Better Healthcare Newsletter from Patrick Malone

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Stigmatization is the name for a major scourge in medical and mental health care Where do biases come from? Stigma can cause

PATRICK MALONE

Words matter: Be educated, factual, and careful in thinking & talking about others U.S. medical system struggles to eradicate array of inequities

It is an old problem in medical care -- and human life. The stigma of some human conditions -- weight gain, mental health, substance abuse, and now monkey pox, to name a few -- brings shame. And shame brings silence. And silence makes it hard for those who need help to get it. As modern societies and health care workers struggle to eliminate unacceptable inequities of many different kinds, stigmatization is gaining increased attention. So let's spend a little quiet time with stigma: why it hurts, how to make it better. In this newsletter, five things we all need to know -- for ourselves, our loved ones, and our society. Photo credit: detail from Auguste Rodin, The Burghers of Calais, Rodin Museum, Philadelphia. 1. Stigmatization is the name for a major scourge in medical & mental health care

In ancient Greece, people who were regarded as shameful,

Their body signs were called stigma, or stigmata in the plural.

disgraceful, or requiring punishment — including slaves, prisoners,

and traitors — were tattooed or marked, so they would be avoided.

The religious recognize these terms, too, because they also have been associated (quoting an encyclopedia definition) with "bodily marks, scars, or pains corresponding to those of the crucified Jesus Christ — that is, on the hands, on the feet, near the heart, and sometimes on the head (from the crown of thorns) or shoulders and back (from carrying the cross and scourging)." In health terms, stigmatization refers to sharply negative attitudes toward or beliefs about those with illness, injury, or marked physical or mental differences. This wrongful thinking, experts say, manifests itself in ugly behaviors — discrimination by race, gender, and sexual orientation, as well as other ways of abusing others in speech and action. As the federal Centers for Disease Control and Prevention

"Stigma is discrimination against an identifiable group of people, a

fears about disease and death, and gossip that spreads rumors and

This isn't abstract or esoteric stuff. During the pandemic, for example,

ignorant and outspoken associated the coronavirus's lethal effects with

the Western outbreak of monkeypox, seeking to avoid negative views about a disease that has been more prevalent in Africa and its current, most common means of transmission — chiefly among men who have

Photo credit: Edvard Munch, Melancholy, Børre Høstland/Lathion, Jacques,

place, or a nation. Stigma is associated with a lack of knowledge about how [for example, disease] spreads, a need to blame someone,

explains on its website:

myths."

the mere happenstance of where the disease was first identified (in Asia). This prompted the unbalanced to physically attack and make derogatory remarks against Asian Americans in record numbers. When doctors first began to diagnose HIV-AIDS cases, some medical professionals and health care facilities declined to treat infected patients, and many of the sick, particularly those with the related, visible Kaposi's sarcoma, were forced out of housing and out of public sight. Now, public health officials have walked a tightrope in battling

sex with other men and with multiple partners.

2. Where do biases come from?

Nasjonalmuseet (National Museum of Norway)

hate crimes against Americans of Asian descent spiked as the

Human beliefs and behaviors aren't always easy to explain, deal with or alter. When people stigmatize others due to disease or injury, however, mental health experts have research-based theories about why those with certain conditions suffer opprobrium while others do not. In more backward times, people stigmatized the sick or injured — both

inside and outside their tribal societies — not only because they were

Stigmatization also provides insights into baser parts of ourselves and our character: We reject in others what we fear or dislike in ourselves,

experts say. This can be oversimplified, and it is hard to shorthand the

We do not want to be thought of as weak, so we abhor weakness in

mental illnesses or chronic conditions like cancer. We put such a high

value on skin-deep beauty that we recoil at those disfigured by injury

monkeypox that can cause pustules to erupt all over the face, hands,

We hold our own character at such heights that we hold in contempt those we blame for having personal failings that result in substance abuse, not accounting for the debilitating and addictive qualities of

others, shunning those we think are "feeble" because they have

or those with scarring diseases like leprosy or illnesses like

3. Stigma can cause real damage

and body.

drugs and alcohol.

afraid and ignorant but also as a crude self-protection against

believed were associated with others' injuries.

outsiders' contagions and the harms that uninformed individuals

complexities of people's thinking. But experts say that we worry, for example, that others think us lazy, undisciplined, and fat, so we point at others carrying excess weight and deride their problem as a major deficiency. We "fat shame" them.

