Words Matter: Addiction Terminology, Accuracy and Stigma

25th Anniversary Presentation
Presented by: Richard Saitz MD, MPH, FACP, DFASAM
JAMA

UpToDate®

Alcohol, Other Drugs, and Health: Current Evidence

Addiction Science & Clinical Practice

www.aodhealth.org
What I Will Tell You...

• Alcohol and drug use are like other health risks
• Substance use disorders are health conditions
  o There is a spectrum of use and consequences and the distinctions matter
• We talk about and address alcohol and drugs differently from other health risks and conditions
  o Those are related...
  o Language contributes to and reflects stigma (and it affects policy and care)
• Consensus is emerging around accurate non-stigmatizing terminology
Richard Nixon - 1970
Creates DEA and declares a 'War on Drugs'

Keep Calm and Just Say No

Just Say No

25th Anniversary
SMART Recovery 1994-2019
• What happens to people with diabetes who are incarcerated?
  
  Insulin is continued

• What happens to pregnant women with diabetes?
  
  They and their babies receive pre- and post-natal care

• What happens to pregnant women who drink alcohol or smoke cigarettes?
  
  They and their babies receive pre- and post-natal care
Alabama’s 2006 Chemical Endangering Law...to prosecute and punish women who give birth to babies with drugs in their systems. (cocaine, opioids, not alcohol, nicotine)
Stigma

Media
Criminal Justice Industrial Complex
Child Welfare System
Alcohol, Tobacco, Pharma Industry
Specialty Sector Addiction Treatment
Rat Experiments

Rats given access to drugs use them to death

Standard Housing: Skinner Box -- Isolated and can give foot shocks
Rat Park
“Choice days”

US soldiers in Vietnam 8-10 months later, of those using drugs, <10% current disorder 2/3rds not using

COMPARISON:
6 months after hospital treatment
70% current disorder
10% not using

Narcotic Use in Southeast Asia and Afterward

An Interview Study of 898 Vietnam Returnees

Lee N. Robins, PhD; John E. Helzer, MD; Darlene H. Davis
National Population-Based Survey

• Of US adults with alcohol dependence prior to the past year, 25% met criteria for dependence in the past year

• Only 25% had received any treatment

Drugs Also Cause Dopamine Release

- **AMPHETAMINE**
  - Time After Amphetamine: 0, 1, 3, 6 hr
  - Graph showing changes in dopamine levels over time.

- **COCAINE**
  - Time After Cocaine: 0, 1, 3, 6 hr
  - Graph showing changes in dopamine levels over time.

- **NICOTINE**
  - Time After Nicotine: 0, 1, 3 hr
  - Graph showing changes in dopamine levels over time.

- **MORPHINE**
  - Time After Morphine: 0, 1, 3, 6 hr
  - Graph showing changes in dopamine levels over time.

Source: Di Chiara and Imperato

Natural Rewards Elevate Dopamine Levels

- **Food**
  - Graph showing dopamine levels in response to food intake.
  - NAc shell

- **Sex**
  - Graph showing dopamine levels in response to sexual activity.
  - DA Concentration (pg/mL)

Choice?

• Selection
  o Not all use is a disease, not all substance use disorders are the same

• No one would choose addiction

• Even if first use is a choice, repeated use leads to brain changes that reduce the capacity to stop

• Multifactorial genetic and environmental etiologies

• We treat the consequences of other choices
Substance Use Disorder (DSM 5)
2 or more in 12 mo; 2-3=mild, 4-5=moderate, 6 or more=severe

1. Recurrent use resulting in a failure to fulfill major role obligations at work, school, or home
2. Recurrent use in situations in which it is physically hazardous
3. Continued use despite having persistent or recurrent social or interpersonal problems
4. Tolerance
5. Withdrawal
6. Use in larger amounts or over a longer period than intended
7. Persistent desire or unsuccessful efforts to cut down
8. A great deal of time is spent obtaining alcohol, using it, recovering from it
9. Important social, occupational, or recreational activities given up or reduced
10. Use despite knowledge of related physical or psychological problem
11. Craving

Moderate to severe is similar to ICD-10 dependence
Unhealthy Use

Terminology for Unhealthy Use

Health Condition/Disease

- Use disorder (DSM)
  - Addiction (ASAM)
- Dependence, harmful (ICD)
  - Like old DSM IV abuse/dependence

