

Changing Language to Change Care: Stigma and Substance Use Disorders

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Sarah E. Wakeman Disclosures

- Dr. Wakeman has no relevant financial relationship(s) with ACCME defined commercial interests to disclose.

The contents of this activity may include discussion of off label or investigative drug uses. The faculty is aware that is their responsibility to disclose this information.

Target Audience

- The overarching goal of PCSS-MAT is to make available the most effective medication-assisted treatments to serve patients in a variety of settings, including primary care, psychiatric care, and pain management settings.

Educational Objectives

- At the conclusion of this activity participants should be able to:
 - Describe three examples of stigma in the way the medical system approaches substance use disorder
 - Explain the importance of using medically appropriate language for substance use disorder
 - Utilize effective terminology when discussing substance use disorder

Outline

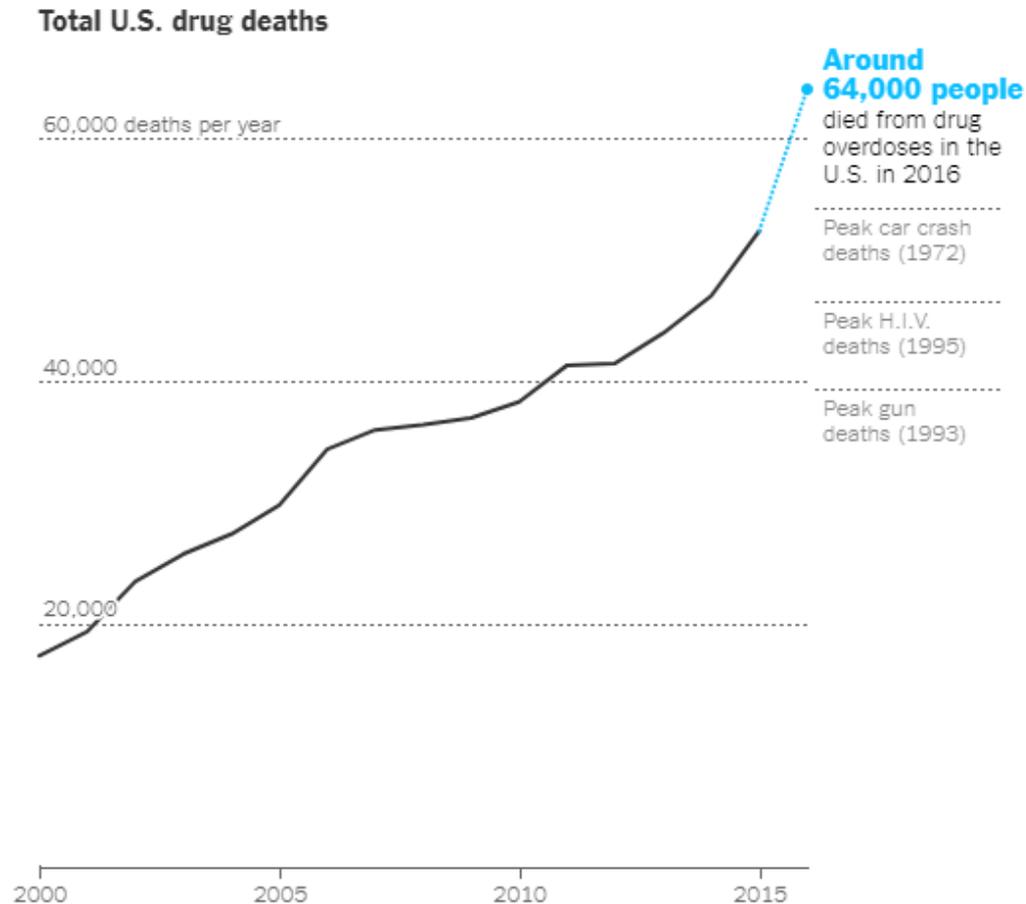
- Substance use disorder is a prevalent, treatable chronic illness
- Stigma results in gaps between science and practice
- Language can perpetuate stigma



Unhealthy Substance Use and Substance Use Disorder Highly Prevalent



Overdose Now Leading Cause of Death for Americans Under 50



Defining Substance Use Disorder

- Primary, chronic brain disease characterized by compulsive substance seeking and use *despite harmful consequences*
- Involves cycles of relapse and remission
- 40-60% genetic

Defining Chronic Illness

- Long in duration—often with protracted clinical course
- Associated with persistent and recurring health problems
- Multi-factorial in etiology, often heritable
- No definite cure
- Requires ongoing medical care

SUD Meets Criteria for Chronic Illness

- Common features with other chronic illnesses:
 - Heritability
 - Influenced by environment and behavior
 - Responds to appropriate treatment
 - Without adequate treatment can be progressive and result in substantial morbidity and mortality
 - Has a biological/physiological basis, is ongoing and long term, can involve recurrences

Treatment and Outcomes Similar to Other Chronic Illnesses

- Treatment outcomes as good as other chronic illnesses
- Relapse or recurrence rates similar
- Adherence and engagement crucial