Stigmatization may seem like a big word, but as experts study it, the term only begins to describe significant harms to those who suffer it, particularly when it comes to treating their medical and mental health

As one medical journal article described the problem:

The American Psychiatric Association reported this:

successful health outcomes."

"[S]tigma [when it occurs] in health facilities is particularly egregious, negatively affecting people seeking health services at a time when they are at their most vulnerable. In health facilities, the manifestations of stigma are widely documented, ranging from outright denial of care, provision of sub-standard care, physical and verbal abuse, to more subtle forms, such as making certain people wait longer or passing their care off to junior colleagues. As a result, stigma is a barrier to care for people seeking services for disease prevention, treatment of acute or chronic conditions, or support to maintain a healthy quality of

life. Within the health system, stigma towards a person living with a specific disease undermines access to diagnosis, treatment, and

"Stigma and discrimination can contribute to worsening symptoms and reduced likelihood of getting treatment. A recent extensive review of research found that self-stigma leads to negative effects on recovery among people diagnosed with severe mental illnesses. Effects can include: reduced hope, lower self-esteem, increased psychiatric symptoms, difficulties with social relationships, reduced likelihood of

staying with treatment, [and] more difficulties at work. A 2017 study involving more than 200 individuals with mental illness over a period of two years found that greater self-stigma was associated with poorer recovery from mental illness after one and two years ... Some of the other harmful effects of stigma can include: Reluctance to seek

housing; bullying, physical violence, or harassment; health insurance that doesn't adequately cover your ... treatment; [and] the belief that you'll never succeed at certain challenges or that you can't improve your situation." 4. History shows how negative views shift

History shows that public attitudes about diseases and injuries can change significantly — mostly for the better. Consider: § How backward the ancient animus towards leprosy now seems; by

themed movie "Ben Hur."

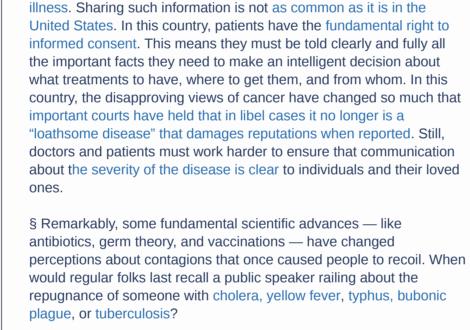


Photo credit: National Library of Medicine, 'Surviving & Thriving' digital exhibition,

5. Words matter: Be educated, factual,

and careful in thinking and talking

HIV-AIDS protest at National Institutes of Health.

about others

§ Travelers to other countries — including China, Japan, Singapore, Spain, Greece, and Italy — are finding that, slowly, longstanding practices are giving way, so that doctors inform patients with

stigmatized chronic diseases like cancer that, yes, they have a serious

If you're human, you're imperfect. We all have blind spots in our thinking and behavior towards those with health and mental health conditions, experts say. But informing ourselves and talking through what we do and don't know about illness, injury, and disability can be crucial in reducing stigma's harms.

comments by sharing facts and experiences. Be conscious of language — remind people that words matter. Encourage

how they would treat someone with cancer or diabetes. Show compassion for those with mental illness. Be honest about

Choose empowerment over shame."

and humanistic insights emerge.

way to say it is that someone "died by suicide."

equality between physical and mental illness — draw comparisons to

treatment — normalize mental health treatment, just like other health care treatment. Let the media know when they are using stigmatizing language presenting stories of mental illness in a stigmatizing way.