Risk

- At-risk, risky,
- Hazardous

“Disease”

- Meets WHO definition and others, and similar to other things we call diseases
- But no need to argue about it
- Arguments are really about choice and responsibility
Stigma

• Stigmatizing terms can affect the perception and behavior of
  o Patients,
  o Their loved ones,
  o The general public,
  o Scientists,
  o Clinicians

• Can also affect the quality of care and health care policies

“Dependence”

• DSM IV/ICD vs. physical
A Day in the Life: NICU Medical Director Tends to Opioid-Addicted Infants
A Day in the Life: NICU Medical Director Tends to Infants With Neonatal Abstinence Syndrome
Stigma Moderated by Two Factors...

• Causal attribution
  o Did they cause it?
    ▪ “It’s not their fault” (decreases stigma; increases compassion)

• Perceived control/Self-regulation
  o Can they help it?
    ▪ “They can’t help it” (decreases stigma; increases compassion)
Two Commonly Used Terms...

• Referring to someone as...
  
  o “a substance abuser” – implies willful misconduct (it is their fault and they can help it)
  
  o “having a substance use disorder” – implies a medical malfunction (it’s not their fault and they cannot help it)

But, does it really matter how we refer to people with these (highly stigmatized)conditions? Can’t we just dismiss this as a well-meaning point, but merely “semantics” and “political correctness”?
Words matter

The words we use to describe drug and alcohol use disorders contribute to stigma around the conditions, psychologist John F. Kelly told attendees at a recent White House Conference on Drug Policy Reform.
Mr. Williams is a substance abuser and is attending a treatment program through the court. As part of the program Mr. Williams is required to remain abstinent from alcohol and other drugs. He has been doing extremely well, until one month ago, when he was found to have two positive urine toxicology screens which revealed drug use and a breathalyzer reading which revealed alcohol consumption. Within the past month there was a further urine toxicology screen revealing drug use. Mr. Williams has been a substance abuser for the past six years. He now awaits his appointment with the judge to determine his status.

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How we talk and write about these conditions and individuals suffering them does matter.

Counselors in the “abuse” condition agreed more with the notion that the person was personally culpable, they were seen as a social threat, treatment was less likely to be recommended, and they thought that punitive measures should be taken.

Methadone Maintenance
Still controversial...

“I don’t believe in methadone...substituting one drug for another...liquid handcuffs...”

Addicts shoot up in Massachusetts General Hospital bathrooms

pril 13 2016 Boston Herald
Opioid Abuse in Chronic Pain — Misconceptions and Mitigation Strategies

Nora D. Volkow, M.D., and A. Thomas McLellan, Ph.D.

CHRONIC PAIN NOT CAUSED BY CANCER IS AMONG THE MOST PREVALENT and debilitating medical conditions but also among the most controversial and complex to manage. The urgency of patients’ needs, the demonstrated effectiveness of opioid analgesics for the management of acute pain, and the limited therapeutic alternatives for chronic pain have combined to produce an overreliance on opioid medications in the United States, with associated alarming increases in diversion, overdose, and addiction. Given the lack of clinical consensus and research-supported guidance, physicians understandably have questions about whether, when, and how to prescribe opioid analgesics for chronic pain without...
April 1, 2016 Boston Globe

Philip Loderer @philiploderer Apr 1
I thought we were done with stigmatizing language. Fed. @EvanMAllen cc @felicejfreyer @Peter_Grinspoon @LeoBeletsky

Felice J. Freyer @felicejfreyer Apr 1
@LeoBeletsky @philiploderer @landmanspeaking @EvanMAllen @Peter_Grinspoon I wish to fight stigma, too, but word choices remain unclear.

Dr. Richard Saitz @UnhealthyAlcOrg

@felicejfreyer @LeoBeletsky @philiploderer @landmanspeaking @EvanMAllen @Peter_Grinspoon howve muddl thru w/no wrd 4 ppl wcancer? #addiction

April 1, 2016 Boston Globe

Karen Landman @landmanspeaking Apr 1
@philiploderer @LeoBeletsky @EvanMAllen @felicejfreyer @Peter_Grinspoon @LeoBeletsky When is almost never have input on choosing headlines. FYI

Philip Loderer @philiploderer Apr 1
@landmanspeaking @EvanMAllen @felicejfreyer @Peter_Grinspoon @LeoBeletsky I know. But Editors do.