COMPARISON OF RELAPSE RATES BETWEEN DRUG ADDICTION AND OTHER CHRONIC ILLNESSES

Percentage of Patients Who Relapse

TYPE 1 DIABETES



DRUG ADDICTION



HYPERTENSION

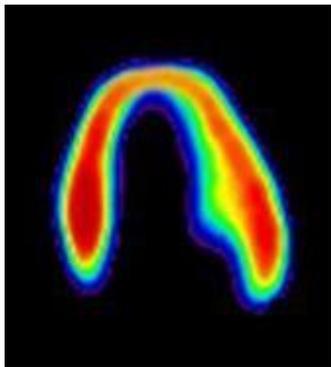


ASTHMA

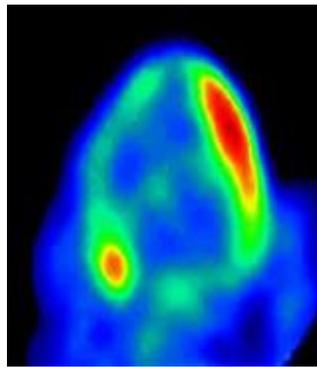


Like Other Chronic Illness, SUD Changes Biology

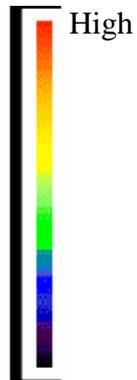
Decreased Heart Metabolism in
Coronary Artery Disease