Read the published research on stigmatization of many different patients — those who have challenges with weight, skin disorders, substance abuse, chronic illness, disfigurement, infectious diseases —

The way we use words really matters. Take suicide, for instance. We used to casually say that someone "committed suicide." Then we recognized that most of those who die by their own volition aren't really in control of their deadly impulses. So now the more accurate

correct." Once people understand what causes health conditions and realize that sufferers cannot fully control circumstances that lead to them, why blame and shame them? Will stigma ease for the overweight when researchers establish that obesity is a complex disease,? Or for substance abuse, that some drugs have walloping addictive powers and that these can underlie substance abuse? Regular folks typically don't ostracize those with strokes, pneumonia, or limb loss due to car wrecks. They see that bad things happen. They offer empathy, compassion, and kindness to those who suffer catastrophic illness or injury. Those are qualities that "better angels" surely can spread around, especially with an estimated 6 in 10

These are not cliches, and not just a roster of what is "politically

Stigmatization harms at least two other notable groups, worsening their health, health care, and To serve well an increasingly diverse and well-being — people living with physical demanding U.S. population, the nation's disabilities and those with intellectual and medical care system must keep taking major steps developmental disabilities. to eliminate all manner of its existing inequities. The system, for example, must stamp out The National Clearinghouse on Abuse in Later Life discrimination by race, gender, sexual orientation, has posted online a worthy article about the big religion, and economic standing. problems confronting the disabled, reporting: This is crucial if, in the wealthiest country on the "According to the Centers for Disease Control and planet, health care becomes a right, not a Prevention (CDC), 61 million adults in the United privilege. It's a huge challenge. States live with a disability. That's roughly 26% of

Usha Lee McFarling, a Pulitzer Prize-winning reporter, and her employer, the science and medical news site Stat, have done commendable work, digging hard into the myriad ways that patients, clinicians, and researchers suffer from inequities in health care. At a time when a nationwide shortage of doctors looms and patients and hospitals can't find enough MDs of color, McFarling reported that black doctors "are forced out of training programs at far higher rates than white residents." She

described how orthopedics, despite efforts by some leaders in the field, persists as not only a

She has detailed how pulse oximeters, key

devices that gained much attention during the

coronavirus pandemic, have a built-in flaw that

care of monkeypox, the coronavirus, women's

reproductive diseases, organ transplantation,

"stubborn outlier" but also "the whitest specialty."

Alzheimer's, and more. McFarling has reported that a "landmark National Academies report 'Unequal Treatment' ... 20 years ago examined how systemic racism leads to poorer medical care for people of color in the U.S." But, she added, "STAT reported [in February] that little progress has been made to address the problems highlighted in the report, and that, despite a pandemic that reinforced the depth and reach of these inequities, complacency could still win out, or new crises, such as the current nursing shortage, could get in the way." Kedar Mate, a physician who leads the Boston-

is pushing health care systems to reduce

disparities in the populations they serve, told

"The big risk is that we'll continue to admire the

problem [of health inequity' and won't get to do

considered themselves to be a person with a disability. Experiencing stigma was the strongest predictor of identifying as disabled.' Throughout history, disabled people have been stigmatized. Disability has been linked to disease and

Washington Healthy Aging and Physical Disability

explaining that the disabled are shunned, isolated,

stereotyped, discriminated against, condescended to, shamed, blamed, and subjected to hate crimes

Rehabilitation Research and Training Center,

adults living in the United States. And yet, these

Dr. Kathleen R. Bogart explains, individuals may be reluctant to identify as disabled. She writes: 'In

a series of studies, my colleagues and I conducted

a survey of factors related to disability identity and disability pride. The first study surveyed 1,105

adults online. Of those people ... 64% indicated

impairment. Of [those with] ... health conditions, only 12% ... agreed or strongly agreed that they

numbers are likely a great underestimate. As

disorder, autism spectrum disorder, cerebral palsy, Turner-Musa et al., 2020)—experienced pronounced diabetes, epilepsy, and psychiatric conditions and population (Krahn & Fox, 2014; Young-Southward et al., greater risk of hospitalization, and almost twice the "As a developmental psychologist and the sister of an autistic adult, I have witnessed firsthand the effects of stigma on the health of people with I/DDs. Health care stigma, including physician

misinformation and bias, is a significant driver of

negative health outcomes. Indeed, I have been

privy to countless stories of doctors who have

expressed preconceived biases, discomfort, or

result, deemed my sister too complex, dangerous, or challenging to treat. ... stigma originates well

doctors' offices. It can be traced back to a lifetime

of experiences and accumulates to create health

outdated knowledge about autism, and, as a

before individuals with I/DDs step foot in their

Hoetz details the top-to-bottom changes that

would benefit those with intellectual and

disparities (Krahn & Fox, 2014)."

medical education and clinical treatment guidelines, as well as improvements and inclusive steps in research. Experts also must reach out with their experience, expertise, and knowledge to shift attitudes among the public. Big reforms are needed for both the disabled and those with intellectual and developmental disability to ensure they get a fair shake at good health and appropriate health care.