Philip Loderer @philiploderer Apr 1
@landmanspeaking @EvanMAllen @felicejfreyer @Peter_Grinspoon @LeoBeletsky Globe itself published this 2 months ago. philiploderer.org/2016/02/06/4/

Felice J. Freyer @felicejfreyer Apr 1
@landmanspeaking @EvanMAllen @Peter_Grinspoon @LeoBeletsky N. Y. Times named against "world of grayness" in vague terminology.

Leo Beletsky @LeoBeletsky Apr 1
@landmanspeaking @philiploderer @EvanMAllen @Peter_Grinspoon "Addict" is effectively negative and harmful. No gray areas.

Felice J. Freyer @felicejfreyer Apr 1
@landmanspeaking @EvanMAllen @Peter_Grinspoon Experts disagree. J. Kelly doesn't like "abuse" but ok w/ "addict".

Leo Beletsky @LeoBeletsky Apr 2
@UnhealthyAlcOrg @felicejfreyer @philiploderer @landmanspeaking @EvanMAllen @Peter_Grinspoon "Addict" analogous to erstwhile term "cripple".
This Is Substance Abuse
ADDICTION TERMINOLOGY STATEMENT

The International Society of Addiction Journal Editors recommends against the use of terminology that can stigmatize people who use alcohol, drugs, other addictive substances or who have an addictive behavior.

Rationale: Terms that stigmatize can affect the perception and behavior of patients/clients, their loved ones, the general public, scientists, and clinicians (Broyles et al., 2014; Kelly, Dow & Westerhoff, 2010; Kelly, Wakeman & Saltz, 2015). For example, Kelly and Westerhoff (2010) found that the terms used to refer to individuals with substance-related conditions affected clinician perceptions. Clinicians who read a clinical vignette about “abuse” and an “abuser” agreed more with notions of personal culpability and an approach that involved punishment than did those who read an identical vignette that replaced “abuse” and “abuser” with “substance use disorder” and “person with a substance use disorder.”

ISAJE is aware that terminology in the addiction field varies across cultures and countries and over time. It is thus not possible to give globally relevant recommendations about the use or non-use of specific terms. “Abuse” and “abuser” or equivalent words in other languages should, however, in general be avoided, unless there is particular scientific justification (an example of scientific justification of the use of “abuse” is when referring to a person who meets criteria for a Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, alcohol abuse; that person would be said to have “alcohol abuse”). Another example of stigmatizing language is describing people as “dirty” (or “clean”) because of a urinalysis that finds the presence (or absence) of a drug (Kelly, Wakeman & Saltz, 2015). Instead, the test results and clinical condition should be described.

The above was approved by the International Society of Addiction Journal Editors at its 2015 annual meeting (Budapest, Hungary, August 31-September 2, 2015).
Stop Talking ‘Dirty’: Clinicians, Language, and Quality of Care for the Leading Cause of Preventable Death in the United States

A patient with diabetes has “an elevated glucose” level. A patient with cardiovascular disease has “a positive exercise tolerance test” result. A clinician within the health care setting addressing the results. An “addict” is not “clean”—he has been “abusing” drugs and has a “dirty” urine sample. Someone outside the system that cares for all other health conditions addresses the results. In the worst case, the drug use is addressed by incarceration. On December 6, 2013, the first ever national drug policy reforms summit was held at the White House. A major thrust of this summit was to mark a philosophical shift away from the “war on drugs” toward a broader public health approach. Much of the summit was devoted to addressing the stigma surrounding addiction and the under-recognized importance of language.

Stigma is defined as an attribute, behavior, or condition that is socially discrediting. It is important because of the 23 million Americans who meet criteria for a substance use disorder each year, only 10% access treatment, and stigma is a major barrier to seeking help. A World Health Organization study of the 18 most stigmatized social problems (including criminal behavior) in 14 countries found that drug addiction was ranked number 1, and alcohol addiction was ranked number 4. Despite harmful consequences. Yet, despite evidence of a strong causal role for genetics and impairment in inhibitory control, stigma is alive and well. Research is now revealing that one contributory factor to the perpetuation of stigma may be the type of language we use.