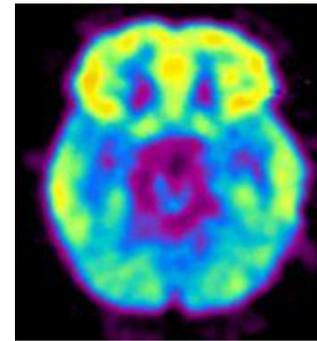
Healthy heart



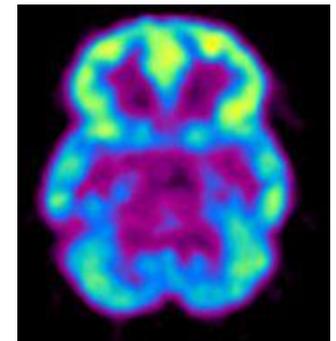
Diseased Heart



Decreased Brain Metabolism in
Addiction



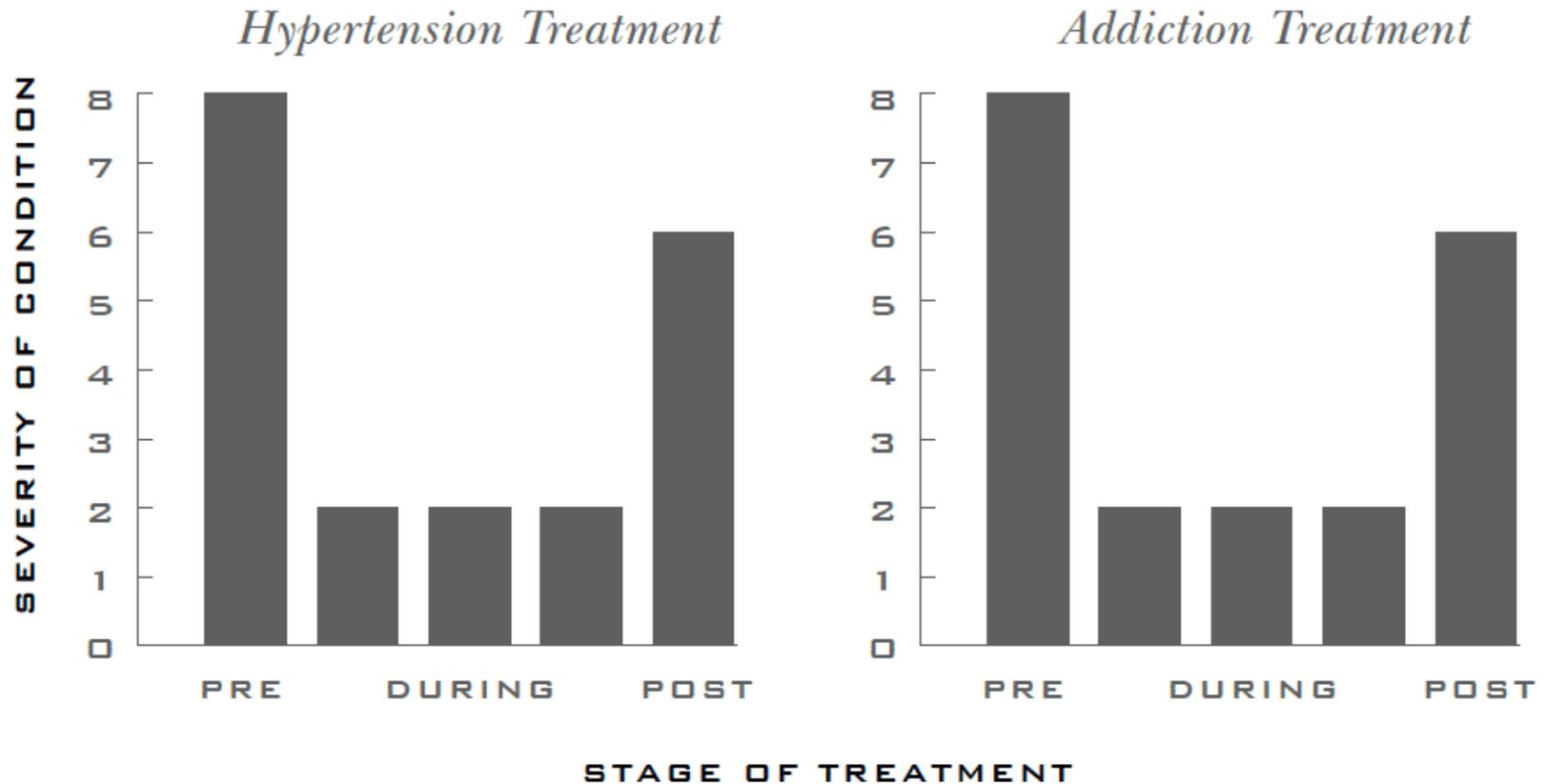
Healthy Brain



Diseased Brain

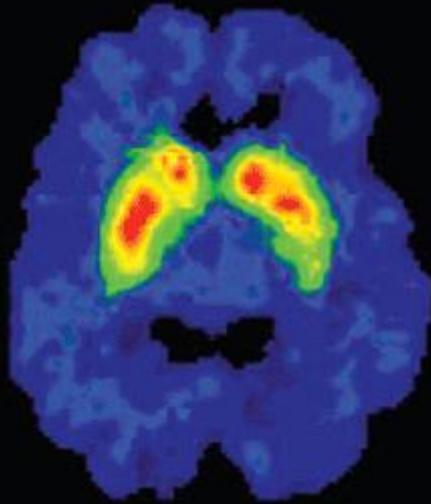
A Treatable Disease

WHY IS ADDICTION TREATMENT EVALUATED DIFFERENTLY?
BOTH REQUIRE ONGOING CARE

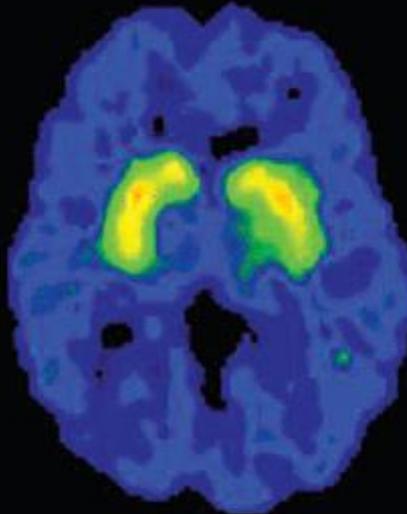


Visualizing Recovery

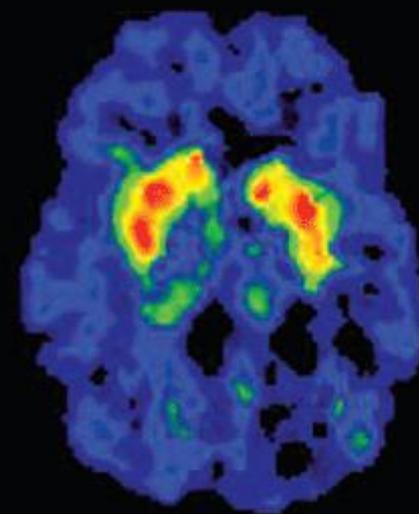
BRAIN RECOVERY WITH PROLONGED ABSTINENCE



