concept.

Our algorithms saturate social media feeds with targeted advertisements, but our health and insurance systems are unable (or unwilling) to take readily available data, such as the nationally standardized diagnosis codes (ICD-10) to drive decision-making logic that, for example, excludes people with terminal illness from medical review.

I answered a call from my long-term disability provider just this week with the question prompt, “What more support do you need from us to get you back to full-time hours?”

Curing my brain cancer would be a good start.

I conclude this post with where I began: Thank you for the generous outpouring of support you showed our family these past two weeks. We are profoundly impacted by your generosity, and all of us are enjoying a better, more peaceful home life as a result of your giving. We stand a chance now of actually getting back on our own two feet—or two feet and a cane, whatever. Our kids continue their activities. Whitney may be able to step away from the several “pick up days” she takes at work. Thank you, thank you.

Still, there is the nagging reality that our deviance is sanctioned, our freedom is policed, and so beyond the existential threat of serious illness, there is the threat of regulatory authority that could take away our protections at any time. That threat may only be met through civil, honest dialogue, and a commitment toward protecting the rights of others. But rather than view people with illness as deviants who must be policed in their dismissal of social roles, how might we lift up the experiences of the seriously ill to teach us all something about humanity? About how to live each day? About insurance and healthcare and what “work” is rewarded. How might we elevate serious illness rather than police it?

We have more work to do.

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