Patients may be reluctant to think ill of their doctors or to imagine that highly educated, rigorously trained professionals could mistreat or cause them harm. Doctors themselves know this picture is

voluntarily responded to an online questionnaire, Medscape — a web-based medical news source — reported this information about doctor misconduct: "Physicians tell us they're seeing more frequent incidents of other doctors acting disrespectfully towards patients or coworkers, too casually about patient privacy, angrily or aggressively at work, and even sometimes criminally.

Such behavior is still relatively uncommon, and many respondents say they are proud of the high standards of attitudes and behavior shown by fellow physicians." When seniors need full-time institutional care, or when the injured or debilitated require similar 24/7 attention, loved ones — and even friends — must take care to read and re-read any documents that nursing homes and other long-term care facilities shove before them to sign during the stressful admissions process. That's because the owners and operators of the facilities soon may create a financial nightmare for the unwitting document signers, fueling what is the huge shame of the U.S. health care system: medical debt. Most regular folks might think that the

testing the public's willingness to delay gratification on seeing big benefits of a landmark measure

with important elements to improve their health and wellbeing. Is it more persuasive to regular

folks that one political party is trying to tackle huge problems, or will relentless naysayers reap rewards for doing little or nothing? As a little more than four score days remain before important midterm elections, Democrats will be seeking to convince voters of the significance of the giant Inflation Reduction Act — aka the much-reduced Build Back Better legislative package originally

 UNOS, the independent medical network responsible for procuring and distributing human organs for transplants in this country, needs big changes because it is failing desperate patients, making screening errors, among other missteps, that have killed dozens of them and caused hundreds to develop procedure-related diseases. The U.S. Senate Finance Committee reviewed hundreds of thousands of pages of subpoenaed documents and other material and investigated the nation's

They're 21 and older, and unlike minor kids carted into urgent, or emergency rooms for treatment, the residents typically have, until their situations suddenly shift, been responsible, including legally, for their lives and personal business. But nursing homes have dragged into court "children, grandchildren, neighbors, and others, many with nearly no financial ties to residents or legal responsibility for their debts," the independent Kaiser Health News service and NPR have reported. Is it time for a glimmer of optimism about reducing at least one unacceptably high health care cost? Say hear, hear then, to the federal Food and Drug Administration's removing the last regulatory block to consumers with mild to moderate hearing loss buying cheaper, easier to access, over-the-counter (OTC) hearing aids — potentially as soon as this fall. Hearing some fading Bronx cheers? Those may be for the regulators who plodded to potentially benefit tens of

88% Peak percentage of 14,000 people who were watching their weight and who reported in a survey that they experienced weight-shaming from a parent, sibling, or other family member, mostly during childhood and adolescence. 9,000+ Number of self-reported incidents of physical attacks or verbal assaults in the U.S. against people of Asian descent between March 2020 and June 2021. The spike in anti-Asian hate crimes, experts say, results from this group's stigmatization during the coronavirus pandemic. Number of serious, wellknown conditions (monkeypox and schizophrenia) that have so much stigma attached to them that experts and advocates say changing their very name may be a necessary and beneficial option. **QUICK LINKS** Our firm's website

Read an excerpt from

Patrick Malone's book:

The life you save

and Avoiding the Worst

life

save

the

you

to Finding the Best

Medical Care —

Nine Steps

f 🔰 in 8+ 攝 🔊

IN THIS ISSUE

real damage

History shows how negative views shift

A battle for fairness for those disabled in

7 in 10

Number of surveyed

employees with high-

substance abuse issues

stigmatization over

mental health or

who reported they missed work time due to

burnout or stress

body and brain

BY THE **NUMBERS**

levels of self-

Translate ▼

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LEARN MORE Read our Patient Safety Blog, which has news and practical advice from the frontlines of medicine for how to become a smarter, healthier patient. Join our Mailing List