Healthy Person

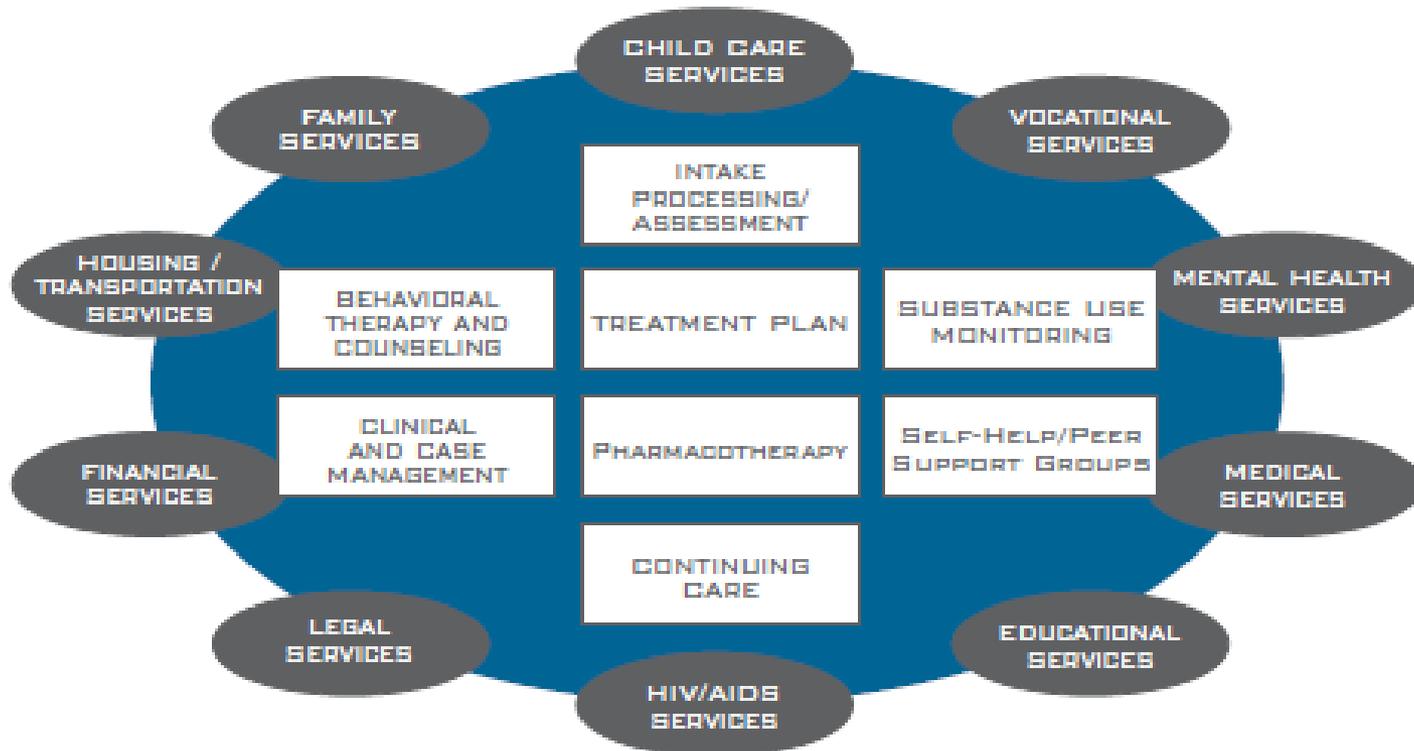


METH
1 month abstinence



METH
14 months abstinence

What is Effective Treatment?



The best treatment programs provide a combination of therapies and other services to meet the needs of the individual patient.

What is Effective Treatment?

Pharmacotherapy

- Alcohol use disorder
 - naltrexone, acamprosate, disulfiram, topiramate*
- Opioid use disorder
 - methadone, buprenorphine, naltrexone
- Tobacco use disorder
 - varenicline, bupropion, NRT
- Cocaine use disorder
 - Topiramate*, naltrexone*

Psychosocial/behavioral

- Levels of care
 - Outpatient, IOP/PHP, residential
- Modalities
 - CBT, MI/MET, CM, TSF

Recovery Supports

- Mutual help/peer support
- Recovery coaching

Similar to Medical Management of Other Chronic Illnesses (e.g. Diabetes or HIV)

- No cure
- Goal is prevention of acute and chronic complications
- Individualized treatment plans and targets
- Treatment includes:
 - Medication
 - Lifestyle changes
 - Regular monitoring for complications
 - Behavioral support



How Long Should Treatment Last?

“In most cases, treatment will be required in the **long term or even throughout life**. The aim of treatment services is not only to reduce or stop opioid use, but also to improve health and social functioning, and to help patients avoid some of the more serious consequences of drug use. **Such long-term treatment, common for many medical conditions, should not be seen as treatment failure, but rather as a cost-effective way of prolonging life and improving quality of life, supporting the natural and long-term process of change and recovery.**”

Learning from HIV/AIDS



Everything has changed. We can end HIV.

“Whenever AIDS has won, stigma, shame, distrust, discrimination and apathy was on its side. Every time AIDS has been defeated, it has been because of trust, openness, dialogue between individuals and communities, family support, human solidarity, and the human perseverance to find new paths and solutions.”

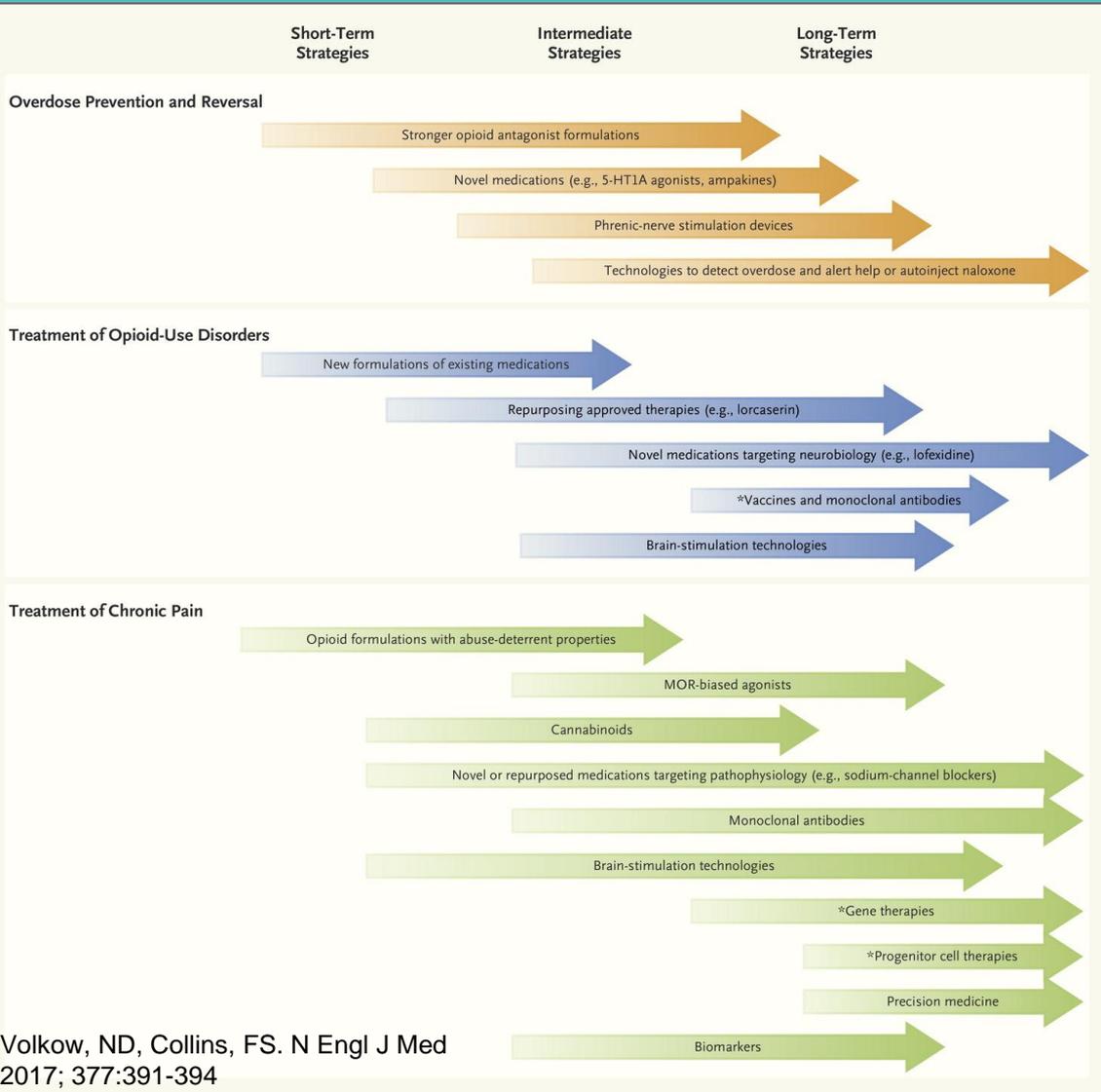
- Michel Sidibé, Executive Director of UNAIDS

