TERMINOLOGY, LANGUAGE, AND STIGMA

TIME FOR AN A-D-DICTIONARY

JOHN KELLY AND RICH SAITZ

ISAJE, BUDAPEST, SEPTEMBER 2015

THE PROBLEM

- Stigmatizing terms can affect the perception and behavior of
  - patients,
  - their loved ones,
  - the general public,
  - of scientists,
  - and clinicians.
- Can also affect the quality of care and health care policies

Broyles LM, Binswanger IA, Jenkins JA, Finnell DS, Faseru B, Cavaiola A, Pugatch M, Gordon AJ. Confronting inadvertent stigma and pejorative language in addiction scholarship: a recognition and response. Subst Abus. 2014;35(3):217-21.

Toward an Addiction-ary: A Proposal for More Precise Terminology

John F. Kelly, PhD

ABSTRACT. A confusing array of terms is used to describe alcohol- and other drug-related problems and individuals with such problems. The terms used to describe these phenomena should be explicit, precisely defined, and used consistently to aid unambiguous clinical and scientific communication and promote clearer appraisal of, and generalizations from, empirical findings. Furthermore, because our terminology has implications for patients (e.g., stigma), programs (e.g., treatment access), and policy (e.g., appropriation of healthcare funding), we should think more critically about our choice of terms and what may be communicated by their use. Specific language is suggested along with a simple

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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.

SUD STIGMA MODERATED BY TWO FACTORS…

- Causal attribution
  - **Did they cause it?**
    - "It's not their fault" (decreases stigma; increase compassion)
- Perceived Control/self-regulation
  - **Can they help it?**
    - "They can't help it" (decreases stigma; increases compassion)

TWO COMMONLY USED TERMS…

- Referring to someone as…
  - "a substance abuser" – implies willful misconduct (it is their fault and they can help it)
  - "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"?

Doctoral-level clinicians (n=516) randomized to receive one of two terms….

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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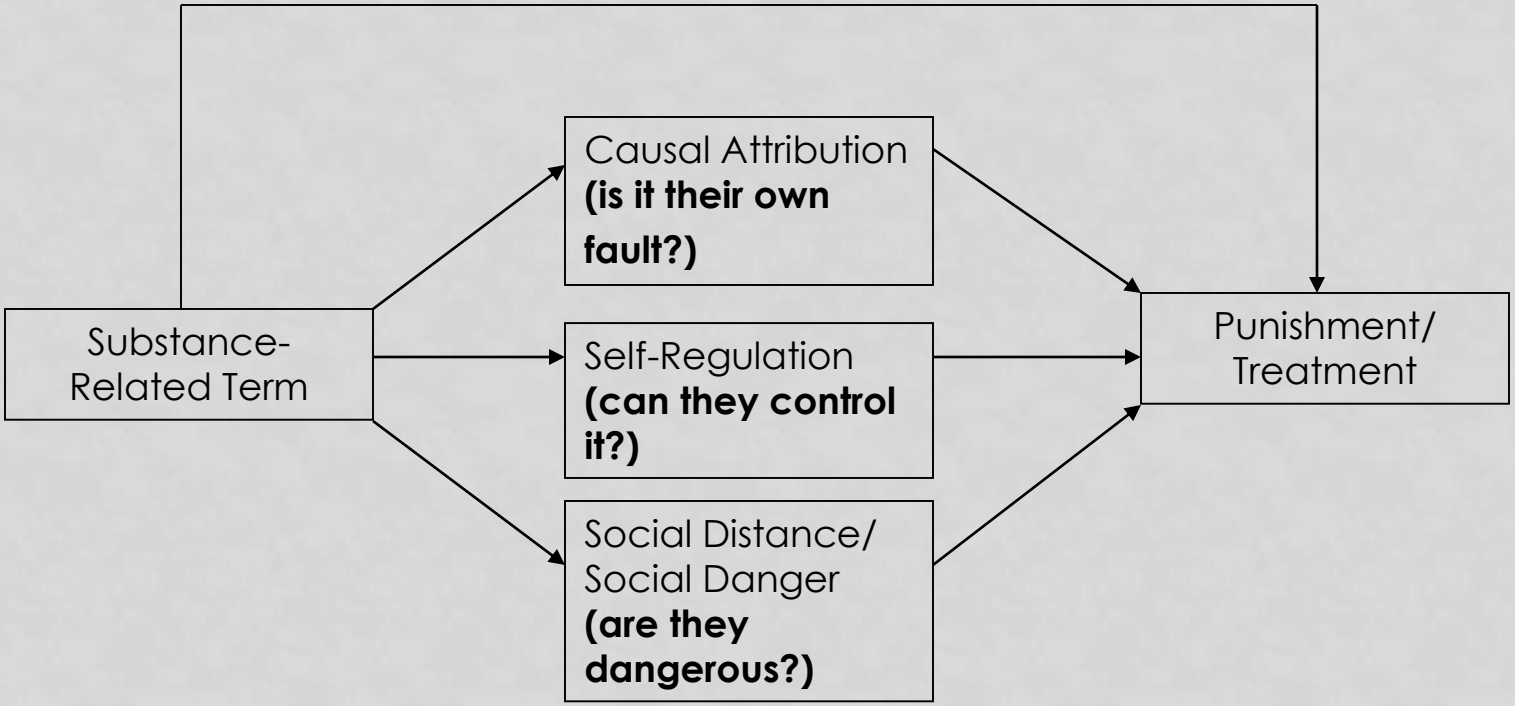
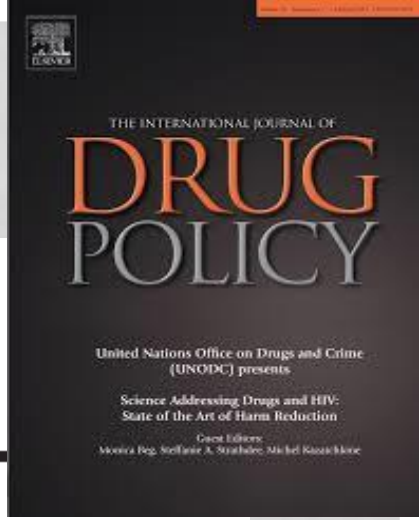
STUDY CONCEPTUAL MODEL



