

PIPC Patient Blog: ‘Value’ Measures for Rationing Healthcare Devalue My Life

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By Rosie Bartel

Nine years ago, I had a routine knee replacement surgery. Instead of recovering and getting back on my feet, however, I contracted a surgical infection which took my right leg, hip, and part of my pelvic bone. My doctors told me I should have died. One said I had just a 30 percent chance of survival. But I’m a fighter. My life changed, and I am now confined to a wheelchair — but my passion for life didn’t change. I began fighting for the rights of people like myself and it has been the most meaningful work of my life.

People like me who live with disabilities are too often overlooked and viewed as less-than. I’ve had people talk down to me and talk over me because all they see is a wheelchair, not the person with dreams and a life and meaning. My disability pushed me out of my dream job as a religious educator across Wisconsin, but I’ve found a new mission: ending healthcare-acquired infections like the one that took my leg and empowering people with disabilities to live the life they choose.

Unfortunately, some people in the healthcare industry think they know better than the people living with these conditions and try to make our own life choices for us. It’s bad enough when everyday people think people like me can’t live a full life, and it’s crushing when it’s people who are supposed to be looking out for our health.

In a misguided attempt at cost savings, some healthcare companies resort to blunt “value” measures for care. CVS Caremark’s recently unveiled policy of restricting access to lifesaving drugs based on their cost is an ugly example of this trend. The measure they use — based on what’s known as a quality-adjusted life year, or QALY — reduces people to a number and doesn’t account for how we feel about our own lives and prospects. Even worse, it makes older people and people with disabilities’ lives “worth less” in the accounting of healthcare companies. By assigning a dollar value to our quality of life using someone else’s criteria, CVS would take away our ability to determine for ourselves what is important in our healthcare.

What healthcare companies don't get is that I am an individual first. My value cannot be measured by my disability or my age. Just ask the hospitals I've worked with to fight healthcare-acquired infections, the providers who have helped build the "Think Rosie" campaign to promote hand-washing in hospitals, and my fellow patients I've helped and who have helped me over the past decade. There is enough stigma surrounding people with disabilities. The healthcare industry shouldn't put that stigma into policy by denying care to people with disabilities.

One of my doctors told me I've nearly died several times, but I've got a few lives left in me. I've never let anyone tell me what my life will be like, and since losing my leg I've dedicated myself to making sure that no one else gets an infection like mine. I've also made it my goal that no person living with a disability is told that they can't have a full life.

It's not the job of the healthcare industry to tell people with disabilities what they're worth. It's their job to help us live the life we want to make for ourselves, according to how we value our health and well-being. I'm going to keep on fighting for years to come, both for myself and for others who share my experience. No one could tell me I wasn't going to survive when I contracted an infection in my surgical site wound, and no healthcare company is going to tell me that my life isn't worth living.