Stereotypes of Substance Use Disorder Impact Practice and Policy

“For me the most educational experience of the past three decades was to learn that the traditional image of the addict (weak character, hedonistic, unreliable, depraved, and dangerous) is totally false. This myth, believed by the majority of the medical profession and the general public, has distorted public policy for seventy years.”

- Dr. Dole

Huge Advances in the Science of Addiction and Treatment



“As we have seen repeatedly in the history of medicine, science is one of the strongest allies in resolving public health crises. Ending the opioid epidemic will not be any different. In the past few decades, we have made remarkable strides in our understanding of the biologic mechanisms that underlie pain and addiction.”

Despite Scientific Advances, Huge Gaps in Care

“[The] profound gap between the science of addiction and current practice... is a result of decades of marginalizing addiction as a social problem rather than treating it as a medical condition. Much of what passes for “treatment” of addiction bears little resemblance to the treatment of other health conditions.”

What if...

We treated other diseases the way we treat substance use disorder?

What if...

- You go to the hospital with chest pain and are found to be having a heart attack and you were ...
 - Told it's "your fault" because of your "choices"?
 - Denied treatment because you "did it to yourself"?
 - Given a list of cardiologists and catheterization labs to call?
 - Only given aspirin if you agree to go to counseling?
 - Kicked out of the hospital for more chest pain?

What if...

We treated substance use disorder the way we treat other diseases?

What if...

- The only prerequisite for treatment is having SUD
- System exists to offer treatment on demand
- Care triaged based on who needs it the most
- Not fired for having symptoms of the disease (i.e. relapse)
- Encouraged to go on medications
- Offered a menu of treatment options



Why Does Care Look so Different?

- WHO study of 18 most stigmatized social problems in 14 countries:
 - Drug addiction ranked number 1
 - Alcohol addiction ranked number 4
- Stigma associated with poor mental and physical health among people who use drugs
- Stigma among top reasons people don't access treatment

What is Stigma?

- Attribute, behavior, or condition that is socially discrediting
- Two main factors influence stigma:
 - Cause and controllability
 - Stigma decreases when:
 - “It’s not his fault”
 - “She can’t help it”

Language Used for People with Other Illnesses

Endures
Victim Afflicted
Fighter Suffers
Survivor
Patient

Language Used for People with Substance Use Disorder

A word cloud on a black background. The words are: 'Abuse' in white, 'Misuse' in orange, 'Clean' in teal, 'Dirty' in yellow (written vertically), and 'Abuser' in red.

Stop Talking Dirty: Getting Rid of “Substance Abuse”

- Abuse: Derived from word meaning “wicked act or practice, a shameful thing, a violation of decency”
- Associated with behavior such as rape, domestic violence, and child molestation
- Professionals more likely to view patient as deserving of punishment if described as a “substance abuser”

Types of Stigma for SUD

- Stigma from within
 - Blame self, feel hopeless
- Stigma from recovery community
 - Medications versus “abstinence”
- Stigma from clinicians
 - Belief that treatment is ineffective
- Stigma from outside
 - Choice versus disease

Examples of Stigma

- People with SUD and those on agonist therapy may not be accepted to post-acute care facilities
- People on agonist therapy may not be offered organ transplantation
- People mandated to treatment as a condition of probation who have a positive toxicology despite treatment adherence can be imprisoned

Impact of Stigma

- Erodes confidence that substance use disorder is a valid and treatable health condition
- Barrier to jobs, housing, relationships
- Deters public from wanting to pay for treatment, allows insurers to restrict coverage
- Stops people from seeking help
- Impacts clinical care and treatment decisions

Change Language to Improve Care: The Addictionary

- Avoid: “dirty,” “clean,” “abuse,” and “abuser”
- Consider changing: Medication *Assisted* Treatment
 - Medications for addiction treatment are life-saving similar to insulin for diabetes, which is not called “insulin assisted treatment” despite importance of behavioral interventions with diabetes care
- “Medically supervised withdrawal” also more accurate and less stigmatizing than “Detox”

I PLEDGE

to stop the stigma associated with addiction

Words Matter What we say and how we say it makes a difference.