Use of the more medically and scientifically accurate “substance use disorder” terminology is linked to a public health approach that captures the medical malfunction inherent in addiction. Use of this term may decrease stigma and increase help-seeking. In contrast, tough, punitive, language, including the word “war,” in “war on drugs,” is intended to send an uncompromising message, “You use, you lose,” in the hopes of deterring drug involvement. Accompanying this aggressive rhetoric are terms such as drug “abuse” and drug “abusers,” implying willful misconduct (i.e., “they can help it and it is their fault”). This language increases stigma and reduces help-seeking.

Since the 1970s, such language has become the norm. Even our federal health institutions that address addictions have the term “abuse” in their names (e.g., National Institutes on Drug Abuse), and their materials often refer to affected individuals as substance “abusers.” But, does it really matter what we call it? Rhetorical opposition has persisted regarding the use of stigmatizing language, but there was a

Treatment Terms: Misperceptions

- Avoid “medication-assisted,” “substitution”
  - Treatment, opioid agonist treatment


Samet JH, Fiellin DA. Opioid substitution therapy—time to replace the term
The Lancet, Volume 385, Issue 9977, 1508 - 1509
Thanks to Tom McLellan for the concept
Miller WR. Retire relapse. Substance Use Misuse in press.
Journal of Addiction Medicine

• Humanizing
• Non-stigmatizing
• Medical, scientific terms
• Precise
• Professional consensus-driven

http://journals.lww.com/journaladdictionmedicine/Pages/informationforauthors.aspx#languageandterminologyguidance
Language and Terminology Guidance for Journal of Addiction Medicine (JAM) Manuscripts

• Person-first language
  o Not addict, alcoholic, drunk but person with...

• Avoid “abuse,” “abuser”
  o usually “use” is more accurate (unless referring to DSM dx)

• The disease: substance use disorder (DSM), addiction, other diagnostic terms (ICD dependence, harmful)

• Drug versus medication

• Generally avoid misuse (when disorder is meant; except for prescription), problem, binge, inappropriate, moderate
  o Use low risk, at risk, risky, hazardous, unhealthy (spectrum)

What Do People with SUD Wish to Call Themselves and Others?

• More than 70% of participants used the term ‘addict’ to describe themselves and when speaking with others. However, use of ‘addict’ varied by context, and was most common at 12-Step programs.

• Fewer than 15% reported using ‘user’ or slang terms, most commonly ‘junkie’, in any communications.

• The most-preferred label for others to call them was ‘person who uses drugs’, while the most common label that participants never wanted to be called was ‘heroin misuser’ or ‘heroin-dependent’.

Convenience sample of n=263 med managed inpatient WD.
Health Condition/Disease

• Does not remove responsibility
• Does not mean behavior cannot be objectionable
A Difference, Perhaps, vs Other Health Conditions/Diseases

• High negative externalities
  o Perpetrate violence, crimes, harmful behavior

• Not all
  o Like a chronic infectious disease?

Reasons Why This Is Difficult

• Inertia, language device, brevity, convenience, perceived cumbersome alternatives, even among experts and leaders

• Agency names: NIDA, SAMHSA, single-state agencies for substance abuse services, journal names “Substance Abuse,” society names

• BUT none of that would be an excuse were it cancer, heart disease...

Editor’s Note

Distinguishing Between Substance Use and Substance Use Disorder

McNeely and Saitz\(^1\) are correct that the field of drug use and screening would benefit from clarity in terminology. However, in practice, it can be very challenging to distinguish between substance use and a substance use disorder.

Mitchell H. Katz, MD

Conflict of Interest Disclosures: None reported.

Changing the Language of Addiction

Words matter. In the scientific arena, the routine vocabulary of health care professionals and researchers frames illness and shapes medical judgments. When these terms then enter the public arena, they convey social norms and attitudes. As part of their professional duty, clinicians strive to use language that accurately reflects science, promotes evidence-based treatment, and demonstrates respect for patients.

However, history has also demonstrated how language can cloud understanding and perpetuate societal bias. For example, in the past, people with mental illness were derided as “lunatics” and segregated to “insane asylums.” In the early days of human immuno-

Stigma isolates people coming forward for treatment, knowingly or unknowingly. In a recent survey on drug use and health, 22.5 million people (aged 18) needed specialty treatment for a problem drug use, only an estimated one of six received treatment. 1.6 million received treatment for reasons not seeking treatment, receiving it would adversely affect them.