3 Subscales: 1. Perpetrator- Punishment
2. Social threat
3.Victim-treatment

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



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Research paper

Does it matter how we refer to individuals with substance-related conditions? A randomized study of two commonly used terms☆

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ABSTRACT

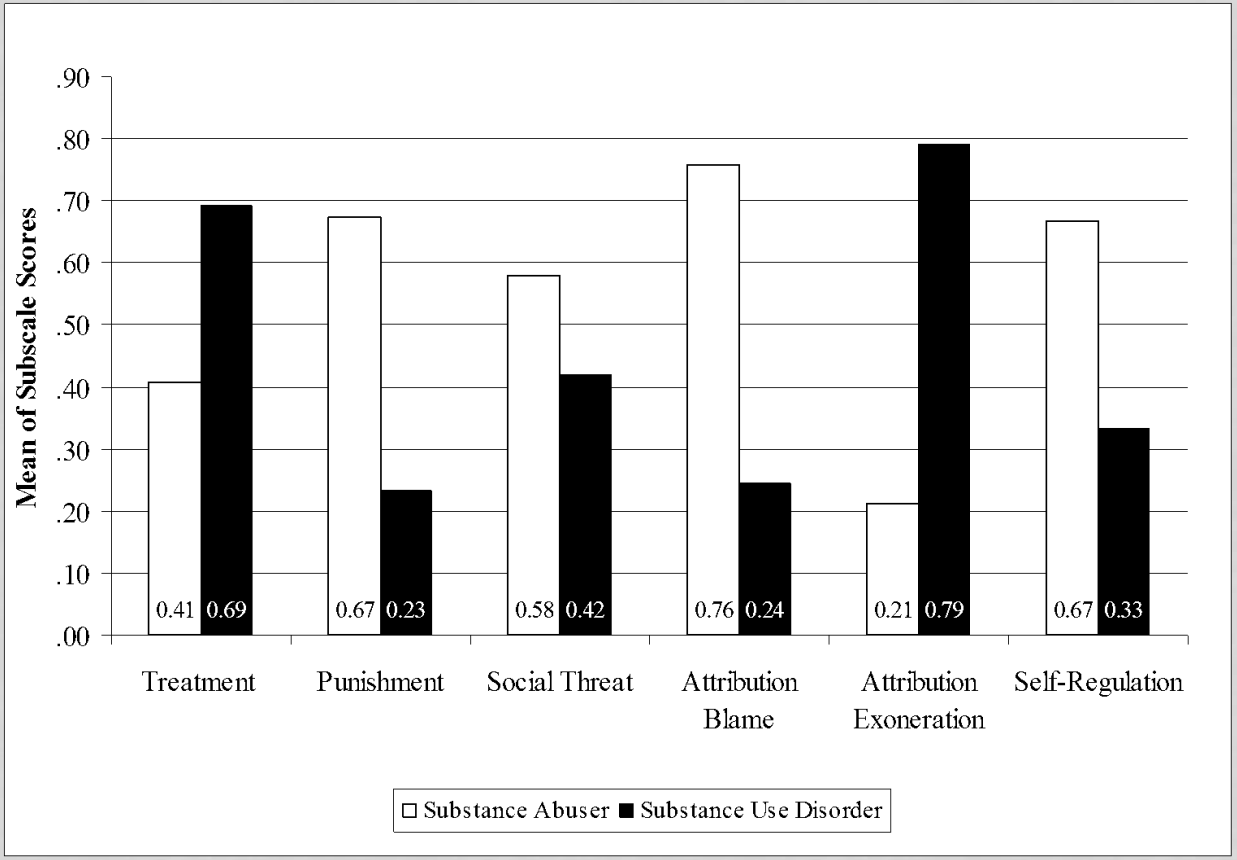
Objective: Stigma is a frequently cited barrier to help-seeking for many with substance-related conditions. Common ways of describing individuals with such problems may perpetuate or diminish stigmatizing attitudes yet little research exists to inform this debate. We sought to determine whether referring to an individual as "a substance abuser" vs. "having a substance use disorder" evokes different judgments about behavioral self-regulation, social threat, and treatment vs. punishment.
Method: A randomized, between-subjects, cross-sectional design was utilized. Participants were asked to read a vignette containing one of the two terms and to rate their agreement with a number of related statements. Clinicians ($N = 516$) attending two mental health conferences (63% female, 81% white, M age 51; 65% doctoral-level) completed the study (71% response rate). A Likert-scaled questionnaire with three subscales ["perpetrator-punishment" ($\alpha = .80$); "social threat" ($\alpha = .86$); "victim-treatment" ($\alpha = .64$)] assessed the perceived causes of the problem, whether the character was a social threat, able to regulate substance use, and should receive therapeutic vs. punitive action.