We can be a model and help to lead the way toward ending the opioid epidemic by using language that de-stigmatizes the disease of substance use disorder.

That means using terminology that recognizes that substance use disorder is a chronic illness, not a moral failing, and people can and do recover.

Why do words matter? Studies show that about one in 12 people with substance use disorder get treatment. Stigma is a key barrier. Using the right language, and putting the person first has a real impact on reducing stigma and helping people with substance use disorder seek and get the treatment they need.

We invite you to sign the Words Matter pledge, originally developed by the Grayken Center for Addiction at Boston Medical Center, and help us toward a goal of creating a stigma-free environment at our hospitals, universities, companies, and in our community.

NON-STIGMATIZING LANGUAGE	STIGMATIZING LANGUAGE
<ul style="list-style-type: none">• Person with a substance use disorder	<ul style="list-style-type: none">• Substance abuser or drug abuser• Alcoholic• Addict• User• Abuser• Drunk• Junkie
<ul style="list-style-type: none">• Substance use disorder or addiction• Use, misuse• Risky, unhealthy, or heavy use	<ul style="list-style-type: none">• Drug habit• Abuse• Problem
<ul style="list-style-type: none">• Person in recovery• Abstinent• Not drinking or taking drugs	<ul style="list-style-type: none">• Clean
<ul style="list-style-type: none">• Treatment or medication for addiction• Medication for Addiction Treatment• Positive, negative (toxicology screen results)	<ul style="list-style-type: none">• Substitution or replacement therapy• Medication-Assisted Treatment• Clean, dirty

The Science is Clear: Medication-Assisted Treatment Works

"The use of opioid agonist medications to treat opioid use disorders has always had its critics. Many people, including some policymakers, authorities in the criminal justice system, and treatment providers, have viewed maintenance treatments as 'substituting one substance for another' and have adhered instead to an abstinence-only philosophy that avoids the use of medications, especially those that activate opioid receptors. Such views are not scientifically supported; the research clearly demonstrates that MAT [medication-assisted treatment] leads to better treatment outcomes compared to behavioral treatments alone. Moreover, withholding medications greatly increases the risk of relapse to illicit opioid use and overdose death. Decades of research have shown that the benefits of MAT greatly outweigh the risks associated with diversion."

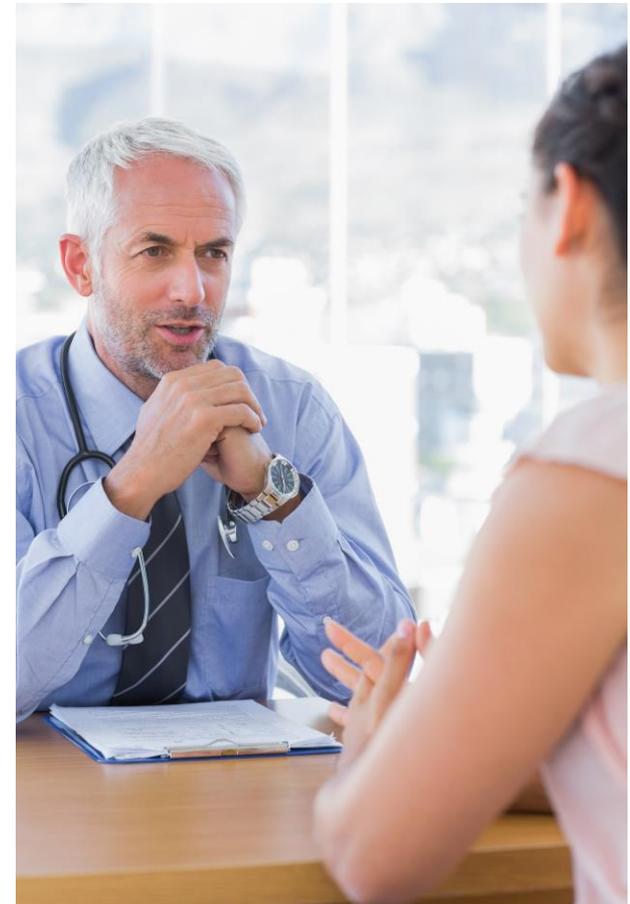
2016 Surgeon General's Report on Alcohol, Drugs, and Health
addiction.surgeongeneral.gov

Small Minority of Physicians are Waivered

Specialty	Number (%) of Waivered Physicians with this Specialty	Number (%) Non-Waivered	Total (%)	Percentage of Specialty with a DEA Waiver
Psychiatry	7,584 (41.6)	39,157 (83.8)	46,741 (5.6)	16.2
Family medicine	4,066 (22.3)	108,913 (96.4)	112,979 (13.6)	3.6
Internal medicine	2,618 (14.4)	119,980 (97.9)	122,598 (14.8)	2.1
Anesthesiology	753 (4.1)	44,884 (98.4)	45,637 (5.5)	1.7
Physical medicine and rehab	471 (2.6)	8,441 (94.7)	8,912 (1.1)	5.3
Emergency medicine	370 (2.0)	37,645 (99.0)	38,015 (4.6)	1.0
Other specialty	339 (1.9)	71,891 (99.5)	72,230 (8.7)	0.5
Internal medicine sub-specialties	333(1.8)	112,155 (99.7)	112,488 (13.6)	0.3
Pain management	279 (1.5)	1,559 (84.8)	1,838 (0.2)	15.2
Surgery and sub specialties	227 (1.3)	116,442 (99.8)	116,669 (14.1)	0.2
Addiction medicine*	182 (1.0)	62 (25.4)	244 (0.03)	74.6
Obstetrics-gynecology	181 (1.0)	41,541 (99.6)	41,722 (5.0)	0.4
Pediatrics and sub-specialties	147 (0.8)	76,449 (99.8)	76,596 (9.2)	0.2
Neurology	147 (0.8)	13,521 (98.9)	13,668 (1.7)	1.1
Missing specialty	528 (2.9)	18,179 (97.2)	18,707 (2.3)	2.8
Total	18,225 (100.0)	810,819 (100.0)	829,044 (100.0)	2.2