PAST ISSUES

Just say 'Whoa!' to

this summer

harmful

runaway medical costs Staying safe and healthy

Medical "innovations" can be costly and

The healing power of the

Why do we keep letting dangerous doctors put patients at risk? You Can Eat This... But Why Would You? Looking Ahead: Preparing for Long- Term Managing Chronic Pain: It's Complicated Secure Health Records: A Matter of Privacy and Safety Standing Tall Against a More...

help or treatment and less likely to stay with treatment; social isolation; lack of understanding by family, friends, coworkers, or others; fewer opportunities for work, school or social activities or trouble finding the late 1950s, it became a plot point in the award-winning religious-§ How odd it would be if someone fell asleep during Ronald Reagan's presidency and remembered only the cruel, isolating, and widely held negative views about HIV-AIDS so prevalent then. The person now would be startled to see the array of Big Pharma ads splashed on broadcast TV now for prescription pre-exposure prophylaxis or PrEP

The psychiatrists' association, which campaigns against inequitable treatment of those with mental illness, shares these suggestions that also can be generalized as to how to deal with stigmatization: "Talk openly about mental health, such as sharing on social media. Educate yourself and others — respond to misperceptions or negative

Americans living with chronic illness of some kind. Photo credit: a medical exam as part of treatment involving staff of the federal Centers for Disease Control and Prevention. CDC. **U.S. medical system** A battle for fairness for those struggles to eradicate disabled in body and brain array of inequities

the medical system. The social turmoil associated with the George Floyd protests and the 2020-21 Black Lives Matter demonstrations from coast to coast have only added to the pressure for all institutions in this country, including in health care, to undertake desperately needed reforms.

Our firm's newsletter, for example, has discussed

unacceptable ways that women are mistreated by

§ relentless health inequities require urgent

in greater detail how:

redress for African Americans

§ it is too easy to chronicle the many

makes them less accurate and potentially harmful to patients with darker skin — and how black engineers are committed to remedying this design shortcoming. Stat has published news articles, too, on the dearth of diversity in clinical trials and how this can undercut innovative treatment for women and people of color. The site has detailed, including with opinion pieces from medical experts, how inequities affect

We have much work to do to ensure that U.S. patients get medical services that are safe, accessible, affordable, efficient, equitable, and excellent. Photo credit: Health care workers at all six Johns Hopkins hospitals gathered on June 5, 2020, as part of an event

helplessness, and in some cultures, disability is associated with ancestral curses." The article cites work by the University of

they had any type of health condition or

As for the issues affecting those with intellectual and developmental disabilities, Emily Hoetz has written an impassioned, research-based article posted on the site of the Association for Psychological Science, reporting this: "Even before the pandemic ... individuals with I/DDs—including attention-deficit/hyperactivity learning disabilities, seizures, developmental delays, and intellectual impairment (Bagcchi, 2020; health disparities (Scior et al., 2016), such as increased rates of cardiovascular disease, decreased life expectancy relative to the general 2017). Perhaps unsurprisingly, during the pandemic, they experienced more severe illness, case fatality rates (Turk et al., 2020).

President Biden and congressional Democrats have embarked on a major political experiment,

transplant network for 2½ years, assailing UNOS for its operational and oversight laxity, the

based Institute for Healthcare Improvement, which

McFarling this:

anything about it."

Here are some recent posts on our patient safety blog that might interest you:

proposed by President Biden.

Washington Post reported

organized by White Coats for Black Lives. Johns Hopkins. **Recent Health Care Blog Posts** communication, as well as in transportation, public policies and programs affecting them, and in economic, social, and other factors that affect their equitable health care.

and violence. They face difficulties with

developmental disabilities, including reforms in

way too rosy for some of their colleagues. In a survey of 1,500 practicing MDs, all of whom

millions of folks, who were forking over \$5,000 for pairs of medically prescribed devices that previously also required expensive attention of doctors and audiologists. Patients also were ripped for the costs of this care, which typically was not covered by traditional insurance or Medicare. HERE'S TO A HEALTHY (REST OF) 2022!

financial obligations incurred in long-term care facilities rightly belong to the adult residents.

Sincerely.

trick Moloce Patrick Malone **Patrick Malone & Associates**

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