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Commentary

Improving the lives altered by brain injury

By Laura S. Lorenz

The wars in Iraq and Afghanistan have drawn more attention to the plight of brain-injury survivors, as has the NFL's recent acknowledgment that some of its players are suffering neurological consequences from repeated concussions. But our health policies and treatment practices have yet to catch up to the staggering toll of this complex and insidious condition.

Five million Americans are living with disabilities from brain injuries. There are 80,000 to 90,000 new long-term disabilities from brain injuries each year, and a new traumatic brain injury is sustained every 23 seconds.

For all our lifesaving modern technology and medicine, we know little about brain-injury survivors' lives. How do they cope? How can they find new meaning and purpose in life? And how can we help them?

My brother was an avid youth hockey player in the 1960s and '70s, when little was known about brain injury. His team sometimes played more than 150 games a year, and two of his teammates went on to play for the NHL. My brother's life, however, took a different trajectory.

A small but scrappy competitor who never hesitated to take on bigger and stronger players, he suffered several concussions, leading to behavioral consequences suggestive of brain injury. Before he reached the age of 30, he took his own life.

Now we know a great deal more about the impact of concussions - especially repeated concussions - than we did 30 years ago. We have unfortunate opportunities to research the effects of blast injuries on military personnel who have served in Iraq and Afghanistan. Meanwhile, scientists are beginning to study the brains of football players who have developed early-onset dementia as a result of multiple concussions.

Now the NHL, NFL, and some high schools require that players be evaluated and forced to rest after having their "bells rung." What has not changed, however, is our approach to brain-injury policy and treatment.

We chronically underfund disability and rehabilitation research, according to the Institute on Medicine, and brain-injury survivors have limited access to cognitive rehabilitation services.

Far too often, we fail to consider or evaluate how policies affect the lives of brain-injury survivors.

For people whose brain injuries are labeled "mild" - those that involved little or no loss of consciousness - the challenges are particularly acute. The vast majority of the 1.4 million brain injuries diagnosed in emergency rooms every year are classified as mild. Most of those patients fully recover.

Yet the estimated 10 to 20 percent who suffer long-term consequences from those injuries - memory loss, difficulty making decisions, irritability, loss of coordination, fatigue, hearing and vision loss, and inability to complete tasks - are seen as malingerers. They are called lazy, stupid, or crazy.

Their injuries are invisible to the imaging technologies we currently use. And if scientists, physicians, and health insurers can't see an injury, the thinking often goes, it probably doesn't exist.

Take Peggi, who was a successful respiratory therapist before a mild traumatic brain injury left her feeling dazed. She ignored the injury until her coworkers told her she didn't seem like herself and should get it checked. Now, six years later, clinical tests show she is still suffering from poor memory, organization, and hearing. But she looks well; her injury is invisible.

Like many brain-injury survivors, Peggi has spent years learning about her "new self." Photos she took to help tell her story represent the dichotomy of her life - darkness and light, old self and new. A skylight in a dark ceiling is a metaphor for an old life and career now out of reach. A ladder on a steep, muddy path in the woods symbolizes her struggle to heal.

Many of our current policies do a disservice to brain-injury survivors like Peggi and their families. For example, we prevent survivors from getting the cognitive rehabilitation services that could help them improve and contribute to their families and communities.

We need to pay more attention to what people tell us about their lives with brain injuries. By listening, we can contribute to healing, improve the quality of care, and reduce costs. As we reform our health-care system, let's take note of the invaluable evidence from brain-injury survivors' lives.

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