The Need for Change

“For nearly a century, physicians were indoctrinated with the societal attitude that addicts brought upon themselves the suffering they deserve. Even after we began to regard addicts as having a disease, our policies continued to reflect our attitude: addicts are sick, they need help, but they also sin, so do not help them too much. Until the correct mindset is restored in the physician, the mere availability of an effective medication will not make a difference. To put it another way, for buprenorphine to succeed clinically, physicians themselves must first change before they can help patients change their lives.”



Language and Approach Crucial When Caring for People with SUD

- Hospitalized patients who have SUD often feel stigmatized
- Language and approach to managing withdrawal, pain, and medical care matter

Patient Narratives

- “If I wouldn’t have been so sick [i.e. experiencing opiate withdrawal], if they would listen about my drug needs, I would stay [in hospital]. Just take it seriously.”
- “I wouldn’t be leaving the hospital. It would make me want to deal with my medical issues. I would stay there ‘cause when I’m up there [in hospital] I want to use drugs. I know a lot of people that go to the hospital that are drug users, and they leave the hospital ‘cause they want to do drugs..”
- “The hospital should ask the person, ‘Do you need anything? Are you using anything?’ Heroin, it’s an addictive drug. If my doctor was giving me pain medication, then I wouldn’t have to use heroin...If you’re a junkie and go in the hospital, they won’t give you anything. How do they expect you to stay?”

Hospitalized Patients with SUD Fearful Based on Prior Experiences

- Patients perceive that treatment of pain and withdrawal to be extremely variable
 - *“The last time, they took me to the operating room, put me to sleep, gave me pain meds, and I was in and out in two days.... This crew was hard! It’s like the Civil War. ‘He’s a trooper, get out the saw’. . .”*
- Patients fearful they will be punished for their drug use.
 - *“I mentioned that I would need methadone, and I heard one of them chuckle. . .in a negative, condescending way. You’re very sensitive because you expect problems getting adequate pain management because you have a history of drug use. . . He showed me that he was actually in the opposite corner, across the ring from me.”*

What Can Clinicians Do?

- Treat addiction with science-based strategies
 - MD/DO/NP/PA Get Waivered!!
- Speak out against stigma and discrimination
- Keep hope alive
- Be mindful of language
- Treat affected individuals with dignity



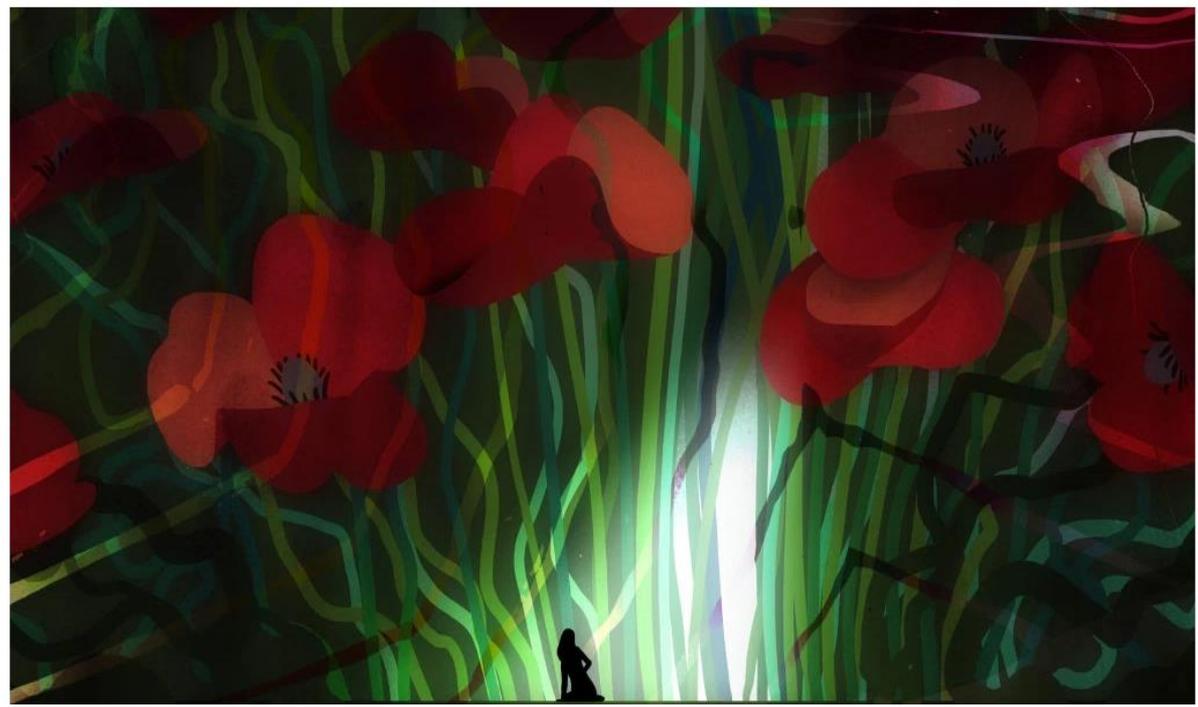
What Can Family or Friends Do?