Results: No differences were detected between groups on the social threat or victim-treatment subscales. However, a difference was detected on the perpetrator-punishment scale. Compared to those in the "substance use disorder" condition, those in the "substance abuser" condition agreed more with the notion that the character was personally culpable and that punitive measures should be taken.
Conclusions: Even among highly trained mental health professionals, exposure to these two commonly used terms evokes systematically different judgments. The commonly used "substance abuser" term may perpetuate stigmatizing attitudes.

DOES OUR CHOICE OF SUBSTANCE-RELATED TERMS INFLUENCE PERCEPTIONS OF TREATMENT NEED? AN EMPIRICAL INVESTIGATION WITH TWO COMMONLY USED TERMS

JOHN F. KELLY, SARAH J. DOW, CARA WESTERHOFF

Substance-related terminology is often a contentious topic because certain terms may convey meanings that have stigmatizing consequences and present a barrier to treatment. Chief among these are the labels, "abuse" and "abuser." While intense rhetoric has persisted on this topic, little empirical information exists to inform this debate. We tested whether referring to an individual as "a substance abuser (SA)" versus "having a substance use disorder" (SUD) evokes different judgments about treatment need, punishment, social threat, problem etiology, and self-regulation. Participants (N = 314, 76% female, 81% White, M age 38) from an urban setting completed an online 35-item assessment comparing two individuals labeled with these terms. Dependent t-tests were used to examine subscale differences. Compared to the SUD individual, the SA was perceived as engaging in willful misconduct, a greater social threat, and more deserving of punishment. The "abuser" label may perpetuate stigmatizing attitudes and serve as a barrier to help-seeking.