Things that Work, Things that Don’t Work, and Things that Matter—Including Words

Richard Saitz, MD, MPH, FACP, DFASAM

Medications for Addiction Treatment: Changing Language to Improve Care

Sarah E. Vokonas, MD, DFASAM

COMMENT & RESPONSE

Substance Use Terminology

To the Editor: We share the concerns of the authors of a Viewpoint about the prevalent use of stigmatizing language to refer to unhealthy substance use and the people afflicted by it. Movements at the national level are occurring to encourage the use of nonstigmatizing language, such as the addiction terminology statement by the International Society of Addiction Journal Editors, which marks an important step in developing a consensus on stigmatizing language among medical journals worldwide. In particular, it discourages the use of “dirty,” “clean,” “abuse,” and “abuser.”

The authors discussed the draft document about addiction language from the Office of National Drug Control Policy. We wish to point out that it includes misuse and medication-assisted treatment as preferred terms. Certainly “misuse” could apply to a medication that has an intended use, but it could be stigmatizing when used to refer to a disorder (as per its current use by the Department of Veterans Affairs for alcohol, for which the disorder comes under “severe” misuse). However, life-saving opioid agonist treatments should not be relegated to “assistance” status. They are medication treatments just as insulin is for diabetes (which also has behavioral treatments), nor therapies that merely “assist” some other treatment. In fact, it has been difficult to detect the effects of psychosocial care above those of opioid agonists in clinical trials. This term may help explain in part the limited use of and stigma surrounding the treatment.

Katherine E. Calver, PhD
Richard Saitz, MD

October 4, 2016
Valid, Reproducible, Clinically Useful, Nonstigmatizing Terminology for the Disease and Its Treatment: Addiction, Substance Use Disorder, and Medication

Richard Saitz, MD, MPH, FACP, DFASAM

The Importance of Language
Throughout September, everyone in the BMC community is encouraged to take the "Words Matter" pledge to show their commitment to using non-stigmatizing language when talking about addiction. The pledge recognizes the fact that what we say and how we say it makes a difference to our patients with substance use disorder.

APStylebook.com Help Center topics

What's new in the 2017 edition
This edition of the Stylebook contains nearly 200 new and modified entries.

We now allow use of they as a singular pronoun in limited cases. However, we stress that it is usually possible and always preferable to rework a sentence instead.

A new entry covers gender-related issues and terms, including cisgender, gender nonconforming (n.), gender-nonconforming (adj.) and intersex. We say the terms LGBTQ and LGBT are both acceptable in all references. We accept the word homophobia in broad uses, along with xenophobia and Islamophobia.

We added a detailed entry on addiction, noting that addiction to alcohol and other drugs is considered a disease and cautioning against words like abuse or problem. We also advise to avoid words like alcoholic, addict, user and abuser unless they are in quotations or names of organizations.
EXECUTIVE OFFICE OF THE PRESIDENT
OFFICE OF NATIONAL DRUG CONTROL POLICY
Washington, D.C. 20503

January 9, 2017

MEMORANDUM TO HEADS OF EXECUTIVE DEPARTMENTS AND AGENCIES

FROM: Michael P. Botticelli
Director

SUBJECT: Changing Federal Terminology Regarding Substance Use and Substance Use Disorders
What I Think I Told You...

• Alcohol and drug *use* have health risks
• Substance use disorders are health conditions
  o There is a spectrum of use and consequences and the distinctions matter
• We **talk about** and **address** alcohol and drugs differently from other health risks and conditions
  o Those are related...
  o Language contributes to and reflects stigma and it affects policy and care)
• Consensus is emerging around accurate non-stigmatizing terminology
**Words Matter: What we say and how we say it makes a difference to our patients with substance use disorder**

<table>
<thead>
<tr>
<th>Non-stigmatizing language</th>
<th>Stigmatizing language</th>
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<tr>
<td>Use disorder (DSM) or addiction (ASAM); Person first language: person with/who...</td>
<td>Abuser, user, addict, alcoholic</td>
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<td>At risk, risky, hazardous,</td>
<td>Drunk, junkie</td>
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<td>Unhealthy, excessive, heavy use, episode</td>
<td>Clean, dirty</td>
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<td>Relapse</td>
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<td>Person in recovery</td>
<td>Binge*</td>
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<td>Enabling</td>
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<td>(misuse*, relapse*)</td>
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http://www.bu.edu/sph/academics/departments/community-health-sciences/