What Science Says To Do If Your Loved One Has An Opioid Addiction

By [Maia Szalavitz](#)
Filed under [Addiction](#)
Published Jul. 19, 2016



- Learn about addiction
- Intervene gently:
“The data doesn’t support [the tough love] approach. Interventions are almost always destructive, and sometimes, they destroy families.”
- Understand science based treatment
- Remember that relapse isn’t failure



References

- American Society of Addiction Medicine. <http://www.asam.org/quality-practice/definition-of-addiction>
- American Society of Addiction Medicine. April 12, 2011. www.asam.org
- CASA Columbia. Addiction Medicine: Closing the Gap between Science and Practice www.casacolumbia.org
- DSM-5 <http://www.dsm5.org/documents/substance%20use%20disorder%20fact%20sheet.pdf>
- Dole, VP. Drug and Alcohol Review. 1994; 13: pp. 3-4
- Goodman RA, et al. Prev Chronic Dis 2013;10:120239.
- <https://www.avert.org/professionals/hiv-social-issues/stigma-discrimination>
- Katz J. The New York Times. September 2, 2107.
<https://www.nytimes.com/interactive/2017/09/02/upshot/fentanyl-drug-overdose-deaths.html?mcubz=1>
- Kelly JF, Westerhoff CM. Int J Drug Policy. 2010;21(3):202---207
- Ling. J Neuroimmune Pharmacol (2016) 11:394–400
- Martic CM. Can Fam Physician. 2007 Dec; 53(12): 2086–2091
- McLellan et al. JAMA. 2000 Oct 4;284(13):1689-95
- McNeil et al. Addiction. 2016 April ; 111(4): 685–694.
- Merrill JO, et al. J Gen Intern Med. 2002. May;17(5):327-33.
- National Institute on Drug Abuse (NIDA), 2012 https://d14rmgtrwzf5a.cloudfront.net/sites/default/files/podat_1.pdf
- NIDA <https://archives.drugabuse.gov/publications/drug-abuse-addiction-one-americas-most-challenging-public-health-problems/addiction-chronic-disease>
- NIDA. August, 2010. <http://www.drugabuse.gov/publications/science-addiction>

References

- NIDA. Drugs, Brains, and Behavior: The Science of Addiction. <https://www.drugabuse.gov/publications/drugs-brains-behavior-science-addiction/drug-abuse-addiction>
- NIDA. Principles of Drug Addiction Treatment. 2012. McLellan et al., JAMA, 284:1689-1695, 2000 .
- Rosenblatt et al. Ann Fam Med January/February 2015 vol. 13 no. 1 23-26
- SAMHSA National Survey on Drug Use and Health. Retrieved from http://iusbirt.org/wp-content/uploads/2014/09/NSDUH14-0904_infographic.jpg
- Szalavitz M. What Science Says to do if Your Loved One Has Addiction. July 19, 2016 <https://fivethirtyeight.com/features/what-science-says-to-do-if-your-loved-one-has-an-opioid-addiction/>
- Volkow, ND, Collins, FS. N Engl J Med 2017; 377:391-394
- Wakeman SE. Am J Public Health. 2013 April; 103(4): e1–e2.

PCSS Mentor Program

- PCSS Mentor Program is designed to offer general information to clinicians about evidence-based clinical practices in prescribing medications for opioid addiction.
- PCSS mentors are a national network of providers with expertise in **addictions, pain, evidence-based treatment including medication-assisted treatment.**
- 3-tiered approach allows every mentor/mentee relationship to be unique and catered to the specific needs of the mentee.
- No cost.

For more information visit:

pcssNOW.org/clinical-coaching

PCSS Discussion Forum

Have a clinical question?



Ask a Colleague

A simple and direct way to receive an answer related to medication-assisted treatment. Designed to provide a prompt response to simple practice-related questions.

[Ask Now >](#)



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MAT

TRAINING

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PROVIDERS' CLINICAL SUPPORT SYSTEM

For Medication Assisted Treatment

PCSS-MAT is a collaborative effort led by the American Academy of Addiction Psychiatry (AAAP) in partnership with the: Addiction Technology Transfer Center (ATTC); American Academy of Family Physicians (AAFP); American Academy of Neurology (AAN); American Academy of Pain Medicine (AAPM); American Academy of Pediatrics (AAP); American College of Emergency Physicians (ACEP); American College of Physicians (ACP); American Dental Association (ADA); American Medical Association (AMA); American Osteopathic Academy of Addiction Medicine (AOAAM); American Psychiatric Association (APA); American Psychiatric Nurses Association (APNA); American Society of Addiction Medicine (ASAM); American Society for Pain Management Nursing (ASPMN); Association for Medical Education and Research in Substance Abuse (AMERSA); International Nurses Society on Addictions (IntNSA); National Association of Community Health Centers (NACHC); National Association of Drug Court Professionals (NADCP), and the Southeast Consortium for Substance Abuse Training (SECSAT).

For more information: www.pcssNOW.org



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