Figure 1. Subscales comparing the "substance abuser" and "substance use disorder" descriptive labels



Kelly, JF, Dow, SJ, Westerhoff, C. Does our choice of substance-related terms influence perceptions of treatment need? An empirical investigation with two commonly used terms (2010) *Journal of Drug Issues*

IMPLICATIONS

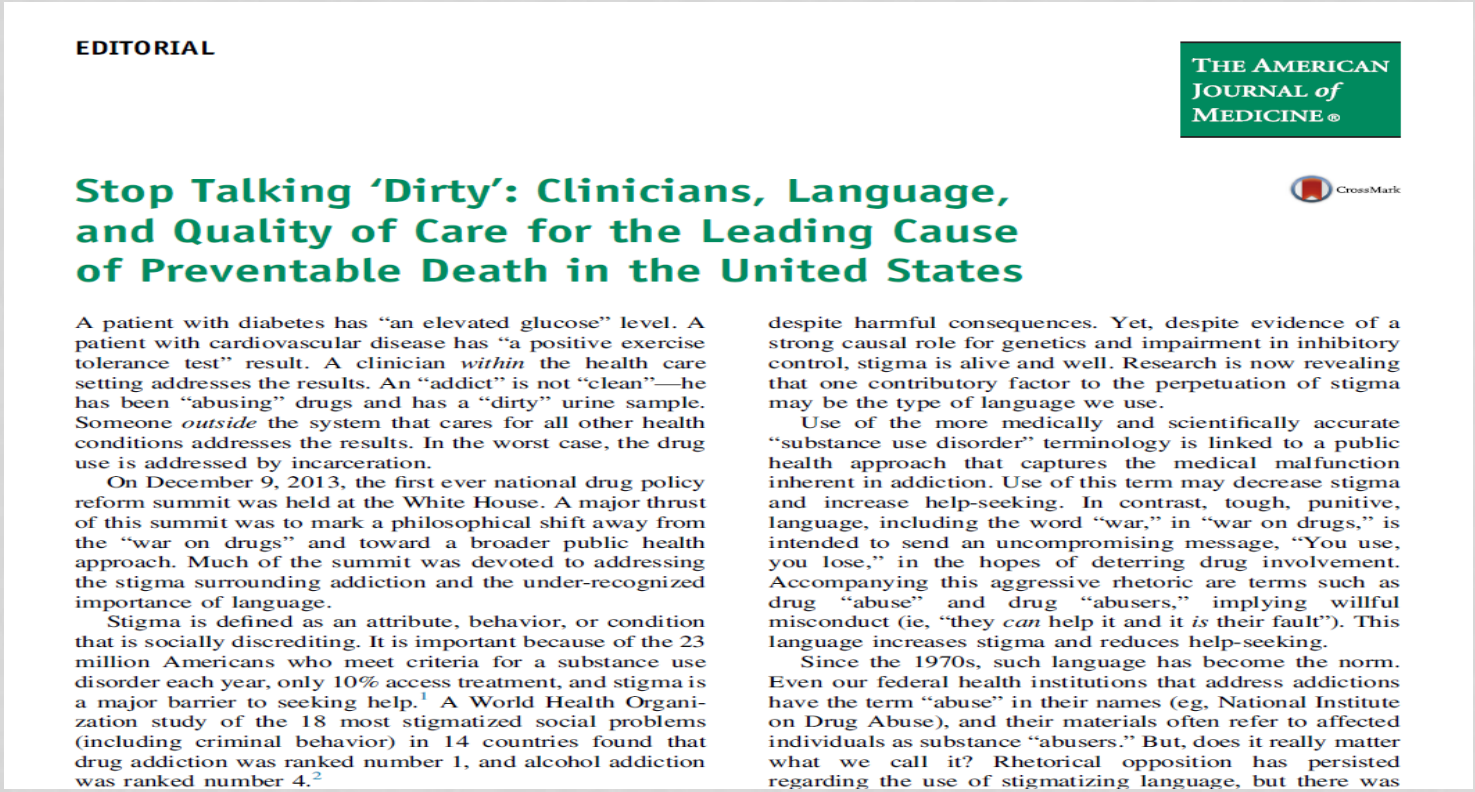
- Even well-trained doctoral clinicians judged *same individual* differently and *more punitively depending* on to *which term* they were exposed
- **Use of the "abuser" term may activate an implicit cognitive bias** that perpetuates stigmatizing attitudes – these could have broad stroke societal ramifications for treatment/funding
- Let's learn from our colleagues treating allied disorders: Individuals with "eating-related conditions" are uniformly described as "having an eating disorder" NEVER as "food abusers"
- Referring to individuals as suffering from "substance use disorders" is likely to diminish stigma and may enhance treatment and recovery

Kelly JF, Westerhoff C. Does it matter how we refer to individuals with substance-related problems? A randomized study with two commonly used terms. Int J Drug Policy, 21 (2010), pp. 202–207

Kelly JF, Dow SJ, Westerhoff C. Does our choice of substance-related terms influence perceptions of treatment need? An empirical investigation with two commonly used terms J Drug Issues, 40 (2010), pp. 805–818

STOP TALKING DIRTY

- Avoid "dirty," "clean," "abuser"
  - Negative urine test for drugs



EDITORIAL

THE AMERICAN JOURNAL of MEDICINE®

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 addresses 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 9, 2013, the first ever national drug policy reform 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" and 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.[1] 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.[2] 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 (ie, "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 (eg, National Institute 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

Kelly JF, Wakeman SE, Saitz R. Stop talking 'dirty': clinicians, language, and quality of care for the leading cause of preventable death in the United States. Am J Med. 2015 Jan;128(1):8-9. doi: 10.1016/j.amjmed.2014.07.043. Epub 2014 Sep 3.

RELAPSE?

- Doesn't add to "use" or "return to use"
- Black and white
- Abstinence violation effect
- Negative connotation
- Sets an unrealistic expectation for behavior change, not consistent with how we know it occurs

Miller WR. What is a relapse? Addiction 1996;91:S15-S27.
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

JOURNAL OF ADDICTION MEDICINE

- Person-first language
  - Not addict, alcoholic, drunk but person with…
- Avoid "abuse," "abuser"
  - 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
  - Use low risk, at risk, risky, hazardous, unhealthy (spectrum)

http://www.asam.org/advocacy/find-a-policy-statement/view-policy-statement/public-policy-statements/2014/08/01/terminology-related-to-the-spectrum-of-unhealthy-substance-use

JOURNAL OF ADDICTION MEDICINE

- Avoid "medication-assisted," "substitution"
  - Treatment, opioid agonist treatment
- Avoid "frequent flyer," "recidivist"
  - Use person suffering recurrence…
- Avoid "patient failed treatment"
  - Use treatment was not efficacious

Friedmann PD, Schwartz RP. Just call it "treatment." Addiction Science & Clinical Practice 2012, 7:10

Samet JH, Fiellin DA. Opioid substitution therapy—time to replace the term The Lancet , Volume 385 , Issue 9977 , 1508 - 1509

"It is only by increasing standardization and promoting creative diversity that the impossible dream may be realized."
Babor & Hall

- Is it an impossible dream to
  - Agree on scientific and clinical language that can maximize accuracy and precision and minimize stigma?
    - Across languages?
      - Do stigmatizing terms differ across languages?
      - At least agree within languages?
  - Standardize while encouraging innovation?
    - Define terms when used?
    - Avoiding stigmatizing terms does not necessarily mean agreeing to one diagnostic system, it just means agreeing to appropriate clinical and scientific terms
  - Strongly encourage/require it across journals?
    - A lexicon?
    - A summit?

World Health Organization. Lexicon of Alcohol and Drug Terms. Geneva: World Health Organization; 1994. Available at: http://www.who.int/substance_abuse/terminology/who_lexicon/en/
BABOR, T. F. and HALL, W. (2007), Standardizing terminology in addiction science: to achieve the impossible dream. Addiction, 102: 1015–1018. doi: 10.1111/j.1360-0443.2007.01845.x